An Exploration of the Friendship Experiences of
Working-Age Adults with Aphasia


A thesis submitted for the degree of Doctor of
Philosophy



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# Abstract

Aphasia impairs using and understanding language, and thus impacts on communication, identity and relationships. However, little research has investigated how people with aphasia understand friends and friendship.

This Participatory Action Research (PAR) study explored how younger adults with aphasia experience friendship. Participants were 28 people with aphasia, some of whom were members of the Research Group. Data from 12 initial interviews in Phase 1 of the study led to a model of friendship and aphasia. This underpinned development of peer-led Friendship Events in Phase 2 of the study, after which 16 additional participants with aphasia were interviewed, contributing to elaboration of the model.

Within the context of living with aphasia, which was central for all participants, eight inter-connected themes emerged. Friends could be anchors in a time of change and trusted stabilising influences while reconfiguring identity. Participants described the hard work of friendship, the place of communication in supporting friendship, and the challenge of equality within post-aphasia friendships. Time, humour and two-way flexibility were crucial in developing new kinds of friendship. Participants categorised a wide variety of relationships as friendship.

These findings elucidate understandings of friendship loss and change as well as strategies to maintain friendship post-onset of aphasia. The study sheds new light on social connectedness and social support provided by friends, family and peers with aphasia. It emphasises the role of friendship in re-configuring identity, and offers practical recommendations for harnessing the benefits of friends and friendship in life with aphasia.

PAR methodology facilitated creation of accessible tools to support conversations and awareness-raising about friendship. The study highlights the strengths of relational methods for researching friendship and the transformative potential of doing PAR with marginalised groups such as people with aphasia.

## Acknowledgements

# Preface

Preparing the thesis has entailed a number of decisions relating to clarity, confidentiality and presentation of spoken text.

## Terminology

I employ the term 'people or person with aphasia' rather than 'stroke survivor' to refer to participants with aphasia. This is the terminology preferred by members of the Research Group who have aphasia.

Different Strokes and Connect are national organisations that support people living with stroke and aphasia.

## Confidentiality

I have used pseudonyms for all participants in the research interviews. Although Research Group members are happy to be identified by name, I took the decision to anonymise their contributions within the thesis. Preserving confidentiality has required altering or redacting names as they appear in various artefacts including Research Group notes and materials developed for recruitment and dissemination.

This study frequently used visual material such as digital photographs to support the reading comprehension of people who have aphasia. Where these photographs specifically identify individuals from the Research Group I have removed the images from the original documents. All photographs included within appendices are used with the express permission of study participants.

## Quotations

Participants' words are generally presented verbatim within single quotation marks. Dialogue preserves the style of speakers with aphasia, inclusive of hesitations, distortions and non-traditional grammar. To clarify meaning, I have enhanced verbatim quotes with description of context and paralinguistic features of talk. Sometimes I use more extended sequences of dialogue. This is to ensure the 'voice' of people with more marked aphasia is also present within the thesis.

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# Introduction

## 1.0    Introduction

This chapter describes the context in which the Friendship and Aphasia study took place. It situates me, as PhD researcher, and my colleagues with aphasia, as co-researchers, within the project. It presents an overview of the study and describes the structure of the thesis. The chapter also introduces the lived experience of aphasia as described within first-hand published accounts.  These orient the study to the issues and priorities of those who experience aphasia and the context in which they experience friendship.

## 1.1    About the study

Given the ubiquity of friendship within contemporary culture and the power of communication capital in modern society, friendship is a surprisingly invisible topic within studies of adults who acquire communication disabilities. Since communication connects us to personal communities and social worlds, loss of language poses obvious challenges to the maintenance of social engagement and emotional wellbeing.

There is compelling evidence that people with aphasia face heightened risk of depression (Kauhanen et al, 2000), diminished social networks (Hilari and Northcott, 2006) and social exclusion (Parr, 2007). Knowledge of the social participation of working-age adults with aphasia is fragmented and their long-term social and emotional needs are poorly addressed (Dalemans et al, 2008; McKevitt et al, 2011). This study asked what happens to friends and friendship when individuals acquire aphasia following stroke. The primary research question was:

> How do working-age adults with aphasia experience and make sense of friendship?

Sensitive to the widespread exclusion of people with language impairment from mainstream stroke research (Brady et al, 2013), the study sought to

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explore the meanings of friendship from the perspective of those who live with language difficulties. A participatory methodology shaped the focus on friendship, and the relational methods that were employed to explore experiences of friendship. This ensured an action-oriented approach, geared to developing knowledge and social innovation with and for people with aphasia. This gave rise to a second question focused on methodological issues:

What are the meanings of doing Participatory Action Research (PAR) with people with aphasia?

The inclusive ethos of the study encouraged maximum participation of people with aphasia. They were not only respondents in interviews but also involved as Research Group members, and participants in cycles of action and reflection. Nine people with aphasia joined the project Research Group, and 28 people with aphasia, including some members of the Research Group, took part in semi-structured interviews. Interviewees included 16 participants who attended Friendship Events created for this project.

## 1.2     Why me? Situating myself in the study

Nel mezzo del cammin di nostra vita

Mi ritrovai per una selva oscura

Che la diritta via era smarrita

*In the middle of the journey of our life I came to myself in a dark wood where the straight way was lost*

Dante, Canto 1, Inferno (Sinclair, 1975:22, 23)

I have always been fascinated by language. My first degree was in Modern Languages. When a spinal injury brought about an enforced career rethink in my early twenties I was fortunate to find a path into speech and language therapy. I instantly engaged with the language of aphasia that has been the primary focus of my professional practice for the last 25 years. For me, aphasia presented a series of mysteries: a mystery about the structure and retrieval of language, a mystery about personhood when masked by the veil of aphasia and a mystery about how people with communication disability (re-)

integrated socially and culturally into a world increasingly dominated by communication capital and social networking. Learning to understand the language and culture of aphasia have consistently fuelled my curiosity and my practice.

At first, I embraced the detective work of cognitive neuropsychology that shone an enthralling light on brain and language. Language processing models based on disconnections or transitions of words and sounds through defined boxes and arrows gave me, and hopefully my clients with aphasia, a tiny handle on the chaos of language that faced us. However, this offered limited support in dealing with the daunting changes to self and altered interactions with others. This required different insights and a more human psychology.

Intensive rehabilitation offered some more holistic approaches to supporting individuals with aphasia. It was clear, however, that the toughest part of rehabilitation for most people was when they left the focused world of rehabilitation, to re-enter the rest of life. I remember how unprepared I was after my own rehabilitation, even armed with full access to language, to deal with uncertainties about disability, the comments and assumptions of others, and the challenge of navigating opaque barriers to work and welfare. Discovering the social model of disability had a profound effect on my thinking and practice. It spoke to my ambivalent feelings as both a disabled person and a therapist. It spoke to some of the frustrations I felt about my own disability and to the anger I experienced on behalf of my friends with aphasia. Thinking about barriers and identity as they applied to aphasia and ways to promote more inclusive, grounded models of practice became a new focus. Eventually this led to setting up and working at Connect, the communication disability network. Drawing on social model principles and values of respect, inclusion, collaboration and communication, I led the innovation services at Connect for ten years, working alongside people with and without aphasia to create innovative long term therapy and support interventions for people living with aphasia. These experiences have shaped my professional identity and

influenced the values and participative worldview I brought to my new identity as a PhD researcher.

Doucet (2008) uses the metaphor of gossamer walls to describe the sheer but solid walls to conceptualise types of reflexivity important in qualitative research. Gossamer walls, she asserts, can separate researchers from their own multiple selves and identities, as well as existing in the relationships between themselves and research participants and the audiences of their research. The process of thinking about friendship and disability has uncovered the value I place on friendships at work and play. With hindsight, and with insights gained during the research process, I realise how current and past friendships have helped me walk through some dark woods associated with acquiring and living with a disability. In the context of this research, relationships with members of the project Research Group over three years of travel have provided another source of constancy and steady, knowing, presence. These experiences have challenged previous unexplored assumptions I held both professionally and personally about the nature and form of friendship for disabled and non-disabled individuals.

### 1.3     Why us? Situating the Research Group in the study

In my PhD studies I wanted to think with and be a resource for a collective group of aphasia colleagues and activists. Many people with aphasia have been friends, peers and teachers to me over the years. Most remain unemployed and unrewarded for sharing their expertise. People with aphasia are not generally known for their activist tendencies.  The people I asked to travel with me on this research journey are people whose expertise and experience I value and respect. They are each leaders in their way who will no doubt continue to advocate with passion for their friends and peers with aphasia well beyond the project's conclusion.

The process of undertaking a participatory project with people with aphasia has posed two main challenges that run throughout this thesis. Firstly, there has been the challenge of managing the process of thinking, discussing, theorising and articulating research topics when communication is a struggle

and research processes are fundamentally grounded in language. Aphasia affects expressive and receptive aspects of language, reading and writing, as well as speaking and understanding spoken language. Many people with aphasia also describe difficulties using memory efficiently when language is impaired. These impairments, alongside fatigue, pain and mobility impairments, are familiar aspects of everyday life to researchers with aphasia in the Research Group.

Secondly, a major issue common to many PAR processes, is disentangling the work and contribution of the Research Group, who are central to the action and reflection within this study, from my own contribution (Herr and Anderson, 2005). What have *we* done within the project and what have *I* done as author of this thesis? For transparency, I have employed the collective pronoun 'we' to denote the shared work of the research project and elsewhere used 'I' to describe my agency as thesis author.

Entanglements and disentanglements also relate to the issue of presenting a thesis, converting the 'braided process of exploration, reflection and action' (McIntyre, 2008:5) into a neat, written sequence of research methods, findings and discussion. The corkscrewing, inter-linking cycles of planning, reflection and action do not translate readily to the neat linearity required of a thesis. There are multiple choices for organising the thesis material, each with their strengths and limitations. Ultimately I opted for a three-part structure, sandwiching the collaborative activity of the project (section B), between my perspective as researcher on the research context and methodological decision-making (section A) and, my reflection and discussion of the major research questions and findings (section C). These reflections are fed by collaborative process and action within the Research Group, but are presented from my standpoint.

## 1.4    Overview of the study

This study comprised two main phases. In Phase 1, the PAR group formed and determined the focus of the project and the design of the exploratory stage of the study. This phase explored aphasia and friendship using 12 in-

depth interviews with working-age adults with aphasia and led to the development of a preliminary model of friendship and aphasia. This model underpinned the Friendship and Aphasia Events created in Phase 2 of the study.

Phase 2 began with a one-year period of innovation as the Research Group designed and developed a series of activities and materials for the participative Friendship and Aphasia Events. A new group of working-age adults with aphasia were recruited in two locations. These individuals attended the events and subsequently 16 of them participated in semi-structured interviews. These Phase 2 interviews explored participants' responses to the events as well as personal understandings of friendship and aphasia. The Research Group discussed these new findings in relation to the original model of friendship, elaborating and adding branches to produce a final model.

## 1.5    Structure of the thesis

Part A of the thesis describes the context for the study and early decision-making about methodology and design. Chapter 1 describes my motivation for undertaking the research and, in keeping with the participatory ethos of the study, introduces the lived experience of aphasia as portrayed in first-hand accounts identified by the Research Group.

Chapter 2 presents the research context for the study by reviewing cross-disciplinary literature on friendship generally before critically appraising the small body of literature specific to friendship and aphasia. Chapter 3 describes the choice of Participatory Action Research as the study methodology and Chapter 4 presents an overview of project design.

Part B of the thesis documents the methods and findings of Phases 1 and 2. Chapter 5 details the methods employed in the exploratory phase of the project, carrying out 12 in-depth interviews. Chapters 6 and 7 present findings. Participants in both phases of the study described friendship experiences that were embedded in core experiences of living with aphasia. Chapter 6 discusses related findings for both groups of participants. Chapter 7 presents

Phase 1 findings on friendship and aphasia and the preliminary model developed for these.

Chapter 8 details the methods employed in Phase 2 of the study, and describes the Friendship Events and materials. Chapter 9 presents the findings that emerged from the semi-structured interviews with event participants. This chapter describes how these findings were used to develop the model further and discusses new understandings of friendship and aphasia revealed in Phase 2.

Part C of the thesis discusses and synthesises findings from the whole study. Chapter 10 focuses on the meanings of doing PAR with people with aphasia. This chapter describes the participatory practices and processes employed throughout the study, and offers insights into the benefits and challenges of doing friendship research collaboratively with people with aphasia.

Chapter 11 discusses the findings from Phase 1 and Phase 2 of the study in the light of existing knowledge and theory. It examines how this study's findings cast new light on the diverse and dynamic experiences of friendship after onset of aphasia. This chapter also reflects on the strengths and limitations of the study and critically appraises issues of quality for participative inquiry.

Finally, Chapter 12 summarises the study's findings and contributions as well as how these inform recommendations for a range of stakeholders: people with aphasia, their friends and family members, service providers, policy makers and researchers. Figure 1.1 summarises the structure of the thesis.

**Figure 1.1 Thesis structure**
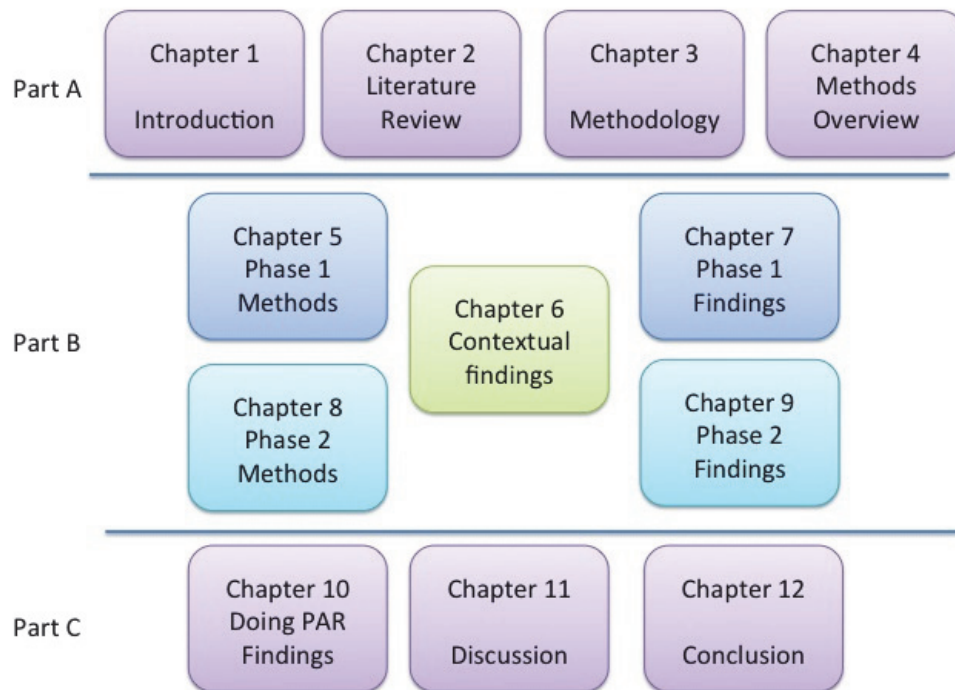


## 1.6    What is the experience of aphasia?

Before presenting the academic context to the study, this section introduces the experience of aphasia from first-person published accounts. It offers a selective synthesis of the ideas and issues which people with aphasia, particularly those working with me on the Research Group, highlight as important and relevant. Research into aphasia has seldom included the views and shaping influence of those who live with it. Professional interpretations of aphasia have largely offered professional solutions that deny a space for the creativity and agency of people with aphasia and those who live alongside them.   In keeping with the participatory ethos of the study this section prioritises accounts and experiences selected by Research Group members with aphasia.

Relatively straightforward linguistic or neurological accounts stress the loss of linguistic ability associated with neuropathology in the left hemisphere

(Benson and Ardila, 1996). Approximately one third of people who survive stroke acquire aphasia. Whilst stroke is the major cause of aphasia, it may also occur after other neurological conditions such as traumatic brain injury, brain tumours and dementia. Up to 250,000 people are thought to live with it at any one time (Aphasia Alliance, 2013). However, many people who acquire aphasia have never heard of it. Some people talk of not realising they had it for many years. People with aphasia tend not to talk about *aphasia* or *language* directly but refer to it as a myriad of symptoms and experiences (Parr, Byng, Gilpin & Ireland, 1997).

My BRAIN is bigger than
My WORDS
Maybe loud cymbols in LIFE

My WORD is bigger than
My BRAIN
Maybe viel visions insight

My BLUE is bluer than
My WORLD
Maybe reflect crazy mirrors[1]
(Ireland and Pound 2003:152).

In her poem 'My Asphasia World' (above), Chris Ireland describes the daily struggles of language impairment and the complex, personal emotions that interact with and amplify her distress and exhaustion. Windows into aphasia worlds are not straightforward for those on the outside. Ireland, for example, uses the cryptic phrase 'viel visions' to describe the shrouded view/ veil/' vie' of her aphasia world (Ireland and Pound, 2003). Ireland proposes that poetry and metaphor are an important way to capture the power and creativity of language that may be both lost and enhanced by aphasia. Poetry, like aphasia, she explains, breaks the rules of language and employs words

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[1] As described in the Preface, quotations from people with aphasia retain the person's own use of language.

differently. 'I look at aphasia as different but not as deficient' (Ireland, in Ireland and Pound, 2003:150). In a view consistent with an affirmative model of disability (Swain and French, 2000), the different experience of language can be considered unusual and creative rather than deviant or deficient.

### 1.6.1  Language and thinking

Hussey (2010) describes the symbiotic relationship between language and thought as he struggles for vocabulary and grammatical structure:

> 'I want to be well, clear and right. I start talking by going forward in my speech. I want to talk the sentence and continue. The word continues but doesn't go forward. I go back again. I'm thinking ahead. The structure is wrong. I think that's what I mean. I can't hold down the words, the sounds. My mind goes off' (Hussey, 2010:9).

It is clear from the behaviour and accounts of many people with aphasia that loss of language does not equate to absence of thought. However, Black and Ireland (2003) discuss the subtle impact of disrupted inner language, the ability to talk to ourselves, on aspects of thinking. Inner language, they argue, enables us to attend more closely to thoughts, hold onto them, shape and manipulate them. Drawing on cognitive linguistic theories (Jackendoff, 1997; Luria, 1963; Sokolov, 1972) they agree that language becomes a tool or handle with which to grasp and pin down a concept.

Comparing aphasia to the experience of reduced access to inner speech when mentally crossing between her native Italian and emergent English language, Black (the linguist) remarks to Ireland (the poet with aphasia):

> ''Language roots my thinking', you said. When I asked you whether you meant *roots* or *routes* you decided it was both.  Like you, I need them both to make sense of my experience. Language seems to anchor my thinking and allow me to retrace my mental steps more directly' (Black and Ireland, 2003:29).

Black and Ireland (2003) contend that internal and external dialogues can be important both cognitively and emotionally as verbal struggles meet with alternative existential states.

### 1.6.2   Identity and existential dimensions of aphasia

> 'With aphasia I get a sense of an idea and it remains opaque, like
> seeing through a frosted glass, without precise definition. Or a concept
> wrapped in cellophane seen from afar' (Khosa, 2003:19).

Introspecting on the slippery nature of language, thought and identity, a
number of people with aphasia draw on metaphors of mists and masks in their
narrative accounts.  A detachment from language and a distance from more
familiar life can have profound consequences on connection to self and
connection to others.

Johnson (Pound and Johnson, 2010) draws on Rawl's concept of a 'veil of
ignorance' (Rawls, 1971), a mutual barrier to engagement and understanding,
in describing the fog that separates him from others and others from him.  The
changing day-to-day experience of words going missing, the unpredictable
response of others, and the lack of fit with public awareness of disability all
compound a sense of aphasia being hard to grasp. It is only as the holes in
the fog get bigger that connections with friends and family become sharper.

An unfamiliar sense of present time created by aphasia can engender a focus
on the past:

> I remember the stroke.
> That was a big event.
> So all the things that happened
> Before the stroke
> Were all really important. For
> After the stroke,
> There were three years,
> I didn't know what I was doing
> (Grant, Disability Arts Online, 2011).

However, for some, the experience of acquiring aphasia and re-evaluating life
can also open a new window on identity:

> 'Aphasia has not just been a disadvantage. In hindsight, the brain
> haemorrhage and subsequent aphasia forced me to gather the flotsam

and jetsam of my life and do some spring cleaning: throwing the rubbish away that I had gathered over the years that was no longer useful and keeping the bits that are precious' (Khosa, 2008:116, in Swain and French)

Some conceptualisations of aphasia emphasise an existential and social aspect to alienation. Paediatrician Christopher Green portrays his experience of going home after the 'torture' of two months rehabilitation:

'After 2 months of torture, they let me go home for a night. I arrived at the front door of my house. I was terrified - I didn't want to go in. I didn't feel I belonged there anymore, I felt like a stranger in my own home. Though my wife and boys looked after me so well - I was so loved - life had changed. The only ones who treated me as if nothing had happened were my two dogs. They saw no difference in me. I remember waking up the first morning back at home. For a moment everything seemed normal. Then I realized I couldn't speak' (Green with Waks, 2008:128-129)

Making contact across the void of language and aphasia can be hard for relatives and friends also. Writing of his experience of his relationship with his aphasic father Phillip Gross also describes a space of silence in his poem, 'Something Like the Sea':

*On the shores of Lake Aphasia*
Mist seeps upwards, early morning, in fine strands
Like milk in water. Almost Japanese.

In some Zen light, or Pure Land
We might see it so:
      The more
White paper, the more eloquent:
           Silence
Measuring the distance between this and this
(Gross 2011: 27)

In addition to isolation and alienation, people with aphasia identify humiliation and inferiority as common existential dimensions of aphasia. Writing of her early days as a person with aphasia, Boazman (1999) recalls:

> 'With my ability to communicate destroyed, it seemed as if the very core of my personality had been wrenched from me. In retrospect, not being able to express my feelings and emotions verbally was the biggest loss of all, at that time. I felt I was at the mercy of the nursing staff at the hospital, and of the well-wishers who came to visit me. With my thought processes still intact, losing my speech was like being locked inside my own head' (Boazman, 1999:15, in Corker and French).

Loss of language imposes a similar loss of control and an absence of words to cushion or negotiate what is happening. Writer Tom Lubbock experienced progressive loss of language as the consequence of a brain tumour. Contemplating the gradual degradation of language he wrote:

> 'the loss of language will amount to the loss of mind. I know what this feels like - no insides, no internal echo...something in my head is hurrying to kill me' (Lubbock 2010:9 Observer Review 07.11.10.).

### 1.6.3   Language, power and control

Powerlessness and the struggle for day-to-day control over conversation and participating in life are often at the core of published narratives. The first cup of tea is a common story told by those with aphasia. It is a powerful emblem of how language influences the minutiae of daily life. Writing in his life with aphasia blog, Louis de la Foret, describes one such moment where his aphasia interferes with a simple request for tea with no milk:

> 'I open my mouth to answer and get nothing. … This is the first time I have not been able to express myself except for trying to explain some errant school-boy behaviour to my father. I have lived relying the spoken and written word. I <u>want</u> to say them, but I <u>can't.</u> The tea comes with milk and no sugar – it is indicative of the day ahead, indeed, it points to a whole new way of life.' (de la Foret, 2011).

Others comment more explicitly on issues of language and power. MacKay, a sociologist who acquired aphasia, highlights how medical model ideologies reinforce lack of agency, lack of competence and voicelessness:

> 'Doctor: Mr MacKay
>
> MacKay nods.
>
> Doctor: Mr MacKay, I'm going to help you
>
> Doctor: Point to your peas.
>
> MacKay points to peas
>
> Doctor: Mr MacKay, point to your crackers.
>
> MacKay points to crackers.
>
> Doctor: Point to the carnations.
>
> MacKay looks around the room, eventually sees them behind his back and points to them.
>
> Doctor: Mr MacKay, you missed that one. Mr MacKay I'm going to help you recover the loss of cognitive functioning. I'm going to send an occupational therapist up to see you. You understand what I am saying?
>
> MacKay nods.
>
> Doctor leaves.
>
> MacKay and Paul (a friend in the room) exchange knowing glances' (MacKay, 2003:814-815).

MacKay contends that defining aphasia as a social rather than medical construction is a pre-requisite both to engagement in communication and affirmation of identity (MacKay, 2003).  A focus by medical practitioners, family and friends on loss of words denies identity and reinforces powerlessness and incompetence.

### 1.6.4   Return to work and play: Access, engagement and citizenship

As a consequence of aphasia, many people are unable to return to their previous work or leisure activities. For example, only one of the thirty people interviewed by Parr et al (1997) who were previously in employment had returned to full time work. Frustration and boredom punctuate the tales of people with aphasia. Many working-age adults with aphasia who were

previously active in employment, community and family roles, describe people, systems and temporal norms as unable to adapt to their changed communication.

Hewitt and colleagues highlight the role of communication access in the exclusion and potential inclusion of people with aphasia in work and as autonomous decision makers:

> 'if you can't get into a building physically you can't participate in the discussions and activities that happen there. If you can't get into a conversation or understand the papers for a meeting you can't participate in the important decisions. You're lost.' (Hewitt, DVD presentation, in Parr et al, 2008)

Time to construct emails and contributions to meetings, time to digest written material, time for breaks in the hard work of processing language, time for work colleagues and managers to communicate appropriately - all tend to be in short supply in busy workplace settings (Parr et al, 2003).

Access to old and new leisure activities may similarly be a casualty of poor communicative access compounding loss of confidence and a questioning of competence by self and others. Some people with aphasia highlight connection with peers as a powerful context for exploring engagement in the context of disability and difference. In a previous study, I reported evaluations of two community projects grounded in the solidarity of peer support. Individuals contrasted the sense of purpose and engagement they associated with joining a community of equals, rather than perpetually hiding and apologising:

> 'This is a really great way to meet other people with aphasia and talk to them and get to know them and realise you are not on your own. That you could have an idea for people with aphasia to get out there and enjoy themselves and learn about the world and how they can live in it and not hide from it. And don't ask permission. Human beings with a purpose to be' (Pound, 2011:201)

### 1.6.5   Personal relationships and social connection

The power of language and communication to form, maintain, and continuously negotiate social connection undergirds relationships, which are focal to this study. Unsurprisingly many people with aphasia describe the challenge of maintaining satisfying relationships at home when both they and those around them are bewildered by sudden language change.

The experience is not an easy one for relatives either. Changes in roles and problems talking when there are pressing practical and emotional issues to deal with can be frustrating and stressful on both sides:

> 'Yesterday I came home from work and Colin was in the studio and I really wanted to talk to him about our finances, the girls – everything. So I said 'I really need to talk to you but I can't. That made him cry. Then me too. I said sorry. But I *do* need to talk to him – *he* is the person I always talk to' (Knight, 2005:19).

Living with a sense of yearning for a partner who has disappeared is a common topic of accounts by relatives.

> 'I want to stop time dead in its tracks. I want to rewind and fix everything. Take us back. I'll fix it. This isn't a fleeting thought, it's a constant yearning, for many months. Sometimes I daydream that it's possible, like rewriting a story. With the realisation that it can't be done, I double up in despair' (Maxwell, 2009:45).

Reconnecting with families and friends requires acknowledging and navigating powerful emotions as well as learning different strategies for communicating. Some relationships fracture under the strain or people drift apart before new ways of communicating become established and relationships evolve (Parr et al, 1997).

### 1.6.6   Perspectives on rehabilitation

Many people with aphasia welcome the listening ear of encouraging therapists and the guiding focus of rehabilitation. However, many caution against the mismatch of timescales and of ending therapy and support too soon. Others

talk of finding therapy programmes demeaning and out of touch with their own emotional responses and priorities. For example, Green described his anger at being given speech therapy exercises when he wasn't yet sure if he wanted to re-join the human race:

> I had to wait 5 days until I was strong enough to shuffle to the bathroom. Then I took the speechie's programme and flushed it down the toilet' (Green with Waks, 2008:128).

Accounts of people with aphasia often highlight lack of attention to psychological, emotional and social issues. Clarke (1998) who later joined this study's Research Group, recalled his dismay at finding no-one prepared to address his emotional needs rather than his physical and speech needs. This experience later prompted him to train as a counsellor for others with aphasia. Within his own rehabilitation, he noticed both the absence of male therapists and a perceived taboo of breaching topics of relationships and intimacy. Advising on the need for psychological support within stroke service improvement, he asserts:

> 'We're not just legs and arms and a mouth...we are human beings with a mixture of emotions. All these feelings...self esteem, self worth, confidence, identity ...they're all under attack after a stroke...you can feel vulnerable, frightened and you can lose yourself. Psychological support puts you back together again - especially psychological support from someone who's been down that road before. The timing can't be predicted...sometimes it's when you come out into your real world after hospital or it may be two - or more - years later when you discover that you will not make a 'full' recovery (Clarke, 2011:4 in Gillham and Clark, 2011).

### 1.6.7 Gaining new insights, making new connections

The consequences of aphasia can be extreme, dramatic and wide reaching. A spotlight on communication, identity and life within some published accounts also illuminates the new meanings and opportunities that the experience of aphasia can present. Some narratives of aphasia describe the impact of

aphasia on promoting self-understanding, improved relationships with others and a sense of external purpose (Hinckley, 2006).

Clarke (2003) reflecting of his personal experience and that of the clients he counsels talks of his aphasia as a 'sweetly liberating' journey of personal growth and self-discovery (Clarke, 2003:89 in Parr et al, 2003). His philosophy of 'doing less and being more' mirrors the stillness and silence he describes employing when counselling others with aphasia.

Learning to enjoy time away from work and relaxing in different ways is also possible. For some people with aphasia, more time with family and friends can bring unanticipated pleasures alongside new challenges to communication. Others describe hard-won access to self and community in the context of stroke support groups or new leisure activities.

Hussey (2010) recounts his own transformation though finding meaningful roles at his support and advocacy group. This came after four years when he wanted to die.

> 'I am no longer silent. My life has changed...  ...I am now able to use my skills to help in training and giving peer support. I have a life. I can be relevant – not useless' (Hussey 2010:9).

## 1.7    Summary

This chapter has introduced background motivations for the Friendship and Aphasia study and outlined the phases of the project and the structure of the thesis. Personal accounts of aphasia have sketched a brief picture of the diverse, complex and challenging experience of aphasia from the perspective of those who live with it. People report experiences of loss, bemusement, isolation and oppression as well as personal growth, liberation and new ways of making connections and feeling 'relevant'. Aphasia also has a profound impact on personal relationships yet discussion of the friendship experiences of those who live with aphasia has been largely overlooked. The personal accounts illustrated in this chapter set the context for reviewing research on the features and functions of friendship.

# Chapter 2
# Literature Review

## 2.0    Introduction

The purpose of this chapter is twofold. The first section presents a cross-disciplinary overview of notions of friendship, drawing on philosophy, psychology and sociology. This describes commonly employed typologies, features and theories of friendship that challenge taken-for-granted assumptions about its nature.  The second section synthesises research that links friendship (and lack of friendship) to experiences of health, illness and disability. Literature included in both of these sections has been gathered and appraised on an ongoing basis during the course of the study. This is supported as a strategy for becoming familiar with emerging knowledge in an area and contextualising a broad body of work as research questions take shape (Haverkamp and Young, 2007; Levy and Ellis, 2006). The chapter concludes with a thorough critical narrative review of all studies relevant to studies of friendship and living with aphasia.

## 2.1    Defining friendship and its functions

Given the familiarity of the term 'friend' and the ubiquity of 'friendship' as a concept in contemporary society, friends and friendship are surprisingly challenging to define. Most sociological and philosophical texts on friendship open with explanations of the nature of friendship which stress its ambiguity, complexity and specificity to personal, social, material, cultural and historical contexts (Adams and Allan, 1998; Spencer and Pahl, 2006; Vernon, 2010). Popular texts on friendship (e.g. Barnard, 2011) attempt to explain its depth and mystique by drawing on examples from literary works and modern culture as well as philosophy and the social sciences. Multiple perspectives seem useful here. Comparison of the hundreds of friends collected on Facebook sites with the rare and discerning 'soul friendship' described by philosophers such as Montaigne (1533-1592) and Aristotle (384-322 BC) draws attention to quantity, quality and diversity in describing the features and functions of friendships (Vernon, 2010).

### 2.1.1   Philosophy and friendship

Whilst social scientists have contributed to the study of different types of friends and friendship in their social context, philosophers have tended to focus on the fundamental nature and meaning of friendship. Vernon (2010) acknowledges the challenge of shaping an unequivocal definition of friendship but recommends exploration of its philosophical ambiguities as a promising starting point.   In his treatise on friendship within the Nicomachean Ethics (Aristotle, 1991), Aristotle differentiates friends of utility, friends of pleasure and friends of virtue. This tripartite categorisation of friends offers enduring clarity in framing understandings of friendship without imposing realist assumptions about what it means to be a friend (Smith, 2011). Friends of utility refer to relationships of reciprocity and goodwill driven by the functional need to be useful to each other. These friendships might, for example, be relationships between work colleagues or politicians and their allies where both parties stand to gain something from the friendship. Friendships of pleasure refer to those based on experiencing a mutual, activity-based pleasure such as a conversation, shopping, playing football. Friendly relations such as these are important for the individual and for society, since they are grounded in goodwill towards others, compassion and social justice (Vernon, 2010). Reciprocal bonds of beneficence and goodwill are important for citizenship and society and therefore the qualities of friendship are considered important underpinnings of social and political as well as personal wellbeing (Smith, 2011).  Friendships of pleasure and utility inherently include aspects of self-interest. Aristotle adopts a fairly unsentimental approach to these utilitarian forms of friendship which are considered to align with a sense of acquaintance or more distant friendship, defined by Homer (The Odyssey) as 'guest – friendship' (Stern-Gillet, 1995).   By definition, friends of utility and friends of pleasure are at risk of disappearing if the source of the utility or pleasure is removed (Aristotle, 2009; Stern-Gillet, 1995).

Aristotle's third type of friendship, friendships of virtue, in contrast, describes higher order relationships that move beyond instrumental functionality to something altogether more profound.  Friends of virtue are those referred to as soul friends or best friends or close friends (Barnard, 2011; Vernon, 2010).

This deeper dimension of friendship is associated with spiritual knowing and a level of communication and communion that places friendship at the pinnacle of rewarding human relationships. It moves beyond doing activities with friends to being with them (Smith, 2011). In Aristotle's view, true happiness can be achieved only through friends of virtue since, in addition to being a companion for external activity, they allow a person to develop morally and internally. These friends can hold up a mirror enabling friends to engage in a process of self-examination and self-discovery. To know one's friend, according to Aristotle, brings a requirement of knowing oneself and liking oneself. It is a process of deep communication about character, values and personhood leading to both pleasure and self-sufficiency (Stern-Gillet, 1995).

Aristotle's typology is appealing in supporting the flexibility and open-endedness that underpins both classical and more modern understandings of friendship. For example, Little (2000) proposed a slightly modified version of Aristotle's three friendship types which are helpful in bridging modern dimensions of friendship and linking philosophy and social science. His first category of friendship, *social friendship*, subsumes Aristotle's friends of pleasure and friends of utility, and is about friendliness with workmates and playmates. The second type*, familiar friendships*, reproduce relationships of the ideal family where friends provide support and continuity. This is the friendship of good neighbourliness and brotherly or sisterly love. His third category combines aspects of Aristotle's friends of virtue with Freudian principles of attachment and individuality. *Communicating friendship* is pure friendship built on the conversation and communion of two individuals: 'The heart of friendship is not companionship or sympathy, though these are likely to be involved, but mutual self awareness' (Little, 2000:15). This is the form of friendship that reaches beyond mere sociability, referencing instead self-discovery, and an expansion of identities through knowing another and knowing oneself.

Aristotle is an exponent of the 'mirror view' of friendship. A friend of virtue is like a second self, reflecting back an image of oneself and emphasising like-mindedness between friends. Some modern philosophers criticize the mirror

view of friendship as overly narcissistic and static. For example, Cocking and Kennet (1998) contrasted the 'mirror view' to the 'secrets view', where growing friendship is built on increasing degrees of self-disclosure and a deepening of mutual trust. Sharing secrets is a sign of commitment, affection and vulnerability and how these secrets are received and interpreted allows for a more dynamic interplay between friends. The 'secrets view' therefore places greater emphasis on a process of change that is both creative and dynamic. Friends give back not a reflection but an interpretation that Pahl (2000) aligns with the symbolic interaction tradition of Mead (1934) and Blumer (1969).

Other philosophers have also tackled friendship. Montaigne (1533-1592) described a form of deep, soul friendship. In his essay, *On Friendship,* he refers to his great friend and 'other self', La Boetie. For Montaigne, this is a pure and rare form of friendship that comes along infrequently. He associated the intimacy of soul friendship with imagination, creativity and energy (Little, 2000). Friendship of this quality fuels self-understanding, personal enrichment and cherished possibilities of human flourishing (Montaigne, 1991). Montaigne's essay also adds an emotional quality to the more intellectual pleasure of friendship emphasised by Aristotle. Recalling a short-lived friendship, due to the untimely death of La Boetie, Montaigne's treatise highlights the painful, lingering sense of loss and loneliness when a friend dies. Montaigne both mourned his friend and followed the classical philosophical advice of visualising his dead friend as a guiding spirit for the remainder of his career (Bakewell, 2011).

Unlike the Renaissance-influenced secular humanism of Montaigne, Soren Kierkegard's contribution to the understanding of friendship promotes a more divine dimension. Interested both in meanings of being human and in meanings of being a Christian, Kierkegard (1813-1855) was critical of the narcissism and self interest of reciprocated self love in Aristotle's form of pure friendship. There is an inherent tension in his struggle to reconcile the selfish motivations of friendship with a theology founded on divine love. His philosophy of friendship underpinned by the commandment to 'love thy neighbour', emphasised charity and giving. Faith and friendship compete

because in requiring faithful, committed service, a Christian view of friendship presupposes a serving rather than equal relationship (Little, 2000). This is relevant to understandings of friendship within health contexts where friendship becomes entangled with notions of care and support.

### 2.1.2 Communication and friendship

Clearly communication is core to studies of aphasia and studies of friendship. For the ancient philosophers, conversation with friends represented a pathway to happiness. Good conversation and contemplation among virtuous circles of friends equated to mutually exploring meanings and selves, a theme also explored by Plato in the *Lysis* (Plato 2005). An interpretation of this treatise by Vernon is that friendship is based in dialogue and that 'the motor of friendship is the delight of always finding more in the friend and in friendship' (Vernon, 2007:179). The art and pleasure of companionable, reflective conversation also represented the pinnacle of good friendship for Aristotle. Sustained friendship therefore demanded living in close proximity, being together and talking together: 'Many a friendship has lack of conversation broken' (Aristotle, 2009:147).

Little's terminology of 'communicating friendships' also stresses the presumed supremacy of communication in forging and sustaining the closest friendships. Shared thinking is based on reflection, dialogue and discourse between friends. For Little, 'Conversation is vital to friendship …conversation carries more mutuality than any other social relation…conversation is how we maintain the liveliness, the mutual understanding, the common consciousness that make up relatedness itself' (Little, 2000: 32). The salience of conversation within 'communicating friendships' threatens the very possibility of this form of friendship in the context of aphasia.

Rawlins (2009) also focuses on communication and interaction in his discussion of friendship. He places a series of dialectics, including the dialectic of individuation and participation at the centre of his work on friendship and communication between friends. Through communication and discursive activities such as storytelling and dialogue, friends can be both spectators and

involved participants, relating new discoveries about a person to our own experiences and perspectives. The goodwill of friendship causes this co-telling and co-witnessing to be significant in how we think of others and how we think of ourselves. For Rawlins, 'A humanising blend of personal autonomy and social participation lives at the heart of friendship' (Rawlins, 2009: 9).

Philosophical approaches to friendship reveal both the scope of friendship and its tendency to engender intriguing ambivalence and ambiguity in relation to how it is defined (Vernon, 2010). Classical approaches also highlight strong themes of communication, identity and personal growth with and in the company of friends.  The profound impacts of aphasia on conversation and identity suggest that individuals may be at high risk of losing the range and quality of friendships experienced prior to the onset of aphasia.

### 2.1.3   Social sciences and research into friendship

Adams and Allan (1998) trace the historical development of friendship studies from largely psychology-dominated studies of individuals and their measured attributes to a growing acknowledgement of the importance of the dyad and the interactional process of the relationship.  The importance of individual actors, the dynamic of the relationship and its location in a structural network of social operating must also, they argue, draw on study of the wider social and economic context in which these relationships play out. Adams and Allan (1998) and Pahl (2000) reflect on the relative absence of attention to the informal social ties of friendship within the sociological literature.

Many social science and epidemiological perspectives on social life and friendship have focused on types and numbers of people in different network categories and the behaviours of these particular groups. These studies only help to some extent with definitions of friends and friendship, as social network typologies define friends and their differentiation from other social relations in a somewhat arbitrary fashion (Victor et al, 2009; Bowling, 2005). Population studies for example tend to locate family members as distinct from non-kin relations. Neighbours too may occupy a different label (Wenger, 1991; Litwin, 2001). Friends are distinguished by a non-kin, voluntary relationship. Overlap

between spouses who are 'best friends' (Oliker, 1989) and neighbours who provide important affective as well as purely instrumental support suggest however that, in reality, a blurring of boundaries is commonplace.

Spencer and Pahl's elegant qualitative study (2006) of the personal communities of 70 people, aged between 18 and 75, demonstrates the complex meshing of friends and family, as well as other intersecting social connections. They provide an optimistic appraisal of contemporary adult friendship in the age of fast-paced lives and virtual communities, critiquing the myth of disintegrating social and community life. Their study 'Rethinking Friendship: Hidden Solidarities Today' suggests that individuals choose and experience a diverse range of friends and friendship patterns. Types of friends vary from a 'simpler' dimension of friendship such as 'useful associates' or 'fun friends' through to more 'complex' friendships such as comforters, confidants and soul mates. Different individuals in their study displayed different friendship repertoires. Some selected people as important to their personal community based on simpler friendships, for example those branded as predominantly fun friendships or loose acquaintances. Others tended toward more intense repertoires with complex friends. Other respondents had a mix of both simple and complex friendship types.

Spencer and Pahl (2006) question the meaning of the familiar adage 'you can choose your friends but you can't choose your family'. Their respondents illustrate two-way patterns of 'suffusion' between friends and family: friends who were perceived as like family ('he's like a brother to me') and family who became like friends ('my wife is my best friend').  Like Little (2000), Spencer and Pahl (2006) note that family-as-friends and family-like friends tend to engender feelings of trust and commitment. This complexity, they concluded, requires researchers to unpack friendships on a one-by-one basis. Studies of the social worlds of people with stroke that impose rigid categorisations may fail to reveal how friends and family take on these multiple and overlapping roles.

Changing demographics and ageing populations have intensified the social policy interest on friendships in later life and their role in supporting positive health and wellbeing. For example, personal identity is known to face threat at times of crisis and transition. At different points in the life course, the positive benefits of friendship may include security and self-validation, development of confidence and sociability, buffering against stress and maintenance of identity (Hartup and Stevens, 1997). There is some evidence to suggest that friends as well as family play an important role in supporting the renegotiation of identity and the resilience to cope with traumatic change such as illness, redundancy and divorce (Hartup and Stevens, 1997; Watts et al, 2009). For example, Wilcox (1981) suggested that adult women who divorce fare better where they have strong friendships rather than family networks to help them cope with traumatic relationship breakdown. Within the gerontology literature, female confidantes are a well-acknowledged source of support for older women who outlive their partners (Adams and Blieszner, 1989). Studies of friendship and healthy ageing are discussed in more depth below.

The large social psychology and sociology literature on friendship, ageing and the life course has been critiqued for focusing on social networks and the numbers of contacts within them at the expense of more qualitative aspects of friendship (Hartup and Stevens, 1997; Victor et al, 2009). Hartup (1996) argues that merely possessing friends fails to elucidate the complex experience of friendship. Friendships are qualitatively variable in terms of their content (what people do together), their constructiveness (how differences are negotiated), their closeness (the degree of self-disclosure), their symmetry (is social power distributed equally?) and their affective character (how supportive or conflict-ridden they may be) (Hartup and Stevens, 1997). A recurrent measure of friendship quality within the social psychology literature is an emphasis on symmetry and the give and take of friendship, as will be discussed below.

### 2.1.4   Reciprocity and social exchange

Friendship is often assumed to be a voluntary, open-ended social tie built on unspoken conditions of balance and reciprocity (Jerrome, 1990; Rook, 1989).

It lacks the obligation and formality of family ties or work relations but is nevertheless embedded in an ethic of equality and mutual engagement between peers (Pahl, 2000). A fair trade in the give and take of social relationships, the principle of reciprocity, constitutes a cornerstone of *social exchange theory* (Blau, 1964), and *social equity theory* (Hatfield, 1995). These theories focus on the exchange and value of social goods, examining how relationships might strengthen or dwindle on the basis of equitable or inequitable trade within a dyad.

Rook (1987) notes the importance attached to exchange of companionship, instrumental aid and emotional support in relationships between friends. Individuals connected through peer ties, she suggests, are not based in reciprocity in the sense of 'tit for tat' exchange but on an 'equality of affect'. Associations between peers differ from kin-based exchanges that encompass an element of duty in addition to motivations of concern and affection. In her study of 120 older women, she found evidence that experiences of reciprocity were stronger in interactions between friends than family and were associated with positive feelings about relationships.

Glover and Parry (2008) argue that utility is not the purpose of modern friendship and that resource exchange within friendship should be seen as a by-product rather than the primary reason for the relationship. In their investigation of friendships between women experiencing infertility problems, they contend that 'Friendship is presumably 'equal' because a balance usually pervades in the symbolic, emotional, and material exchanges between friends' (Glover and Parry, 2008:210). Although there may be times when friends are justifiably called on for more prolonged help and support the notion of reciprocity was key.

These studies suggest that the notion of give and take within friendships is important but that changed circumstances such as the presence of aphasia may require a re-construal, on both sides, of the emotional and instrumental resources that individuals have to exchange.

**2.1.5   Friendship differences**

The meaning and importance of friendship may vary across different groups. Different friendship patterns across gender, age, class and context have all received attention in the sociological literature.  There are notable differences in the patterns of male and female friendships particularly amongst older adults. There is evidence, for example, that men tend to rely more on spouses for emotional support whilst women utilise female friends (McDaniel and McKinnon 1993; Oliker, 1998). Studies of women's friendships highlight the affective, interactional nature of their relationships in contrast to a tendency for men to form friendships based on shared activity such as work or sporting interests (Adams et al, 2000; Wright, 1989). Women's friendship networks may be smaller but are likely to be more intimate (Hess, 1982) and whilst women will typically pick female confidantes as close friends, men will often select their spouse or partner (Due et al, 1999).

Although Pahl and Pevalin (2005) caution against drawing causal relationships between class and friendship, there is some evidence that working class friends are more likely to exchange practical support and material goods whilst middle class friends exchange network contacts and leisure activities (MacRae, 1996; Walker, 1995). Allan (1997) described findings of more context-bound working class male friendships, predominantly situated locally within shared economic and historical settings, compared to the more diversely situated, interaction based middle class friendships. He also suggested that these constraints could be changing in line with altered domestic and social environments.  Shared contexts that emphasize equality and shared experience are natural and fertile environments for friendships to grow.

Numbers of friends vary over the life course, suggesting that research into friendship after stroke, where many participants fall into an older age group, needs to take greater account of these different patterns. Whilst newlyweds have the most friends in adulthood, middle-aged adults have fewer friends and spend less time with them though networks may increase again preceding retirement (Hartup and Stevens, 1999).  Fukukawa et al (2004) explored age

and social interactions as moderators of depression and social activities in middle-aged and older adults with health problems. This study was set in the context of normative life events theory that states that health problems will have a greater impact on wellbeing when they are not expected, for example in a younger period of life (Pearlin and Lieberman, 1979). Findings indicated that emotional support buffered the impact of depression in middle-aged adults whereas instrumental support buffered decline of social activities in older adults. This study is unusual in comparing effects across age groups and sources of support.

### 2.1.6   Towards a definition of friendship

In summary, social sciences research sheds light on patterns of friendship associated with demographic variables such as age, gender and class. Evidence reveals a complex blurring of boundaries across different social relationships, such as friends, spouses and other family members. Similarly, research suggests a need for methodologies that take account of the individual and social nature of friendship and the understandings that different individuals bring to it. In contrast to other social ties, friendship highlights relationships founded on mutual liking, reciprocal exchange and companionship. Although some friendships develop from or into dutiful family-like bonds, most are situated within principles of choice and agency. The range of possible forms of friendship makes it a relationship with different degrees of choice, commitment and social exchange.

Friendships are also hard to define because they are fluid, dynamic and characterised by natural change across a person's life course. Absence of a set definition of friendship supports the need for enquiry into qualitative meanings of friends and friendship.

### 2.2   Troubles in friendships

The fluidity and ambivalence of friendship may also become a source of tension, disappointment and drama.  In consigning Brutus and Cassius to the very lowest reaches of Inferno for the murder of their friend Caesar, Dante encouraged his readers to heed the serious moral consequences of

friendships betrayed. The dramatic possibilities of the darker side of friendship are much exploited in literature, drama and film. Friends lost through betrayals of trust, desertion or falling-out have been less frequently addressed within friendship research. A potential consequence of personal transformation, for example following life-changing events such as stroke and aphasia, is that 'if we have greatly transformed ourselves, those friends of ours who have not been transformed become like ghosts of our past' (Nietzche, writing of the fracturing of his relationship with Wagner, quoted in Vernon, 2007:53). Prolonged periods of company with suffering and pain rather than time shared in pleasurable pursuits can test friendships and often cause them to rupture (Aristotle, 2009). These are areas of interest within this study as long-term illness and disability is known to exert strain on both friendships and family relationships (Lyons, 1991; Lyons et al, 1995).

Relatively little is known about friendship troubles in adulthood. Moreman's (2008a) grounded theory study of 26 older American women reported stories of deep hurt, and disappointment when friendships fractured under the strain of broken confidences, betrayal and unequal reciprocal exchange. The most frequent cause of relationship strain in her participants was when unspoken expectations of friendship were breached. Rook (1989) discussed breaking implicit rules in friendship in a study exploring the tensions that arise in friendships when social reciprocities and exchanges fall out of balance. Reciprocities are more typical of friendships as opposed to family relations and therefore may be more sensitive to disruption of symmetry. Rook's findings also suggest that the negative side of friendships are more powerful than the positive consequences of good friendships. Conflict or loss of friendships when unspoken 'rules' are broken can lead to stress, isolation and loss of access to the emotional and instrumental support that is a by-product of good social companionship. This may be even more apparent where illness and disability challenge the natural balance of reciprocal exchange between friends.

**2.3     Friends in times of sickness and health**

As stated, friendship is known to bring positive benefits to health, happiness and quality of life. People with strong social relations live longer, are more protected from the ravages of loneliness and depression, and have access to greater support resources from their community of friends in times of need (Berkman and Syme, 1979; Jerrome and Wenger, 1999; Litwin, 2007).

Absence of friends, infrequent contact with friends and inability to make new friends, all feature strongly in indices of social isolation (Scharf et al, 2002). Lack of friends is known to link to feelings of loneliness (Dykstra, 1995). People who experience loneliness are more likely to experience poor physical and mental health (Adams et al, 2004; Cacioppo et al, 2006) and rate their own health as poorer than those who do not feel lonely (Victor et al, 2009). Research has also indicated health effects resulting from problematic and ambivalent friendships. Relationships characterised by a mix of positive and negative aspects have been associated with increased levels of depression (Uchino et al, 2001) and higher blood pressure (Holt-Lunstad et al, 2003). However, relatively little is known about why individuals persist with or terminate ambivalent relationships (Bushman and Holt-Lunstad, 2009; Rook et al, 2012).

Many studies relating to the health benefits of friends are situated within a burgeoning literature on social support. For example, Glass and Maddox (1992) reported more positive outcomes after stroke where individuals were able to access good social support. However, within the field of acquired disability including stroke, enquiry into friendship, rather than the provision of uni-directional social support is rare (Lyons et al, 1995). The specifics of friendship as compared with the provision of family support are not well differentiated and there is a tendency for the concept of social networks and social support to be used interchangeably (Cohen, 2004), further blurring the boundaries between friends and family.

Both family and friends are significant members of social networks. Social networks refer to the web of social relationships that exist around an individual

and the nature of the social bonds with those people (Bowling, 2005). They are the structure through which individuals may access social support. Social support refers to the provision of instrumental, informational or emotional resources (Helgeson, 2003; House and Kahn, 1985). Some authors break social support down further. For example, Sherbourne and Stewart (1991) identified emotional support (someone to confide in and show empathy), informational support, tangible support, affectionate support (someone to show love and affection), and social companionship (social integration and belongingness).

Most often, measurements of social support relate to perceived social support rather than actual support received (Bowling, 2005). It is perceived social support, or a belief about being cared for, loved and valued which buffers the impact of stress on wellbeing (Cohen and Wills, 1985). Studies of the impacts of social support often fail to unravel the complex interdependencies within participants' micro-social worlds and the diverse functions played by individual family, friends and loose social ties within personal networks (Pahl, 2003). Understanding the meaning and supportive possibilities of friendship after aphasia requires careful unpacking of personal definitions.

In the context of older and disabled individuals, friends have been noted as an important source of emotional support (Siebert et al, 1999; Gallant et al, 2007) and a potential protection against depression (Fukukawa et al, 2004). Friends and confidants within social networks provide important support in 'buffering' the stresses of illness and negative changes associated with ageing such as the loss of a partner (Cohen and Wills, 1985; Moreman, 2008b). Friends may offer greater opportunities for socialisation and companionship than family members (Crohan and Antonucci, 1989). There are also suggestions that friends may be helpful in facilitating adjustment to disability and self-management of chronic illnesses associated with older age (Gallant, 2003). Friends may play a different role to family members in supporting those in middle and older age (Fukukawa et al, 2004; Dunkel-Schetter and Bennet, 1990). For example, in their study of Asian adults with health problems, family relationships were found to buffer the impact of health problems that persisted

over a long period more than social support provided by a group of 'other relationships' defined as friends or acquaintances.

However, the voluntary, reciprocal nature of friendships may be at the root of findings that contact with friends has a more positive impact on the subjective wellbeing of older adults than contact with family members (Pinquart and Sorensen, 2000). The concept of giving (Aked et al, 2008) and being able to participate in acts of reciprocity (Rook, 1987), have been associated with positive emotions, such as self-esteem (Lee and Sheehan, 1989), and linked to friendship rather than family relationships. Friendship and the reciprocal elements of friendship are largely invisible within studies of social support and close social relationships after stroke where the concept of caregiver burden underlines the assumed imbalance of care and support (Greenwood et al, 2009).

### 2.3.1   Friendship and disability studies

Friendship is a surprisingly muted topic within adult disability studies. In a review of major publications and journals on disability, Shakespeare (2006) remarks on the minimal attention paid to matters of friendship, sexuality and loneliness. This is in the context of strong evidence, particularly from people who have learning difficulties and mental illness, that isolation, diminished social networks and limited social integration are commonplace. For example, Pinfold (2004) reported that 84% of mentally ill people in their study felt isolated in comparison with 28% of participants from the general population. Robertson et al (2001) suggested from their review of learning disability services that only one in three people accessing services had even a single friend.

Shakespeare (2000), in discussing the sexual politics of disability, suggests a range of possible reasons for this limited focus on relationships and intimacy. Firstly, disability scholarship has, of necessity, prioritised the struggles for equal rights and social inclusion. Secondly, the strongly politicised, direct action campaigns did not fit easily with a focus on the more domestic and intimate causes that disabled feminists espoused in the 1990s (see Chapter

3). Thirdly, he considers that a focus on issues of friendship and isolation may have been too distressing for emancipatory researchers and participants.

Struggles to achieve positive disabled identity and sense of self are important foundations for developing and sustaining relationships. Disabled people are more likely to live in poverty, be unemployed, single and have less access to leisure, culture and sport based activities than their non-disabled counterparts (Office for Disability Issues, 2013). Barriers to friendship may reflect usual inequalities, such as lack of opportunities for work, inaccessible transport and financial deprivation. But social isolation is often a consequence of both discrimination and impairment effects, particularly those impacting on communication and competence (Shakespeare, 2006).

Studies of social relationships and support relationships within disability studies have highlighted both the gendered nature of caring and the blurring of relationships between care staff and disabled people. For example, in a review of studies exploring friendship and community connection between people with and without developmental disabilities, Traustadottir (1993) noted the over-representation of women amongst the friendships of disabled men and women. In a small qualitative study, Pockney (2006) examined friendship experiences from the perspective of people with learning difficulties and their support workers. Whilst many of the learning disabled participants identified support workers as important friends within their social circles, their support workers were more likely to differentiate friendly feelings from friendship. Friendships may require an aspect of caring and caring may lead to close relationships and friendship. Traustadottir (2004) argued that skilful caring *about* rather than caring *for* might translate from support work to genuine commitment and involvement that is more associated with friendship and advocacy (Traustadottir, 2004).

Mistaken friendship or friendship embedded in paternalistic, highly structured activities were also emergent themes from Bjarnasan's (2004) qualitative study of 36 young disabled adults. This study revealed complex, nuanced and valued relationships between disabled adults, their friends and carers. Despite

the complexity of these relationships Bjarnasan concluded: 'Having one good, close trustworthy friend may mean the difference between quality in one's life and 'just living'. Having at least one non-disabled friend may ensure active participation as a fully fledged young adult in mainstream society' (Bjarnasan, 2004:189, in Kristiansen and Traustadottir, 2004). This argument seems likely to apply equally to adults who acquire a disability.

Disability studies research also highlights the importance of considering who is doing the evaluating within studies of friends and friendships. For example, Chappell (1994) noted that professionals gave inferior value to peer friendships between people with learning difficulties than to friends who were non-learning disabled. A recent survey of people with schizophrenia (Harley, Boardman and Craig, 2012) reported that whilst the number of people participants counted as friends was low, people with schizophrenia did not perceive this as problematic. Researchers, on the other hand, tended to view both the number of contacts, and the quality of relationships, in a more negative light. Studies of friendship that prioritise the perspective of professionals or of relatives who are caregivers may also misrepresent the experiences of individuals who live with a condition. Within stroke studies this has often been the situation for people who have communication difficulties. This reinforces the need for inclusive research methodologies that prioritise people with aphasia in interpreting as well as directly providing data.

### 2.3.2   Stroke and friendship

Most people who experience aphasia do so as a consequence of stroke. Conceptualisation of friendship has not been well addressed within the stroke literature despite the fact that stroke is the major cause of adult disability in the UK, affecting approximately 110,000 new individuals annually, including approximately a quarter under the age of 65 (Department of Health, 2007).

Wide-ranging social impacts of stroke for those of working age include loss of work, (Daniel et al, 2009) reduction in social activities (Kersten et al, 2002; Niemi et al, 1988) deterioration in social relationships (Dowswell et al, 2000), and changes to social roles (Alaszewski et al, 2004) and social participation

(Dalemans et al, 2008). There is consensus that the long-term social consequences of stroke remain poorly explored from the perspective of people who live with stroke (Wolfe et al, 2008), that services addressing the social consequences of stroke are under-developed (Reed et al, 2012) and that many of the longer term social and emotional needs of people with stroke are not well-addressed (McKevitt et al, 2011; National Audit Office, 2010).

Within stroke research friends feature either in the context of these loss-related impacts or as a source of social support associated with adjustment and coping. For example, Astrom et al (1993) associated loss of non-family social contacts with a heightened risk of depression. Angelieri et al (1993) also linked failure to resume social activities with post-stroke depression. In a meta-synthesis of qualitative literature, Reed et al (2012) highlighted the importance of friends and family as a supportive web of social support. Sumathipala et al (2012) concluded that practical and social support received from family and friends was an important factor related to buffering the negative social impacts of stroke and facilitating opportunities for social participation. Several studies have indicated that friends within the context of stroke support groups may inspire hope and recovery (Ch'ng et al 2008; Cross and Schneider, 2010). Some studies also suggest that friends can be a part of the support network that encourages a return to previously valued activities (Robison et al, 2009; Kubina et al, 2013).

However, as with studies of other acquired neurological conditions and social relationships, this discourse remains dominated by a focus on negative changes in family relationships and the provision of social support (Lyons et al, 1995; Ward et al, 2012). Mention of friends is often peripheral or loosely grouped within discussion of social relationships and social participation. Although the importance of social relationships and social connectedness is gaining a higher profile within qualitative explorations of life after stroke (Satink et al, 2013; Kubina et al, 2013) the persisting tendency to view stroke through a medicalised lens has arguably limited detailed explorations of friendship. Furthermore where stroke studies do refer to friends, it is often unclear whether people with aphasia have been included in the study. Where they

have, the means by which they have been authentically involved (e.g. via adapted questionnaires and interviews, with or without the support of relative caregivers) has not usually been made explicit (Brady et al, 2013). This points to the need for studies that probe understandings of friends and friendship in a more sophisticated fashion, and from the viewpoint of individuals who live with aphasia.

## 2.4    Summary of background literature

Philosophical discussions of friendship emphasise meanings rooted in communication, identity and the pursuit of happiness through learning and self-knowledge. Categorisations of friendship such as offered by Aristotle also suggest that different types of friendships may perform different functions. Some groups, such as friends of utility and friends of pleasure, may be more prone to rupture if the shared activity ceases or circumstances change. Sociological and social psychology studies also highlight friendship differences based for example on gender or degrees of self-disclosure. Literature from philosophy and social sciences agree that friendship is a complex relationship that defies simplistic definition.

Attempts to define friendship also highlight the complex blurring of boundaries that can arise between friends and family. This is significant within studies of social networks and social support that demonstrate there may be differential effects of contact with friends or family.  Empirical studies reveal the alluring benefits and possibilities offered by non-kin based relationships. Friendships may be good for physiological health, emotional wellbeing and self-management of long-term conditions. They may buffer the impact of stress and provide creative, alternative opportunities to explore new identities post-onset of acquired disability. This is particularly relevant in the context of acquired disability such as stroke where friendship loss and the negative impacts of disability on the quality and quantity of social relationships is prevalent.

Friendship has not been prominent within studies of disabled people and those affected by stroke where a focus on caregiving and the provision of

social support dominates studies of close personal relationships. Apart from the studies appraised below, non-kin relationships grounded in mutual reciprocity and social exchange have been neglected within stroke research.

Studies pertaining more directly to friendship and aphasia will be reviewed against this conceptual and methodological background.

## 2.5    Friendship and aphasia

### 2.5.1    Searching the literature

An initial literature review undertaken in 2010 using the terms 'aphasia' and 'friends' OR 'friendship' revealed eight key studies pertaining to the focus of this project. A thorough literature search was repeated in January 2013 identifying a further seven studies. In this sense the literature review was iterative and evolving as advocated by Levy and Ellis (2006). The purpose of the review was to identify and critically appraise primary studies pertaining to the research question exploring how working-age adults with aphasia experience and understand friendship.

Narrative reviews are considered more appropriate than systematic reviews and meta-analyses where fields are under-developed and where there is no clear clinical intervention question under scrutiny (Baumeister and Leary, 1997; Petticrew and Roberts, 2006). Critical narrative reviews are well placed to draw together knowledge produced across methodologically diverse studies, and appraise problems, limitations and inconsistencies across a body of work (Pope et al, 2007; Baumeister and Leary, 1997). This critical narrative review aims to contextualise the Friendship and Aphasia study within current knowledge about experiences of friendship after the onset of aphasia and to highlight the strengths and limitations of existing work.

The following electronic databases were searched: CINAHL PLUS; PsycINFO; Academic Search Complete; SCOPUS; AMED initially using a full text search employing the truncated search terms 'aphasi*' AND 'friends*'. Because few studies have focused exclusively on friends and friendship, further systematic searches were carried out aimed at maximising the sensitivity or

comprehensiveness of the search over more complex searches that emphasise precision (McKibbon et al, 2006, Walters et al, 2006, Wiczynski et al, 2007). This second round of searching employed the terms 'social relations*' OR 'social participation' OR 'social networks' as these topics typically encompass discussions of social relationships beyond family members. Following the strategy described by Bates (1989), a range of further search strategies were employed consistent with an overall approach of 'berrypicking' (Bates, 1989). 'Berrypicking' acknowledges the dynamic and evolving nature of information retrieval and encourages the use of a series of techniques rather than relying solely on searches of bibliographic databases. Berrypicking strategies include: following up on references in key papers (backward chaining); tracking citations (forward chaining); hand searching key journals (journal runs); area scanning (reviewing collocated items); author scanning (reviewing other research papers by key authors) (Bates, 1989; Barroso et al, 2003). In addition to using the above techniques, locating relevant literature was enhanced through drawing on personal and academic networks and serendipitous findings (Wilson et al, 2007; Greenhalgh and Peacock, 2005). A summary of the key search terms and sources of bibliographic search are presented in table 2.1.

| Table 2.1 Summary of search terms and bibliographic sources | | | |
|---|---|---|---|
| **Search terms** | Aphasi* | AND friends* AND 'social participation AND 'social relations*' AND 'social networks' | |
| **Databases** | CINAHL PLUS Academic Search Complete | PsycINFO SCOPUS WEB OF KNOWLEDGE | AMED Cochrane Library |
| **Journal run** | Aphasiology | Int. Journal Lang. & Communication Disorders | Disability & Rehabilitation |

Studies were included if they presented primary research describing the experiences and perspectives of people living with aphasia and made specific

reference to friendship experiences rather than social relationships based on kinship ties alone. Studies were excluded where the focus was on the perspective of health care professionals and family members, where experiences of participants with aphasia were not included or where the primary aims of the study concerned evaluation of interventions.

Because relatively few studies explicitly address the topic of friendship and aphasia, published studies were not excluded on the basis of criteria for quality. Appraising the quality of qualitative studies, which are prominent in this field, remains a contested issue (Mays and Pope, 2006). For example, published reports may lack sufficient detail with respect to theoretical perspectives, methodological transparency and reflexivity (Dixon-Woods et al, 2004). Checklist questions from the Critical Appraisal Skills Programme (http://www.casp-uk.net/) are recognised tools for appraising research and acted as a background guide for critically reviewing studies (Dixon-Woods et al, 2007). For example, the CASP tool for evaluating qualitative research asks a series of ten prompt questions to guide scrutiny of methodology, transparency, rigour and contribution.

The following review first describes studies with a focus on quantifying social support and social activities of people with aphasia. This leads to a review and critique of more qualitative explorations of life with aphasia and social participation after its onset. Finally, it reviews three studies whose research aims focused more explicitly on describing experiences of friendship for people living with aphasia. Although the current study focuses on the working-age population of adults with aphasia (18 – 65) many studies include both older and younger people and do not explicitly identify issues relating solely to the younger participants in the study. Two Australian studies relating entirely to older people with aphasia have been included as they report seminal work in this field (Davidson et al, 2008; Cruice et al, 2006). Major studies pertaining to this review are summarized in table 2.2.

**2.5.2   Quantifying social support, social networks and social activities**

Two studies adopted a quantitative approach to studying social networks and social activities (Hilari and Northcott, 2006; Cruice, 2006). Both Hilari and Northcott (2006) and Cruice et al (2006) set their studies within broader explorations of quality of life for people with aphasia, its description and relationship with other aspects of health and well being such as healthy ageing (Cruice et al, 2006) and depression (Hilari and Northcott, 2006; Hilari et al, 2010).

Hilari and Northcott (2006) studied the social networks of 83 men and women, mean age 61 years, with aphasia of at least one year's duration. Participants were recruited from two Speech and Language therapy provider services and one voluntary support organisation. This was part of a study exploring the relationship between social support and health-related quality of life (HRQL). Employing cross-sectional interview-based methods the study reported participants' responses on health-related quality of life measures, social support surveys and assessment of social networks. The study looked both at social network size and frequency of contacts.  Whilst 63% of the sample reported reduced contact with friends, most participants reported that frequency of contact with relatives and children remained the same or increased. Interestingly, increased contact with family members did not translate to improved quality of life, which typically was higher for those who maintained similar levels of contact as prior to stroke. The authors suggested that for those participants who saw more of their children, lower scores on HRQL might be due to a perception of being a burden to their relatives. Another key finding of Hilari and Nothcott's study was that approximately 30% of respondents with aphasia reported having no friends at one year post-stroke, though notably 12% of the sample also reported no friends prior to the stroke.

**Table 2.2    Friendship and aphasia literature review: key studies**

| Authors/date Country of origin | Aims of study | Participants | Time post-onset of aphasia / Severity | Data Collection / Data Analysis |
|---|---|---|---|---|
| **Cruice et al, 2006** Australia | Quantify regular social contacts and social activities of chronically aphasic older people. Compare these with matched healthy older people | 30 people with aphasia 57-88 years 71 non-aphasic controls | 10-108 months  Primarily mild - moderate aphasia | Interview Social Network Analysis Social Activities Checklist  Descriptive statistics |
| **Hilari & Northcott, 2006** UK | Examine patterns of social support in people with long-term aphasia  Examine the relationship between social support and quality of life | 83 people with aphasia mean age 61 years | 1 year 1 month - 20 years 10 months (mean = 3.5 years)  Mild - moderate aphasia = 89% | Interview-based survey measures include stroke and aphasia quality-of-life scale (SAQUOL-39) Medical Outcomes Study for social support survey; Social Network questionnaire  Descriptive statistics |
| **Le Dorze & Brassard, 1995** Canada | Understand the consequences of aphasia from the perspective of people with aphasia, and their friends and relatives  Analyse and structure their descriptions using the WHO concepts of impairment, disability, handicap and coping behaviour | 9 people with aphasia, 41-69 years  9 relatives and friends (8 x family, 1 friend) 20-70 years | 2-14 years  Moderate to mild severity of aphasia | Semi-structured interviews  'Discovery of categories' - some procedures based on Strauss and Corbin |
| **Parr, Byng & Gilpin, 1997** UK | Explore insider perspective of life with aphasia | 50 people with aphasia  26-92 years | Mostly > 5 years  Even spread mild, moderate, severe aphasia | In-depth interviews  Framework analysis |
| **Zemva, 1999.** Slovenia | 'Establish handicaps most commonly occurring in the life of aphasic persons | 20 people with Broca's aphasia (17 | 1-48 months | Structured interviews |

| Authors/date Country of origin | Aims of study | Participants | Time post-onset of aphasia / Severity | Data Collection / Data Analysis |
|---|---|---|---|---|
| **Zemva (cont.)** | and their relatives' | male) 57-82 years 20 relatives | Severity not stated | Analysis method not stated |
| **Parr, 2007** UK | Track the everyday experiences of people with severe aphasia. Document levels of social inclusion and exclusion in everyday settings | 20 people with severe aphasia 38-91 years (<65 N=8) | 9 months - 5 years. All participants have severe aphasia | 3 x observations with each participant. Ethnography documenting environments, interactions, events, protagonists. Thematic analysis |
| **Davidson et al, 2008** Australia | Describe everyday communication with friends for older people both with and without aphasia. Examine the nature of friendship conversations | 30 older Australians. 15 with aphasia 63-80 years. 15 healthy older people 63-78 years | 9 months - 9 years. Group participants - from mild to global aphasia. Case study participants - mild aphasia N=1, moderate N=1, severe N=1 | Naturalistic inquiry - Participant observation of 30 older Australians. Collective case study. 3 x interviews - stimulated recall. Interpretive analysis |
| **Barry & Douglas, 2000** Australia | Describe the social integration of 4 participants with aphasia and perceptions of their social interaction within their networks. Identify aphasia related and contextual factors that shape the social participation of individuals with aphasia and their families | 4 males with aphasia living at home. 29-65 years | 9-25 months. Mild aphasia N=2, moderate N=1, severe N = 1 | Structured interview & series of questionnaires. Descriptive analysis |
| **Natterlund, 2010a** Sweden | Describe experiences of everyday activities and social support in daily life | 20 people with aphasia. 14 men and six women | <5 years N=6. >5 years N=14. Severity not stated | Qualitative interviews. Qualitative content analysis around 2 main themes - experiences of everyday activities, and |

| Authors/date Country of origin | Aims of study | Participants | Time post-onset of aphasia Severity | Data Collection Data Analysis |
|---|---|---|---|---|
| Natterlund 2010a (cont.) | | 32-70 years | | experiences of social support in daily life |
| Niemi and Johansson 2013 Finland | Describe and explore how people with aphasia experience engaging in everyday occupations | 6 people with aphasia<br><br>46-75 years (4< 65 years) | 1-4 years<br><br>Moderate - severe N=2<br>Mild - moderate N=4 | Semi-structured interviews<br><br>Occupational perspective<br><br>Analysis method – phenomenological (unclear) |
| Dalemans et al, 2010 Netherlands | Investigate social participation through the eyes of people with aphasia | 13 people with aphasia and their caregivers | 1.4-11 years<br>Mild - moderate aphasia N=12, severe aphasia N=1 | Diaries<br>Semi-structured interviews<br>Focus Group<br>Inductive thematic analysis |
| Brown et al, 2010 Australia | Explore from the perspectives of people with aphasia the meaning of 'living successfully with aphasia' | 25 participants with aphasia living in community<br><br>38-86 years | 2-25years<br><br>Mild aphasia N=18, moderate - severe N=7 | Semi-structured in-depth interviews<br>2nd interview to discuss photos taken by participants describing 'living successfully with aphasia'<br><br>Interpretative Phenomenological Analysis |
| Vickers, 2010 USA | Measure and compare the social networks and frequency of contact within networks before and after aphasia<br>Explore the impact of weekly aphasia group attendance (N=28) compared to a control group (N=12) not attending the aphasia group | 40 people with aphasia<br><br>mean age = 64.4 years (range not stated) | Mean time post stroke = 81.39 months (range not stated)<br><br>Mean severity of aphasia = mild (range not stated) | Social Network interviews<br>Social Networks Inventory<br>Friendship Scale<br>Pilot Survey of Communication & Social Participation<br><br>Descriptive and inferential statistics |
| Northcott & Hilari, 2011 UK | Explore why people lose contact with friends after stroke<br>Identify protective factors<br>Explore how friendship loss and change is perceived by individuals with stroke | 29 participants with stroke diagnosis, 10 with aphasia<br><br>18-90 years (mean | 8 - 15 months post stroke<br><br>Severity of aphasia not stated | In-depth interviews<br>Framework analysis |

| Authors/date Country of origin | Aims of study | Participants | Time post-onset of aphasia Severity | Data Collection Data Analysis |
|---|---|---|---|---|
| **Northcott & Hilari, 2011 cont.** | | age = 68 years old) | Of 10 participants with aphasia N=2 mild stroke, N=1 moderate stroke, N=7 mod - severe stroke | |
| **Brown et al, 2013 Australia** | Explore the role of friendship in 'living successfully with aphasia' | 25 participants with aphasia living in community Range 38-86 years | 24-299 months Mild aphasia N=18, moderate - severe N=7 | Semi-structured interviews Thematic analysis Phenomenological approach |

Degree of contact with friends remained the same for 33%, and increased for 4% of the sample. There were some suggestions of gender differences with size of network showing correlation with improved HRQL in women though not in men. This is consistent with sociological studies looking at patterns of male and female friendships (Antonucci and Akiyama, 1987a; Due et al, 1999). Although associations failed to reach significance, people who had more frequent contact with their friends tended to report better HRQL. Social companionship and informational support, as assessed on the Medical Outcomes Scale Social Support Survey (Sherbourne and Stewart, 1991), were significantly associated with higher HRQL though tangible support was not. The authors concluded that research focusing on forming and maintaining social relationships post-stroke and associated intervention studies were important directions for future research.

Strengths of this study include the large, sample of participants who matched UK averages in most demographic variables and the use of descriptive statistics and correlation analyses to differentiate findings relating to contact with friends and to family. Limitations of the study concern the absence of a comparison group which might illuminate patterns of changed social contact and social support relating to consequences other than aphasia, such as ageing and chronic illness. The authors did not report details of participants' physical disabilities that may also have impacted on differences relating to contact with family members and friends. Also the study did not attempt any qualitative exploration of the nature of changes experienced in social contact with friends. Measures employed to assess social networks were relatively superficial, for example numbers of social contacts were calculated by adding numbers of spouses, children, relatives and friends and asking about frequency of contact before compared to after stroke. The study excluded people with severe aphasia who were unable to self-report on the questionnaire measures employed, indicating that their sample was biased towards those with milder aphasia.

Cruice et al (2006) also employed quantitative methods to investigate patterns of social contacts and social activities of 30 older (age range 57-88) Australian

adults with aphasia and 71 non-aphasic controls. Personal social networks were assessed using self-reported methods adapted from Antonucci and Akiyama's (1987b) model of social network analysis. This analysis uses three concentric circles around the person being interviewed. Participants are asked to identify people they feel are important to them now and locate them in the inner, middle or outer circles depending on degree of closeness. They are then asked a series of follow-up questions about individual contacts in a short interview. Social activities and their frequency were assessed using the Social Activities Checklist (Cruice, 2001) a non-standardised 20 item tool which records leisure items and frequency of participation in each on a six point scale from 'weekly' through to 'not at all'.

Participants reported a wide range of social contacts (5-51) and activities (8-18). Reduced number of social contacts related predominantly to friends, rather than family and those in outer rather than inner circles of contact. These authors' findings suggest a less dramatic loss of friends compared to Hilari and Northcott (2006) and generally more diverse patterns of activity. They nonetheless corroborate findings that friends are more vulnerable to loss than family, and that compared to healthy older controls without aphasia, there is a reduction in the leisure activities for those living with stroke and aphasia.

As with Hilari and Northcott's study, limitations of this work include an emphasis on older individuals with mild–moderate aphasia and on descriptions of the quantification of networks that does little to explicate the complex dynamics of interactions between friends and family. The wide-ranging individual differences in numbers of social contacts suggest caution in generalising about patterns of friendship among people with aphasia. The social activities questionnaire has not been psychometrically tested and the items typically privilege engagement in leisure activities rather than affirmation of self and role in less structured activities. Both studies employed a cross-sectional view that can only present a 'snapshot' of relationships and activities at the time of testing. Both revealed the need for more detailed qualitative exploration of friendship experiences.

### 2.5.3   The impact of aphasia on social lives and social relationships

Eight qualitative studies (Parr et al, 1997; Parr 2007; Le Dorze and Brassard 1995; Zemva, 1999; Dalemans et al, 2010; Natterlund, 2010a; Niemi and Johansson, 2013; Barry and Douglas, 2000) set the context for studying friendship and aphasia by examining the broader lived social experience of aphasia.

Two studies by Parr and colleagues (Parr et al 1997 and Parr 2007) influenced by the social model of disability and a social barriers approach to disability, explored the lived, everyday experience of aphasia. Seminal research by Parr et al (1997) reported on interviews with 50 people with mild, moderate and severe aphasia of more than five years duration. Participants were recruited across the UK via records held by hospitals, speech and language therapy departments and third sector agencies. Age range of the sample was 26-92 years old. Approximately half of the sample was under 65 years and purposive sampling ensured a good balance of gender, ethnicity and living circumstances. In-depth interviewing was identified as the most appropriate method for flexibly including people with communication difficulties in qualitative exploration of their experiences. Interviews were analysed using the Framework method (Ritchie and Spencer, 1994). Particular strengths of the methodology relate to the inclusion of two individuals with aphasia on the research team and the inclusion of individuals with mild, moderate and severe aphasia, although no specific details are provided as to how presence of aphasia and severity were defined.

This study was amongst the first to present a detailed description of the lived, insider experience of aphasia. Within a complex picture of change and barriers imposed at personal and societal levels, the study painted an overarching picture of a constraining of life and, for many, a reduction in friends. Strained relationships with family were subtly differentiated from those with friends. Parr et al (1997) suggested that relationships with friends lacked the scaffolding of habit and were more highly dependent on talking.  Many people in the study reported losing friends in the early whirl of rehabilitation, before either they or their friends had gained the skills necessary to deal with changed

communication.

Obstacles to friendship reported by participants included changes in work, lifestyle and income. Elaborating on communication change, participants commented on the changes in timing, and ability to share fast-paced verbal wit and humour. Frustration at being unable to get into conversations, or make contributions that were suitably detailed, challenged maintenance of the quality of friendships. Some participants reported that their aphasia made writing difficult and difficulty with correspondence caused relationships to wane.  Attitudes to aphasia from both the perspective of the person with aphasia and their communication partners were perceived to cause problems. In particular, people with aphasia talked of their perceptions that friends were busy, impatient, embarrassed or fearful of them. Some expressed feelings of shame and anxiety causing them to withdraw from friendship or to feel the need to apologise constantly. More positive management strategies described by participants included overt acknowledgement of their communication changes and a refusal to apologise. Some participants noted that contact with others 'in the same boat' at stroke support groups was a helpful route to developing new friends and networks.

The strength of this study includes the rigorous population sampling that included many working-aged people. This study probed perceptions of relationship change as part of a wide-ranging single interview covering all aspects of life with aphasia. Data analysis using Framework may not have captured the detail of more in-depth experiences of friendship since the interviews covered all aspects of living with aphasia. Also the authors commented on the challenging nature of conducting interviews with people with severe aphasia, which in some cases were discontinued. This suggests that their findings may best represent the experiences of those with mild to moderate aphasia.

Parr (2007) addressed the issue of including the experience of people with severe aphasia in an ethnographic study. The study aimed to track the day-to-day experiences of people living with severe aphasia and to document their

social inclusion and exclusion in these settings. Participants were recruited through speech and language therapists, voluntary organisations and self-help groups. They were aged between 38 and 91 and had lived with post-stroke aphasia from between nine months and 15 years. The ethnography entailed participant observation during three visits where the researcher observed and, on occasion, engaged in activities and conversation. Data collection included documentation of participant observation and conversations, fieldnotes capturing details of settings, and artefacts available in the environment.

This study corroborated earlier findings by Parr et al (1997) that many people with aphasia (and their close family members) experienced a constraining of life and opportunities. Evidence of social exclusion was noted in multiple settings: rehabilitation and residential care environments, homes, support groups and community leisure settings. Parr's (2007) findings suggested that exclusionary factors operated in a dynamic interplay between personal, interpersonal and infrastructural levels. Structural barriers such as inflexible routines, lack of information or poor access to services, welfare, suitable housing and employment compounded common experiences that those in the social environment lacked skills and support in facilitating communication access to interactions or activities. Aspects of interpersonal exclusion included limited contact with groups and places in society including family, neighbours, friends, work colleagues and peers of similar age, gender and religion. Personal exclusion referred to experiences of alienation, isolation and loss of identity and perceptions of dependence, bewilderment, fear, anger and apathy. Low aspirations, apathy and a sense of hopelessness among the participants with aphasia, were also reported, perhaps accounting for the impression that social withdrawal was sometimes related to a strategy of self-exclusion.

The analysis of personal aspects of exclusion revealed four key issues: isolation, boredom and depression; identity and personhood; lack of control; and frustration and anger (Parr, 2007). Of the 60 observed situations, few focused explicitly on interactions with friends. This may imply that friendship interactions featured rarely in participants' everyday lives or that they were not

a central feature of these data. However, where friends did appear in the observations they featured prominently as examples of positive personal relationships. This engagement with friends was in contrast to the widespread pattern of interpersonal exclusion in much of the data. For example, in the context of minimal expressive language Roger had reintegrated into the local bowls team, Miss Silver continued to enjoy the social contact with her religious community and Mr Fell was reported to enjoy the weekly musical visits from his choir friends. No explanations were provided on why these friendships persisted whilst others waned. More nuanced descriptions of mutuality or perceptions of obligation and commitment between protagonists were also absent. The study highlighted the important role of family members in facilitating and maintaining positive social engagement, for example by modeling good communication skills and behaviours that affirmed rather than undermined the competence of the person with aphasia. Experiences of younger and older participants were not separated.

The strengths of this study include its rigorous methodology, including an advisory group of individuals with aphasia. However, extended discussion of involvement issues highlighted the challenge of authentically integrating the voice of people with aphasia alongside researchers without aphasia (Parr, 2004). A limitation of the study was that the ethnography was based on only three visits per participant. The study is nevertheless unusual in describing in-depth the experiences of people with severe aphasia who are often excluded or less visible in the data of research employing interview methods.

Other qualitative studies have situated their findings within the World Health Organisation frameworks: the International Classification of Impairments, Disabilities and Handicaps (ICIDH) and its successor the International Classification of Functioning, Disability and Health (ICF) (World Health Organisation, 1980; 2001). Typically these studies have a rehabilitation interest in documenting and measuring social and community participation. Le Dorze and Brassard (1995) reported on changes in social relationships and social participation in their exploration of life with aphasia for nine individuals with aphasia (aged 41 – 69) and nine significant others, of which one was a

close friend. Participants were a mean of 78 months post-stroke. Using semi-structured interviews and aspects of grounded theory to guide categorisation of reported 'handicaps' (WHO, 1980), this study highlighted the social consequences arising from aphasia. Both people with aphasia and their communication partner highlighted changed quality of interpersonal relationships and a reduction in social activities and social networks. Participants also reported the loss of friends and the effort required to form new friendships. Experiences of social isolation, frustration in interpersonal relationships and stigmatization on account of impaired communication were commonly reported impacts. Limitations of this study were the small number of participants, with predominantly mild to moderate aphasia, all of whom were recruited through Canadian self-help organisations.

Zemva (1999) reported similar findings. This study employed structured interviews with 20 Slovenian individuals with aphasia and 20 relatives. Like the earlier study by Le Dorze and Brassard (1995), Zemva (1999) noted that both people with aphasia and their relatives reported experiences of loneliness and social isolation, though neither the Canadian nor the Slovenian study provided detailed explorations of friendship experiences. Limitations of the Zemva study included the structured questionnaire format with hand-recorded notes and the skewed sample of participants with aphasia, who were predominantly male and older (only one participant was below 60 years of age).

Dalemans et al (2010) similarly grounded their study in the WHO ICF (2001) framework. They interviewed 13 Dutch individuals with aphasia below the age of 65 and their 'central caregiver' in a study of social participation from the perspective of working-aged people with aphasia. This study complemented their findings from a literature review that concluded that very little is known about the nature of social participation in working-aged people with aphasia (Dalemans et al, 2008). Findings were based on analysis of semi-structured interviews with participants and their caregiver, who, together, had been asked to complete a structured diary over a two-week period. This 2010 study concluded that whilst many of the participants experienced social isolation and

alienation, the concept of social participation was less significant than the experience of social engagement. Social participation was defined as 'performance of people in social life domains through interactions with others ' (Dalemans et al, 2010:537) and the quantity of activities which individuals undertook. By contrast, social engagement was defined by concepts such as being involved, not being burdensome, taking part and being respected. The authors noted that factors influencing social participation could be personal, interpersonal or environmental in nature. Personal factors referred to the communication skills and physical status of the person with aphasia, in addition to psychological factors such as motivation. Factors promoting social engagement related to the role played by the central caregiver and also to the communication skills, aphasia knowledge and 'willingness' of non-aphasic communication partners. Environmental factors related to place and external barriers such as noise and transport.

A major methodological limitation of this study is that interviews and data-verifying focus groups were conducted in the presence of relatives.  These family members are described as acting as both 'translators' and 'informants' although the stated aim was to explore the perspective of people with aphasia. Relatives are known to hold different perspectives from people with aphasia, and, for example, to rate the quality of life of a family member with aphasia more negatively than the individual who has aphasia (Cruice et al, 2005). Although the authors of this study reported monitoring relatives for speaking over or 'speaking for' behaviours (Croteau and Le Dorze, 2006), it is unclear how relatives' views and perceptions were disentangled from those of individuals with aphasia.  Processes of data analysis and strategies to ensure rigour are also unclear.

Together with the research by Parr and colleagues (1997; 2007) and Le Dorze and Brassard (1995), these studies place changes in the social worlds and close personal relationships of people with aphasia in a broader context of social engagement and social inclusion. The studies suggest that there may be a range of interacting personal, social and structural barriers to sustaining satisfying relationships with close family and friends.  Friendship is addressed

as one small part of a bigger picture of the social consequences of aphasia though generally the study findings converge in noting a pattern of reducing social networks and greater preservation of kinship rather than friendship ties. Several smaller scale studies confirm the above findings, as will be reviewed next.

In a small pilot study, using a case study approach, Barry and Douglas (2000) conducted interviews with four working-age males with aphasia (age range 29-65). The purpose of the interviews was to describe their social integration and perceptions of social interaction and engagement within their post-stroke networks. Participants all lived at home, three with their wives, one alone but in close contact with his mother. They were between nine and 25 months post-stroke. Two participants were described as having mild aphasia, one moderate aphasia, and one severe aphasia. Methods included a structured interview schedule which measures the perceived availability and adequacy social support (the Interview Schedule of Social Interaction, Henderson et al, 1981) and the Number of Social Networks Contacts Index and supplementary questions designed to establish the number of members in a social network and the functions they fulfil. A measure of functional communication as perceived by the significant other of participants, the Communication Effectiveness Index (Lomas et al, 1989) and a communication activities inventory adapted from the Hearing Handicap Inventory for the Elderly (Ventry and Weinstein, 1982) were also administered to gauge the reported communication activities of participants.

Findings specific to friendship included the perception that time spent in rehabilitation and fatigue, associated with the endeavour of rehabilitation, could act as barriers to friendship. New contacts with rehabilitation staff artificially inflated the size of reported social networks as the intense regime of therapy created important but transitory relationships with therapists and support workers. In common with Hilari and Northcott (2006), contacts with close family were reported to remain relatively stable. Unlike participants in the Hilari and Northcott study, all individuals perceived improved relationships with their closest family members. Other connections who were more

peripheral in participants' social networks such as work- and leisure-based friends seemed more vulnerable. Participants reported experiences of loss of choice and control as others, including close friends, took a role in deciding what activities they should attend. One participant reported panic attacks in the first 6-7 months related to re-connecting with people in his social network.

Relationship changes were not all negative, however, and some individuals reported placing a deeper value on friendship and enjoying closer relationships with friends and family. Barry and Douglas (2000) interpreted their findings in relation to a fluid, dynamic and individual pattern of social integration that relates both to stages of recovery and stage of the life cycle at which injury is sustained. Methodological limitations of the study concern the small number of participants, all of whom were male and the questionable reliability and validity of the main interview measure, the ISSI, with aphasic individuals. No details are provided as to how or if the assessments were adapted for people with aphasia, particularly the individual with more severe aphasia whose results led the authors to question comprehension and/ or insight into his difficulties. The study was not contextualised in any clear theoretical framework.

More recently two Nordic studies have explored the everyday experiences of life with aphasia. Natterlund (2010a) reported findings from interviews with 20 people with aphasia in Sweden, and Niemi and Johansson (2013) conducted six semi-structured interviews in Finland. Both studies, conducted by occupational therapists, have a focus on describing experiences of engagement in 'everyday occupations' and activities. Samples were recruited from the workplace of the authors and five of six participants in Niemi and Johansson's study had a prior therapeutic relationship with the interviewer. The studies concluded that engagement in everyday occupations is critical to adjusting to the impacts of aphasia. Both studies supported findings of a reduction in social activities and social networks after the onset of aphasia and both emphasised the importance of relational activity as a means of coping with the long-term experience of aphasia. Drawing on Scandinavian phenomenological literature (e.g. Nystrom 2006; 2011), Niemi and Johansson

stressed the importance of engagement in the 'doing' of activities to counter the loss of identity and existential loneliness resulting from loss of language. Natterlund's study divided attention between the importance of everyday activities and social support. Neither of the studies unpacked important differences between family members and friends nor did they offer clear insights into the perceived role of friendship as opposed to more general social support. This is characteristic of much of the literature in this field. Although there is some discussion in both studies of the importance of social support to preserving continuity of identity and psychological wellbeing, their conclusions related predominantly to the importance of the doing of everyday occupations rather than dimensions of being and becoming (Wilcock 1998; Whalley-Hammell, 2004). Friendship change and maintenance was not foregrounded in either study.

In summary, these qualitative explorations suggest that the experience of aphasia produces dramatic changes in the personal and interpersonal lives of people with aphasia and their families. There is some evidence of changes to social participation and social identities and indications that barriers to social inclusion and participation may operate at personal, interpersonal and environmental levels. In general, friendship is one of many factors touched on but not fully explored in the broader context of life with aphasia.

### 2.5.4   Social networks and peers with aphasia

A number of opinion pieces and evaluation studies note the multiple benefits of aphasia support groups including enhanced communication skills, confidence, identity and social wellbeing (Elman 2007; Pound, 2011; van der Gaag et al, 2005). Vickers (2010) explored social networks and frequency of contact before and after onset of aphasia. Although the study was not focussed explicitly on friendships and again looked at the quantification of social networks of (predominantly) older people with aphasia, it provides compelling evidence of the benefits of attending peer support groups. In addition to quantifying the change in number of contacts, this study aimed to investigate the impact of weekly aphasia group attendance on perceived social isolation (versus perceived social support) and frequency of contact. A

non-random convenience sample of 40 people with long-term aphasia was included.  The study compared scores of 28 regular attenders at a university based aphasia support group with 12 matched participants who were not attending groups. Mean age of the group attenders and non-group attenders were 64 and 70 respectively (age range not provided) and most participants (78%) were married or partnered. Participants were a mean of 81 months post onset of aphasia though no range is stated.

Findings across a range of measures including social network interviews and inventories concluded that reduction of social networks and social isolation after onset of aphasia was a cause for concern. Across both groups, friends and acquaintances were susceptible to a reduction in number and in frequency of contact.  Those attending the weekly Communication Recovery Group had less perceived degree of social isolation and greater social connection than those not attending the group.  The author concluded that these findings confirm the positive impact of peer group support as a useful protection against social isolation. A limitation of the study is the use of a non-standardised 47-item questionnaire to survey communication and social participation. Many participants in the therapy group sample appear to be long-term participants in the university-based aphasia group therapy programme. This raises questions about whether the characteristics of this group, for example mobility, confidence, and established relationships at the centre predisposed them to resuming social activities and building new relationships.

In assessing social networks, good friends were co-located in a category with close relatives as distinct from life partners, neighbours/acquaintances, paid workers and other unfamiliar partners in line with the Social Networks Communication Inventory (Blackstone and Hunt-Berg, 2003). As noted above, categorising and defining 'friends' within counts of social networks is a contested issue and may obscure information relating specifically to the nature of friendship. Limited information on the individual characteristics of the population sample limits conclusions that can be drawn about a wider group of people with aphasia.

### 2.5.5   Friendship and aphasia

The final three studies adopted qualitative approaches to offer more in-depth exploration of the friendship experiences of people living with aphasia.

Davidson et al (2008) used a participant observation study of 15 older Australians with aphasia and 15 matched healthy controls without aphasia to examine the nature of friendship conversations. The authors also describe a collective case study where three individuals with aphasia invited a friend to participate in a videotaped conversation and then individually discussed their perceptions of the conversation with the researcher in a stimulated recall interview.

Findings from the observation study revealed marked differences between the two groups. Non-aphasic participants were observed with 52 'friends' compared to 20 for aphasic individuals. Healthy older people tended to talk to a wider range of people in a wider range of settings across social, leisure, sporting, educational and community settings. Those with aphasia had fewer conversations and, of the conversations they took part in, many were related to therapy groups and day care facilities. This reduction in both the number of friends and friendship activities supports the findings of Hilari and Northcott (2006) and Cruice et al (2006).

Interpretative analysis of the observational data revealed five key communication domains: family, friendship, domestic life, leisure/education and community services (including health and non health). The majority of communicative situations fell into the family and friendship domains although older people without aphasia had significantly more instances of social participation with friends than people with aphasia. Differences between healthy older and aphasic people existed in both the quantity and quality or depth of conversations. For example, people with aphasia had brief conversations with visitors to their home whereas non-aphasic individuals were observed in extended discussions and storytelling as they visited others. Phase 2 of the study examined friendship conversations of three individuals in more detail.

Key findings from the stimulated recall interviews in phase 2 related to the importance of time, for example time to respond and management of temporal disruptions such as silences, the role of humour and the importance of shared interests. Although this was only a sample of three individuals with aphasia, the study is important in examining in more detail the role of conversation, as opposed to leisure activities in developing and maintaining friendship. The authors concluded that further research into friendship conversations may help guide interventions addressing the maintenance and development of identity, social connectedness and reconnecting with life.

Like the Cruice et al (2006) study, this research had a focus on older Australian adults. Only one participant of the 15 people with aphasia in phase 1 in this study was living alone. The stimulated recall interview was an innovative method of exploring perceptions of friendship-based conversations and key findings were confirmed by respondents. Participants with aphasia had no input to overall research design and evaluation.

Three studies relating to friendship experiences of individuals with aphasia have been published during the course of this project. In the most relevant study, Northcott and Hilari (2011) used in-depth qualitative interviews with 29 participants with stroke, ten of whom had aphasia. This was part of a larger UK study looking at the assessment of health-related quality of life after stroke. Participants were aged 18-90 years old and 13 were working prior to their stroke. Interviews took place approximately one year post-stroke (range 8-15 months). The title of the paper 'Why do people lose their friends after a stroke?' reveals the study's focus on exploring the perceived causes of friendship loss and change after stroke. Key findings were that friendship loss is associated with a range of factors including physical disability, fatigue, environmental barriers such as lack of suitable transport and toilet facilities, and loss of shared activities previously enjoyed with friends. For people with aphasia, negative responses of others, loss of two–way conversation, difficulty with humour, and struggles to maintain contact when written as well as spoken communication was impaired were all problematic. Some people with aphasia

in their sample had lost their entire friendship network though the authors reported that not all people with aphasia lost friends.

The authors used their findings to further develop the link between loneliness and depression (Hilari et al, 2010) drawing attention to the range of depressive symptoms expressed by their participants: sadness, anxiety, loss of energy, low self esteem and feeling of being stuck. Increased time alone and reduced social participation may lead to loneliness and depression that contribute to further withdrawal and isolation. The authors hypothesised that some people experience 'changed social desires' as they close in on themselves in this cycle of withdrawal. Increased effort, vulnerability, self-consciousness and concern not to let others witness their impairments lead to introversion and self-withdrawal. These findings resonate with other qualitative evidence of a reluctance to socialise post-stroke and a feeling of being a burden (Dowswell et al, 2000) and a strategy of self-exclusion adopted by people with aphasia and other disabling conditions (Hall, 2009; Parr et al, 1997).

Although Northcott and Hilari (2011) emphasised friendship loss they also reported that loss of friends was not inevitable for their participants. Protective factors revealed through their qualitative analysis of participants' accounts included strong non-activity based friendship networks consisting of 'caring' friends who lived locally and were available, mobile and in good health. For some, new or pre-existing groups associated with pubs, clubs or spiritual activities provided a ready-made structural function for maintained social contact through their regularity and familiarity.

These are interesting findings in relation to the current project. Of note, however, is that only two of the participants were under 50, making it difficult to draw conclusions about younger individuals who may have friendship issues post-stroke particularly related to loss of work and lower availability of day-time friends who are still in employment. Participants were interviewed very soon after stroke onset (maximum time post onset 15 months) a timescale that typically coincides with ongoing rehabilitation and early post-stroke trauma. Findings may also have been influenced by professionally

determined concepts of friendship. For example, the study defined friends as people who were not family members or paid carers. In quantifying friendship networks as part of their broader study, participants were asked to select 'people you feel at ease with and can talk about what is on your mind'. Given the lack of comfort about 'talking' experienced by many people with aphasia, this question may have added a level of confusion to the selection and definition of friends. Data analysis used thematic charts constructed via the Framework method (Ritchie and Spencer, 1994). No details were provided on the nature of reflexivity or the involvement of people with aphasia in other processes of enhancing credibility.

In contrast to the Hilari and Nothcott's focus on friendship loss, Brown et al (2013) positioned their friendship study within a 'Living successfully with aphasia' framework and a focus on exploring more positive aspects of friendship maintenance. Brown et al (2010) had previously conducted in-depth interviews with the same group of 25 community dwelling participants in a study to explore the meaning of living successfully with aphasia from the perspective of individuals with aphasia. This earlier study was based on interview and photographic data and employed Interpretive Phenomenological Analysis (IPA). One of the key findings of the 2010 study was the importance of positive social relationships in contributing to experiences of 'living successfully with aphasia'. The four key themes reported in this study were doing things, meaningful relationships, adopting a positive approach to life and the underpinning importance of communication. The meaningful relationships theme highlighted the positive role played by family, friends, neighbours and others who had aphasia in supporting participants' satisfaction with life.

The aim of the 2013 study was to draw on a subset of this data to explore the perspectives of the same 25 individuals with aphasia more specifically on the role of friendship in living successfully with aphasia (Brown et al, 2013). Participants in both studies therefore were between 38 and 86 years old and between 24 and 299 months post-onset of aphasia. 18 participants were described as having mild aphasia, with seven participants demonstrating moderate to severe aphasia as assessed on the Western Aphasia Battery (Kertesz, 1982).

Three key themes emerged from a re-analysis of interview data: 'living with changes in friendship', 'good times together and support from friends' and 'the importance of stroke and aphasia friends'. The first theme reflected participants' views on adjusting to loss of friends and negative changes in friendship such as difficulties in communication and poor understanding of aphasia. Participants also reported a desire for more contact with friends and a greater appreciation of friends who had remained in contact. 'Good times together' encompassed descriptions of the pleasure of spending leisure time with friends, doing things together and enjoying laughter and positive interactions. This theme also reflected the perceived benefits of emotional support from friends. The third overarching theme present in 16/25 transcripts noted the importance of new friends who had aphasia to perceptions of living successfully with aphasia. Sub-themes related to the benefits of mutual understanding and a context of mutual support.

The authors concluded that their study supports the findings of Northcott and Hilari (2011), Vickers (2010) and Davidson et al (2008) and sheds further light on positive aspects of friendship post-onset of aphasia, particularly in relation to their thesis of what helps people with aphasia to live successfully with aphasia. They call for further research with a more explicit focus on friendship experiences, conversational analysis between people with aphasia and their friends and studies that might capture a longitudinal perspective on friendship change.

Critique of this work relates to the professional conceptualisation of 'Living successfully with aphasia', a strategic lens through which the researchers gathered and interpreted data. The 2010 study claimed to be grounded within IPA (Smith and Osborn, 2003) but provided no justification for the large sample nor evidence as to how the authors, all with a speech and language therapy background, interrogated the potential influence of their professional bias on data analysis and interpretation. Although the steps of thematic analysis in the 2013 study were clearly described, the authors did not comment on their theoretical position or the assumptions that may have influenced interpretations. A stronger reflexive position in both studies and/or

greater inclusion of individuals with aphasia in the study design, data analysis and interpretations would have enhanced aspects of rigour and credibility.

## 2.6    Summary

In summary this chapter has reviewed the broader context of friendship and the perils and possibilities of friendship within disabled people's lives. Insights from philosophy, psychology and sociology highlighted the dilemmas of definition and the complex nuanced features of friendship that differ from person to person. This literature suggested that there are different types or categories of friends and that these relationships are differentially susceptible to change across the life course. They also suggested the dangers of assuming that friendship equates to a commonality of experience, even when studying sociologically similar groups. Differences in age, gender and health circumstances may all impact on the size and nature of personal friendship networks and the degree of blurring between friends and family-as-friends.

The complexity and function of social relationships may be particularly relevant in the context of illness and disability where close personal relationships are often the first point of access to social support.  Empirical studies revealed the exciting possibilities of friendship to personal health, and emotional, social and psychological wellbeing. However, within studies of chronic illness attention to one-directional social support has been prominent whilst relationships based on mutual social exchange remain unexplored.

The chapter also critically appraised literature relating to social participation and social relationships, including friendship, post-onset of aphasia. This review suggested that social networks and social activities are under threat when communication is impaired and that friends and friendships may be more susceptible to rupture and wane than family relationships. There is some evidence that friendship may be an important factor in re-engaging in meaningful relationships and activities and developing a more positive view of life after the onset of aphasia. However, the review also noted that focused research describing the nature of relationships with friends among people with aphasia is sparse. Little is known about how friendships change, how people

with aphasia react to changes and how they make sense of friendships that are lost, gained or altered. There is also a lack of description and detail concerning strategies used to maintain old friendships or develop new ones. Studies are methodologically diverse, often with a focus on older people with less severe manifestations of aphasia. Researcher definitions of friendship are either underspecified or rigid. It is therefore difficult to:

- Extrapolate in any detail the issues and experiences of people under 65 who are in a different stage of the life-span from the more widely researched older-aged groups

- Gain detailed insights into friendships that go beyond activity-based interpretations of social participation, or a more superficial, undifferentiated view of social relationships

- Understand how people with aphasia rather than professional researchers and practitioners define and understand friendship.

**Research aims**

This review sets the context for the Friendship and Aphasia study. The aim of this research is to focus explicitly on experiences of friendship from the perspective of and through the researching lens of working-age adults who live with aphasia. It addresses the overarching research question:

- ➢ How do working-age adults with aphasia define, experience and understand friendship?

Research aims are:

- To describe the relationships that constitute friendships for individual participants with aphasia and perceptions about why these relationships are important

- To identify and describe changes in friends and friendship which people with aphasia experience and how they make sense of these

- To describe how participants sustain and develop friendships in the context of aphasia

- To recommend actions and interventions which may support people with aphasia and their friends to maintain and develop satisfying relationships

Studies critiqued above also reveal that the perspectives of researchers without aphasia, most usually Speech and Language Therapists or Occupational Therapists, have dominated previous research into friendship experiences. Whilst these researchers have employed methods to access the views of people with aphasia, most usually those with milder aphasia, they have not included their perspective as co-researchers. This study aimed to explore a more participatory methodology, asking:

> What are the meanings of doing Participatory Action Research with people with aphasia?

The methodology and the rationale for selecting PAR for this study are introduced in the next Chapter.

# Chapter 3
# Methodology

## 3.0    Introduction

This chapter describes the qualitative, participatory research approach used to explore the experiences of friendship and aphasia of participants in this study. The chapter details the principles and practices of PAR and their relevance and fit to exploring friendship in conjunction with co-researchers living with language impairment. PAR approaches are contextualised within two specific critical inquiry influences: disability studies and feminist research. The chapter concludes with a clarification of epistemological, theoretical and methodological assumptions that underpin the research processes of this study.

## 3.1    Participatory action research as a research methodology

Participatory action research sits within the eclectic, cross-disciplinary family of action research practices (Reason and Bradbury, 2006; Stringer, 2007). Action research is 'a participatory, democratic process concerned with developing practical knowing in the pursuit of worthwhile human purposes, grounded in a participatory worldview ... It seeks to bring together action and reflection, theory and practice, in participation with others, in the pursuit of practical solutions to issues of pressing concern to people, and more generally the flourishing of individual persons and their communities' (Reason and Bradbury, 2006:1). These values and aspirations provided a fitting backdrop to the collaborative exploration of friendship with individuals with aphasia.

Action research draws on principles of learning through experience and a process of mutual learning between researchers and those with whom they are researching (Lewin, 1952). Whilst it is frequently collaborative, not all action research is participatory action research.

Participatory action research resists concise definition, though there is broad agreement on its key principles. It is:

- Democratic

- Collaborative and participative

- Practical

- Empowering and emancipatory

- Dynamic

- Based on repeated cycles of reflective thinking and action

- Concerned with process and outcomes

(Cornwall and Jewkes, 1995; Stringer, 2007; Kemmis and McTaggart, 2008)

PAR also draws on the critical pedagogy of Paolo Freire (1970). Freire's work with oppressed groups in South America highlighted the role of shared thinking and critical awareness in pursuing the emancipatory and practical goals of participatory action. Dismissive both of reflection for reflection's sake and activism which was not well grounded in reflection, Freire advocated critical reflection as the basis for catalysing the generation of new knowledge, human flourishing and social action. The principles and goals of Freire's work with marginalised populations disempowered by poverty and literacy has resonances with the processes and concerns of this project, which is contextualised within the social exclusion and disablism experienced by people with aphasia in their everyday lives.

The transformative action associated with PAR is embedded in cycles of engaged looking, thinking and acting (Stringer, 2007) and can operate at multiple levels. Noting the relevance of PAR to research endeavours with people with long-term health conditions, Koch and Kralik (2006), assert that 'the cyclical nature of the participatory action research process promotes reflection and reconstruction of experiences and stories that can lead to the enhancement of our lives, at an individual level, community level, or both' (Koch and Kralik:27).

Storytelling and sharing of expertise by participants with direct experience of the problem under review is central both to the process of PAR (Koch and Kralik, 2006) and to insider perspectives which inform a burgeoning literature within qualitative health research. Before discussing in more detail the relevance and fit of PAR to this particular study of Friendship and Aphasia, the

relationship between PAR and participatory research initiatives within health-related research will be briefly described.

## 3.2    PAR and participation in health and disability research

Participatory action research (PAR) has grown in popularity as a strategy for exploring health- and disability-related issues since the 1990s. It has been particularly prominent in explorations with marginalised groups such as people with mental health issues and indigenous populations (Baum et al, 2006; Bryant et al, 2010). In a recent editorial, Huang (2012) remarked on the relevance of action research and participatory action research to exploring experiences of, and innovative solutions to, the challenges of long-lasting health conditions within modern economies of healthcare.

Both PAR and participatory processes in health and disability research share epistemological assumptions that the lived experience of co-researchers with a particular condition or disability will enhance the quality and authenticity of findings (Beresford, 2002; Boote et al, 2002; Hanley et al, 2003). In the context of user involvement in research, Beresford argues that 'the shorter the distance between direct experience and its interpretation, then the less likely the resulting knowledge is to be inaccurate, unreliable and distorted' (Beresford, 2005:4).

PAR is not synonymous with all initiatives that involve 'service users' in research. Baum et al (2006), for example, differentiate PAR from other participatory processes in health and disability research on three main accounts. PAR emphasises:

- action within reflective cycles of reflection and action
- a dynamic interaction between co-researchers with and without a particular condition
- sustained reflection on power in contrast to other participatory processes where boundaries between the researchers and the researched remain clearly demarcated.

Crucially, Baum et al (2006) note the 'critical edge' of PAR which may be absent or underplayed in projects which privilege professional understandings

and interests, or where co-researchers are accustomed to more passive forms of involvement. Critical reflection and critical awareness constitute a foundation for analysing and understanding experiences and constructing alternative interpretations, stories and actions (Huang, 2012; Koch and Kralik, 2006).

Drawing on a hierarchy of participation proposed by Arnstein (1969), Hanley et al (2003) produced guidelines for INVOLVE (www.invo.org.uk), a national body supporting public involvement in NHS research, characterising the extent and nature of lay researcher participation in health and social care research. INVOLVE's briefing notes for researchers describe a continuum of public involvement in research from consultation to collaboration to control. Within this framework, collaboration refers to sustained and active partnerships between professional and lay researchers as projects are co-designed, and members of the public participate in a full range of research activities. User-controlled research, by contrast, refers to research where the locus of power and decision-making resides with service users rather than professional researchers (Hanley et al, 2003). This framework has been widely employed to describe varying degrees of public involvement in research initiatives and increasingly as a tool to support the evaluation of the impact of different forms of service user participation (Staley, 2009; Boote et al, 2012). Robinson et al (2010) have extended this continuum into a conceptual framework to articulate and audit interacting degrees of collaboration and how far research processes are top-down (researcher-led) or bottom-up (public-led). This research project aspires to maximum collaboration. Within the conceptual framework proposed by Robinson et al (2010) the study would be defined as an example of fully engaged research, where members of the public, with experience of aphasia, actively influence all aspects of the study from design through to dissemination.

## 3.3    PAR and studying friendship with people living with aphasia

Although there are a growing number of initiatives encouraging the involvement of people with stroke in research (Boote et al, 2012; James Lind Alliance, 2012), very few studies have employed PAR as a methodology.

Rare examples that do employ action research or PAR methodologies tend to focus on transformation of professional knowledge and workplace practice (see for example, Mitchell et al, 2005; Kilbride et al, 2011; Kristensen et al, 2011). For example, Kilbride et al (2011) described a Community of Practice approach to improving culture and practice in a Stroke Unit context while Kristensen et al (2011) used a participatory approach to training staff about goal-setting. These studies focus on actions relating to therapists and primary stakeholders who are practitioners and managers. Fudge et al (2008) note the tradition of more passive forms of user involvement within stroke research as compared to more activist forms of engagement within participatory research with people using mental health, HIV and maternity services.

PAR was selected as an apt methodological approach for the investigation of experiences of friendship and aphasia because:

- it is capable of exploring experiences of oppression and disablism at a structural, relational and personal level
- it promotes the construction of knowledge through equitable social relations between researcher and those being researched
- it encourages the use of flexible, pragmatic, accessible methods of inquiry
- it aims to bring about personal and social transformation as well as advancing theorising.

These values are widely promoted as fundamental to PAR inquiries (Kemmis and McTaggart, 2008; McIntyre 2008).

PAR is particularly suited to explorations with communities who are marginalised or disempowered (Khanlou and Peter, 2005; McIntyre, 2008). In the context of Western society, where language and communication capital provide access to power, people with language impairment have been relatively absent from debates within disability and health studies (Thomas and Corker, 2002; Pound, 2011). PAR has a greater emphasis on empowerment, and collaborative decision-making throughout the research process, than less participatory methods. It also has a strong orientation towards issues of equality and the everyday (Koch and Kralik, 2006; Baum et

al, 2006). Mutual learning, active and sustained participation by research advisors with aphasia and a focus on describing and understanding the process of working collaboratively have been underpinning principles and concerns of the Friendship and Aphasia project.

Participatory action research emphasises the democratic and cyclical dimensions entailed in the research process (Koch and Kralik, 2006). Cycles of deliberation, activity and reflection are critical not just to crystallising outputs, but to the process of developing and sustaining the core research relationships where action and knowledge is produced. Kemmis and McTaggart (2008) outline the generally accepted spiral of cycles, which involve:

- planning a change
- acting and observing the process and consequences of change
- reflecting on these processes and consequences
- re-planning
- acting and observing again
- reflecting again

The repeated cycles of planning, acting, reflecting and re-planning as the Friendship and Aphasia project Research Group scrutinised issues and findings and set progressive courses of exploration will be fully described in the Methods chapter that follows. Facilitation of the PAR Group aimed to create ample space and time for reflection and critical, creative thinking without imposing control, a facilitation process described by Wadsworth as 'thoughtful companioning' (Wadsworth, 2006:330).

People living with aphasia experience a wide range of impairments affecting speech, understanding, reading and writing. These vary from minor distortions and impairments that may seem almost imperceptible to listeners, to changes in speech and language that have obvious catastrophic impacts on social communication. People with aphasia often live with additional complex consequences of stroke. Within the Friendship and Aphasia inquiry, it was important to incorporate diverse experiences of both impairment and disability.

Research strategies were required which would be capable of investigating multiple realities and fluid, evolving identities (Mercer, 2002; Thomas, 2007) in the context of limited expressive language. Participatory processes that enabled maximum dialogue between my interpretations of non-traditional interview data and the personal experiences of Research Group members were important to enhance trustworthiness and credibility. Issues of rigour will be discussed more fully in Chapter 4 (Methods overview) and Chapter 11 (Discussion).

PAR's history of supporting research with minority and disadvantaged groups lends itself to the use of creative, visual and performative methods that can embrace flexibility of methods and communication across different languages and culture (McIntyre, 2008; Cornwall and Jewkes, 1995). Participant-centric methods such as storytelling, art, mind-mapping, poetry, drama and dance tend to be more commonplace within PAR than other forms of qualitative research (McIntyre, 2008).

Storytelling is also recognised as fundamental to data generation within PAR (Koch, 1998; Lykes, 2006). Listening *to* and listening *for* different voices and different versions of experience inform a dynamic process of understanding and challenging common storylines (Maguire, 2006; Barrow, 2008). Within explorations of disability and long-term illness, stories constitute a way of reflecting on experience and identity as well as a mechanism underpinning the supportive, trusting relationships that develop between co-researchers. Proponents of PAR highlight the benefits of the group context for generating, sharing and enriching accounts of personal and collective experience as the basis for innovation, action and generating new understandings (Koch and Kralik, 2006; Adili et al, 2012). Creative use of storytelling within PAR groups may simultaneously combine research strategy with the healing functions of group storytelling. For example, Lykes (2006) illustrates the utility of photography and creative arts with a group of Guatemalan women exploring experiences of violence and poverty in post-war communities.

Relational imperatives within PAR groups concern sustained interaction and sustained reflection on the power relations that exist between co-researchers (Baum et al, 2006; McIntyre, 2008). Wadsworth (2006) describes the engaged, inter-subjective reflection between PAR facilitators and participants as one of holding up 'mirrors and magnifying glasses to themselves and each other' (Wadsworth, 2006:333). Friendship and strengthened relationships with peers and allies is often cited as a benefit of participatory inquiries (Koch and Kralik, 2006; Staley, 2009) as relationships shift and there is a blurring of personal and professional boundaries. Strong interpersonal relationships also underpin participatory knowledge generation enriched through relational ways of knowing (Park, 2006).

A final feature of PAR supporting its choice as an apt and meaningful methodology to address the project's research questions is its important concern with both knowledge generation *and* action. Kemmis and McTaggart (2008) call for both more theory and more action from researchers who embrace the activism of PAR. Key to the sustained commitment of Research Group members in this project was a desire for personal understanding and knowledge which would be of actionable, practical benefit to the wider community of people with aphasia. Practical outcomes and enduring consequence and significance are further hallmarks of assessing the quality of research carried out within a participative ethic (Koch and Kralik, 2006; Bradbury and Reason, 2006; Stringer, 2007).

### 3.4 Pitfalls and possibilities associated with PAR

Criticisms of PAR include its unpredictable, open ended and time-consuming nature (Baum et al, 2006). Moreover the schedules and priorities of the researcher and the communities with whom they are researching may not operate on similar systems of time and pace (McIntyre, 2008). These issues are particularly challenging for research processes aiming at maximum involvement of people with language impairment. Good practice in involving people with aphasia in stroke research requires extra resources of time and attention to clear signposting and scaffolding of discussions. Clarity should support communication without exerting undue control over the proceedings

(Swinburn, et al, 2007). Uncertainty can fuel perceptions of people with aphasia that they have not understood discussion and reinforce perceptions of feeling excluded and unable to participate on equal terms (Parr et al, 2008).

PAR has encountered criticism for lacking rigour and being unscientific (Wadsworth, 2006). It has also been criticised for the limited status given to achievements of participants who do not occupy mainstream positions within the academy and who may tend to prioritise action rather than the creation of knowledge perceived of as 'legitimate' by professional experts (Gaventa and Cornwall, 2006).

Many exponents of PAR also warn against exaggerated claims about empowerment within participatory projects (Kemmis and McTaggart, 2008; Maguire, 2006). These views resonate with critical evaluations of emancipatory disability research (Oliver 2009). Contested issues of power, exploitation and ownership are inherent in research collaborations between professional researchers and communities of disabled and disenfranchised individuals (Smith et al, 2010). Close partnerships forged within PAR can bring to the surface different and potentially competing agendas (Baum et al, 2006). The degree of authenticity and action within some PAR projects has also been questioned. Stoecker (2009), for example, questions how well some PAR projects situated in the cultural contexts of charities or government organisations, might be in supporting PAR's goal of social change.

Practicalities of carrying out a PhD study governed by the rules of the academy but grounded in the principles of PAR throw these challenges into sharp relief (Burgess 2006; Huisman, 2008) and contribute to inevitable moments of confusion and discomfort (Smith et al, 2010) for practitioners of PAR based in university settings. Zuber-Skerrit and Fletcher (2007) and Klocker (2012) neatly disentangle the relationship between the process orientation of conducting action research and the product orientation of completing a thesis. In practice, issues such as disengaging from research relationships and clarifying issues of ownership and authorship are ethically and emotionally challenging (Gibbon, 2002; Huissman, 2008).

However, notwithstanding these issues, the appropriateness of PAR principles and ethos are well suited to a collaborative inquiry on the topic of friendship. As well as being embedded in notions of relationship and companionable exploration, PAR has been described as having a philosophical attitude of 'vivencia' (Fals Borda, 2006:31). 'Vivencia' refers to life experience embedded in 'an empathetic attitude towards Others', a simplicity relating to 'symmetry in the social relation' and an uncomplicated 'human touch' (Fals Borda, 2006:31).

In summary, PAR aligns well with the principles of critical empowerment embraced in the Friendship and Aphasia project. As a methodology to explore experiences of friendship it reflected a process based on:

- Trusting, reciprocal and evolving relationships
- Mutual learning
- Sharing stories of everyday experiences
- Human flourishing in creative connection and communication

The flexibility of PAR creates the possibility for different projects and research questions to align with multiple philosophical and theoretical positions. The next section situates the Friendship and Aphasia project within influential ideas from disability studies and feminist research. Both sit within a framework of critical inquiry.

## 3.5 Philosophical and theoretical underpinnings of the Friendship and Aphasia study

### 3.5.1 Critical Inquiry

Critical inquiry embraces a broad range of theoretical and philosophical perspectives (Crotty, 2009). Unifying features of critical inquiry concern considerations of language, power, culture, the many faces of oppression and the reproductive patterns of privilege (and oppression) that systems of class, race and gender create (Packer, 2011). Critical reflection on social reality is also associated with generating knowledge capable of producing practical, social actions and change (Crotty, 2009; Packer 2011).

Critical inquiry underpins methodological approaches with an emancipatory interest such as emancipatory disability research, feminist inquiry and the more participatory variants of action research.  It assumes a critical position to social research that has often been challenged for its failure to take account of issues of exploitation and alienation (Kincheloe and McLaren, 2000).  Issues of language and power in relation to experiences of impairment, friendship and the process of engaging in equitable, reciprocal research relationships are important themes of the Friendship and Aphasia project. The personal, relational and political dimensions of these concerns are familiar territory within disability theory and feminist research.

### 3.5.2   Disability studies and emancipatory disability research

Emancipatory disability research has a focus on social oppression. Rather than merely describe the world as experienced by disabled people, disability research strives to bring about change in the forms of disadvantage that people experience (Barnes and Mercer, 1997). In this respect emancipatory disability research is unashamedly political and partisan. Early debates about the potentially 'parasitical' nature of research practices by non-disabled researchers on disabled people highlighted the typically uneven social relations between researcher and research participants, and the moral imperative for disability research to be especially self-critical with respect to issues of power and paternalism (Oliver, 1992; Hunt, 1981).  Summarising the defining features of emancipatory research, Mercer (2002) noted it should:

- be unambiguously located within a social model approach to disability
- be openly partisan in supporting the struggles of disabled people and the political action needed to bring about change
- promote alternative social relations of research production by challenging  traditional hierarchy and power relating to researcher and researched
- encourage pluralism in its choice of methods and methodologies.

Echoing issues of validity and quality in PAR (Koch and Kralik, 2006; Kemmis, 2006), Oliver suggested evaluations of disability research's success should be

in terms of 'reciprocity, gain and empowerment' (Oliver, 1992:111) for those who are the subject of research.

### 3.5.3   Disability research and disability theory

A focus on the social model of disability and a social barriers approach to a disabling world rather than the functional limitations caused by physical, mental or sensory impairments enables a politicised approach to applied disability research (Moore et al, 1998). Research embedded in a social model of disability exposes and challenges the exclusion of disabled people from contemporary society by proposing that disability is created by social and attitudinal barriers (which are open to change) rather than exploring pathology and impairment (which cannot be changed). Thomas (2007) develops the discussion by defining and explicating the notion of 'disablism', which she sets alongside other oppressing concepts such as ageism, sexism and racism:

> 'Disablism is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional being' (Thomas, 2007:73)

Within this definition, Thomas, in common with other disabled feminist researchers such as Jenny Morris, Sally French and Mairian Corker, creates a space for discussion of the subjective experience of living with impairments.

Experiential and relational aspects of disability are also foregrounded within the Nordic relational model of disability (Traustadottir and Kristiansen, 2004; Tossebro 2004; Gustavsson, 2004). This approach is grounded in the Nordic countries' welfare values of citizenship, equality and the interests of independent living (Traustaddotir, 2004). It is strongly informed by the social model of disability, and emphasizes disability activism based on an understanding of the dynamic interaction of bodies, minds and social environments. Promoting empowering relationships between professionals and disabled people and services oriented towards self-advocacy rather than paternalism, the relational model embraces a philosophy of change based on collaboration (Goodley, 2011).  It is thought to bridge language, cultural and

policy differences across the Nordic countries through its basis on three underpinning principles:

(i) Disability results from the mismatch between a person's individual abilities and the demands of their everyday environment and society – disability concerns the relationship between an individual's impairment and the inadequate adaptation of the environment and broader society

(ii) Disability is situational or contextual – deafness, for example, is not a disability in contexts where everybody employs sign language

(iii) Disability is relative – dichotomies and cut-off points (such as IQ scores) which define individuals as impaired are arbitrary and socially constructed

(Tossebro, 2004; Traustadottir and Kristiansen, 2004)

The combination of the relational approach to disability and the emphasis of some disabled feminist researchers on understanding 'psycho-emotional' dimensions of disability, offer pertinent insights to this study of friendship and aphasia. A willingness to engage with the lived experience and disablism of 'impairment effects' (Thomas,1999:156) creates possibilities of attending to the voices of disabled groups, such as those with impairments of communication, who traditionally occupy more marginalised positions both within mainstream disability studies and user-controlled healthcare research (Thomas and Corker, 2002; Staley, 2009).

### 3.5.4   Impairment effects and psycho-emotional disablism

Developing this discussion, Thomas (2007) links a focus on the body and structural barriers in the 'out there' world with a tendency to focus on the 'can do' rather than the 'can be' of disability (Thomas, 2007:72). Expressions of the complex, inner experiences of impairment may have had less prominence within disability debates for fear of shifting the focus away from the social construction of disability (Morris, 1996; Thomas, 2004). In other words, attention to impairment might risk reinforcing individualistic portrayals of disabled people as tragic and needy and de-politicise struggles against oppressive social practices.

Thomas (1999; 2007) strongly refutes this charge by theorising on the nature of impairments, 'impairment effects', and the way they mesh with disablism and the material, social world.  Within the social relational model of disability she notes that not all restrictions or limitations of activity constitute disability. Using as an example her absent left hand, she refers to her inability to hold items in her left hand as an effect of her impairment. If people occupying positions of power and influence use this limitation of activity to impose restrictions on her employment or outlaw participation in social worlds in non-conventional ways, 'disability' is then imposed through oppressive behaviours and a denial of rights. Impairment effects therefore, refer to 'the restrictions of activity which are associated with being impaired but which are not disabilities in the social relational sense. Impairment effects may become the medium of disability in particular social relational contexts' (Thomas, 1999:43). Invisible but pervasive impairment effects of language are harder to extricate from the medium of disability. Language equates so centrally with the exercise of power and lay perceptions of competence. This reinforces Thomas's position that 'in any 'real' social setting, impairments and impairment effects are thoroughly intermeshed with the social conditions that bring them into being and give them meaning, as is disablism.' (Thomas, 2007:153).

Experiencing the pain and challenge of impairments is embedded in a dynamic interaction between the self and the social world. Scholars such as Morris (1991;1996), French (2004) and Keith (1992) explore the private, the personal and the experiential in their studies of the everyday. Experiencing disablism such as being exposed to prejudice, discrimination and negative attitudes can impact on the subjectivities of disabled individuals in a range of powerful ways that may undermine their psycho-emotional wellbeing (Thomas 1999; 2007) and have profound impacts on their construction of disabled identities (Reeve, 2002). For Thomas, '*psycho-emotional disablism* involves the intended or unintended 'hurtful' words and social actions of non-disabled people (parents, professionals, complete strangers, others) in inter-personal engagements with people with impairments' (Thomas, 2007:72).

Narrative accounts of disabled women's experiences of psycho-emotional disablism in their everyday lives (Thomas, 1999; Reeve 2002) include examples of damaged confidence, low self-esteem and a questioning of identity resulting, for example, from the negative reactions of friends and family members. Other accounts, particularly where impairments are invisible, highlight the struggles caused by dilemmas of concealment and disclosure and the perception that others do not understand the nature of a disabling condition (Lingsom, 2008). These illustrations suggest both the relevance of the concept of psycho-emotional disablism to studies of friendship and language impairment, and that its exploration requires methodologies which can flexibly engage with individual subjectivity as well collective struggles.

### 3.5.5 Feminist research influences on the Friendship and Aphasia study

Nordic disability studies, interested in the intersection of gender and disability, have highlighted the many similarities between issues addressed by disability researchers and feminist scholars (Kristiansen and Traustadottir, 2004). These authors argue that analysis of similarities and differences between these two disciplines may help further methodology, theory and political activism in a cross-disciplinary manner (Traustadottir and Kristiansen, 2004). Feminist research, in common with PAR, has an interest in issues of muted voices, everyday experience and power (Maguire, 2006). It is concerned with non-exploitative relationships grounded in an ethic of reciprocity and friendship (McIntyre, 2008). Disabled feminist researchers stress the importance of relational as well as structural aspects of disability, incorporating, for example the lived experience of caring relationships, parenting, and sexuality as well as issues of friendship and identity (Corker and French, 1999; Morris 1996; Traustadottir and Kristiansen, 2004). Both feminist and disability research fundamentally address matters of exclusion, citizenship and access to equal rights as well as theorising on the relationship between impairment, disability and disabled identity (Thomas 2007; Lunn and Munford, 2007).

Feminist researchers have led the challenge for research which foregrounds marginalised or under-represented voices (Belenky et al,1986; Oakley,1981).

Within disability studies there is widespread recognition that some voices, for example those of people with learning difficulties and people with impairments of cognition and communication have struggled to find a mainstream presence within academic theorising and research (Nind, 2008; Thomas and Corker, 2002). Debating the differing impacts of physical as opposed to sensory impairments, Corker (Thomas and Corker, 2002) suggests that where communication is not merely the means of mediating understanding and advocacy but also the source of disablement, marginalisation is inevitable. Dalemans et al (2009) make a similar argument in relation to the exclusion of people with aphasia from much mainstream stroke research. Ontologically, Corker argues, the nature of her deafness means she experiences and understands the oppression of the external (hearing) world differently. She surmises that the complexity and unpredictability of language may be one of the reasons for the privileging of the body within disability discourses (Thomas and Corker, 2002).

An interest in the personal and private aspects of disability as well as the public and political agenda allows for exploration of relationship, sexuality and intimacy. These topics have been relatively absent from mainstream disability studies (Shakespeare, 2006). Disabled feminists such as Morris, French and Thomas as well as Nordic scholars interested in the intersection of disability and gender (Traustadottir, 1993; Bjarnasan, 2004; Sigurjonsdottir and Traustadottir, 2000) have raised the profile of the ordinary, and everyday in the lives of disabled people, profiling topics such as friendship, family life, parenting and caring. Feminist research has not always advanced the cause of disabled women (Lunn and Munford, 2007). For example, Morris (1995) critiqued (non-disabled) feminist positions on the provision of care. She argued that, by focussing on the burden on female carers and failing to identify with disabled women who may both require and provide care, some feminist studies reinforce stereotypical portrayals of disabled women as passive and lacking agency. Within studies of adults with learning difficulties, the complex blurring of boundaries when (predominantly female) friends are also carers (Traustadottir, 1993) or paid carers and are identified by disabled people as

friends (Pockney, 2006) demonstrates the value of further exploration of friendship and caring relationships.

Reciprocity, exchange and equality are central both to research relationships built on trust and mutual respect and to the concept of friendship. Although the Friendship and Aphasia project does not focus exclusively on the friendship experiences of women, and does not assume a specific feminist epistemology, it is firmly rooted in feminist research values. These promote mutual exchange and reciprocity as part of bi-directional journey towards personal and collective change (Maguire, 2006). Reciprocity within participatory research has been defined as 'an ongoing process of exchange with the aim of establishing and maintaining equality between parties' (Maiter et al, 2008:321). It reinforces the importance of sustained reflection on issues of power and awareness of potentially exploitative relationships between communities and well-meaning but manipulating action researchers (Wadsworth, 2005; Huisman, 2008). Critical reflection and critical self-awareness within PAR and feminist-oriented inquiry places a premium on reflexivity and personal, inter-subjective and collaborative methods of addressing reflexivity (Finlay, 2002).

### 3.6    PAR and plural epistemologies

Coherence within methods, methodology and epistemology can act as a marker of the quality and trustworthiness of qualitative research (Carter and Little, 2007).  Friendship is a complex, social phenomenon and its exploration, particularly with people living with communication impairment, necessarily draws on a range of trans-disciplinary influences and research tools (Adams and Allan, 1998).

Epistemologically, the use of PAR in this project is aligned with critical approaches to understanding social selves and enacting social change. Participatory processes within action research support plural ways of knowing as a benchmark of quality (Bradbury and Reason, 2006; Stringer, 2007). Drawing on epistemological distinctions and terminology cited by Park (2006) the Friendship and Aphasia project aimed to generate action based on three distinctive forms of knowledge: representational, relational and reflective.

*Representational knowledge of an interpretive character* refers to knowledge constructed through dialogical exploration of friendship between a non-aphasic researcher and adults with aphasia in individual interviews and research group meetings. This form of knowledge is useful to creating important cognitive understandings and can equip co-researchers with a sense of *competence* (Park, 2006).

*Relational knowledge* refers to knowledge that moves beyond cognitive relations to understandings generated through the strengthening of affective relationships. Built on interpersonal connections and reciprocity, relational knowledge sits well with feminist values and the concerns of PAR as well as explorations of social relationships in aphasia. Park (2006) links this form of knowledge to *solidarity* and the power to act.

*Reflective knowledge* concerns critical reflection and a raising of consciousness. This is not reflection for reflection sake but reflection geared towards action. This calls to mind Freire's concept of action based on critical reflection or the notion of 'conscientisation' (Freire, 1970). This form of knowing is considered critical to developing co-researchers' confidence to participate in processes of social change. Reflection on personal and collective stories of friendship within the PAR cycles was a pre-requisite to developing the *confidence* to enact change (Park, 2006).

## 3.7    Summary

This chapter has situated the Friendship and Aphasia project within a critical inquiry paradigm of qualitative research. It has described theoretical influences from disability theory and explored the relevance of a relational model of disability that encourages attention to impairment effects and psycho-emotional disablism. These issues may be particularly significant to people who live with hidden disabilities. The chapter has also discussed feminist research interests such as voice and reciprocity that relate to the critical empowerment approach used within this project.

Principles of PAR reinforce research practices grounded in democracy, collaboration and empowering research relationships. PAR processes encourage flexibility and creativity both in the ways methods are employed and the way participants engage in dynamic cycles of refection and action. These principles and practices create opportunities for co-constructing knowledge and action in novel ways. They are therefore well suited to a collaborative study of friendship with a group traditionally marginalised within research, namely individuals with aphasia. The next chapter describes the range of methods employed within Phase 1 of the PAR inquiry.

# Chapter 4
# Methods Overview

## 4.0    Introduction

This chapter provides an overview of the project design and describes how different methods interact with the different sets of findings that will be presented in chapters 6,7,9 and 10. It describes methods relating to the formation and working practices of the Research Group, which shaped decisions regarding all aspects of design, data collection and data analysis. The chapter also provides details of ethical considerations and issues of quality that undergirded all stages of the study.

## 4.1    Project overview

This study aimed to address two overarching research questions:

- How do working-age adults with aphasia define, experience and understand friendship?
- What are the meanings of doing PAR with people with aphasia?

The project consisted of an exploratory phase (Phase 1), and an innovation phase followed by a period of evaluation and elaboration, together constituting Phase 2 of the study.  Project activity was shaped and monitored by the Research Group throughout the three years of the project. This progression is represented diagrammatically in figure 4.1.

Whilst writing is necessarily linear, the cyclical nature of collaborative work within PAR rarely follows a neat and predictable course (Cornwall and Jewkes, 1995; Baum et al, 2006). In this study also, iterative cycles of thinking, acting and reflecting produced many unanticipated twists and turns. Decisions about design and analysis unfolded in relation to the views of the Research Group, the outcomes of previous phases of the study, and pragmatic solutions to practical issues raised by the challenge of working together in the context of language impairment.

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**Figure 4.1    Overview of the Friendship and Aphasia study**
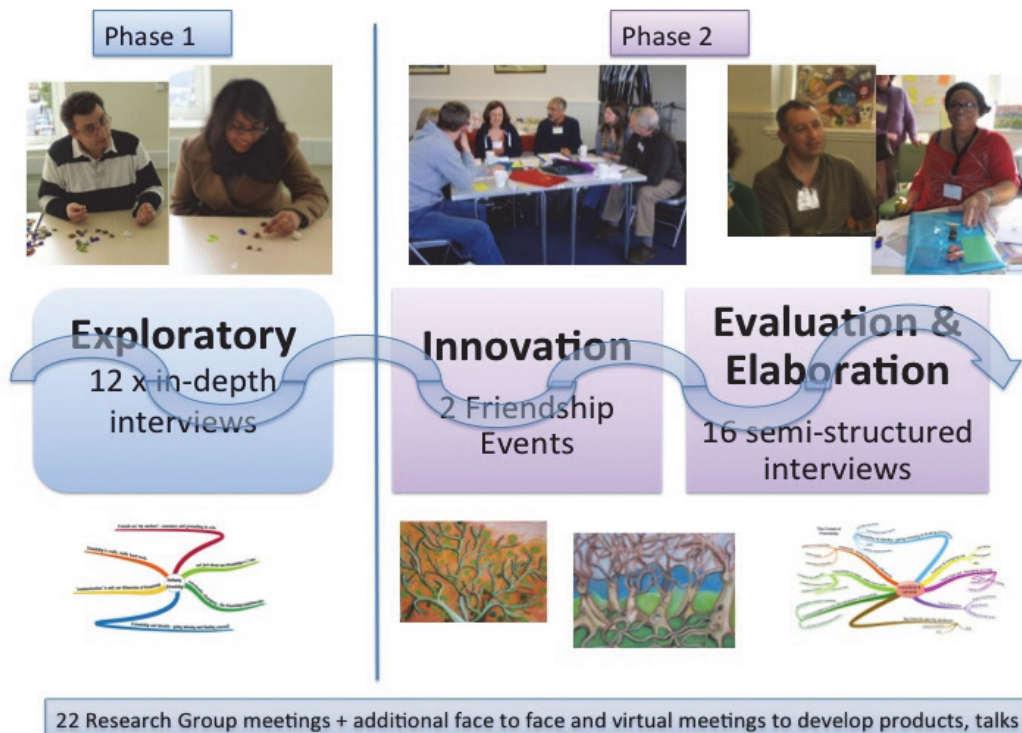


This cork-screwing process has also created certain dilemmas about how best to present different sets of methods and unfolding findings. For clarity, and to avoid unnecessary repetition, this chapter will focus on design and methods that pertain to the whole process of conducting the study. The interviews conducted within Phase 1 (exploration) and Phase 2 (evaluation) had a different format and purpose, and accordingly the methods of data collection and data analysis will be described separately in Chapter 5 and Chapter 8 respectively.  Both sets of interview participants, the 12 individuals who took part in the exploratory phase in-depth interviews and the 16 individuals who were interviewed after the Friendship Events, found it difficult to talk about friendship without locating their experiences in the wider context of life with aphasia. For this reason, Chapter 6 will draw on both sets of interviews to paint a portrait of the landscape of aphasia in which study participants experienced friendship. Findings relating to the process of doing Participatory Action Research with people with aphasia will be reported in Chapter 10.  The

relationships between different methods and findings sections are represented diagrammatically in figure 4.2, below.

**Figure 4.2     Diagram to illustrate the relationship between methods and findings**
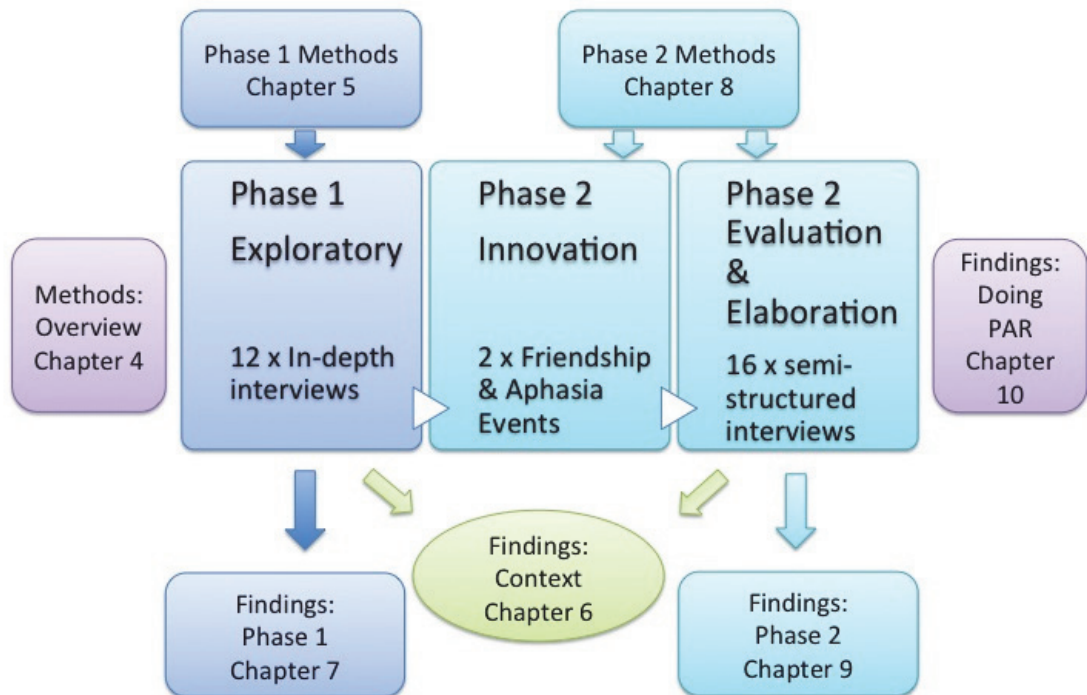


## 4.2     The Research Group

Formation of the Research Group began at the outset of the project in November 2009. The working practices and relationships within the group have guided research activities undertaken throughout Phase 1 and Phase 2.

My goal in establishing a Research Group was to enlist a team of people who could work with me to scrutinise traditional practices in the management of long term aphasia, take ownership of any significant research findings and outputs and advocate for service change with, or preferably without me. I sought input from an ex-colleague with aphasia at Connect, an individual

active in the aphasia world, to develop criteria for potential candidates for the Research Group.

We agreed that individuals should have personal and organisational experience of aphasia. We defined this as a minimum of 18 months living with aphasia and a minimum of one role acting as a service deliverer, teacher, advocate for people with stroke and aphasia generally. A key motivation behind inviting individuals with jobs, roles as Trustees, reference group members, group leaders, or a familiarity with peer support was to ensure that they had a skill set to draw on which might equip them to act as potential peer interviewers, data reviewers, disseminators and group discussants. We considered diversity in terms of age, gender, ethnicity and time post-stroke to be important.

Pragmatically, we required individuals to be able to participate in group discussions, if necessary with communication support. This required both sufficient comprehension of group discussion, and/or the confidence to ask for clarification or other forms of communication support. Ideally we hoped individuals would have the confidence to participate in discussion and, where necessary, to challenge my views as research co-ordinator and colleague in the group, or to stand up to prevailing group opinion or group-think. Project advisors needed to be sufficiently mobile to attend meetings at the Connect centre in London or at Brunel University.

Aware that many of our contacts at that time had personal experience of receiving or delivering services at Connect, I was keen to invite individuals from different parts of the country whose expertise had not been shaped by experience of Connect services and who had experience of different voluntary sector agencies and statutory bodies. Box 4.1 illustrates my early reflections relating to recruitment of Research Group members.

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**Box 4.1 Reflection**

This first meeting of the project didn't quite go to plan! I wasn't expecting that everyone would be so enthusiastic about wanting to join the group, not least because we have so little idea about where we are going yet. What are the implications of researching with people who I know? I would have no qualms about convening a project team of people without aphasia from contacts and recommendations of experienced, reliable people whose work I admire and respect. What are my concerns here then? My worry list:

- A concern about role and boundary blurring (therapist tendencies creeping in?)

- A concern about group-think and 'people like us'. Most of these people had strong professional identities before their stroke. Good to have the diversity of age and ethnicity within the group. I wonder if our similarities will enhance or hinder the quality of our listening?

- A concern that these folks are too busy to find time for another commitment particularly not knowing the nature of the demands ahead

- A concern that they will be overly respectful of me, given that most know me from my founder and director roles at Connect. Weird sharing my personal story with people. I make assumptions that people already know about my disability and how I came to work at Connect

- A concern about the study not becoming just another Connect innovation project – though inevitably our previous connections suggest we share and are comfortable with the values on which Connect operated. I think we were clear enough about the independence of the project from Connect though it's obviously not possible to disentangle our histories and biographies.

But there could be lots of positives too. Already signs that the lubricants of humour, respect and experience will work in our favour.

(Research Journal, January 2010)

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Guided by these criteria and the recommendations of my ex-colleague with aphasia, I approached twelve individuals to attend an introductory meeting. Three of these were interested but unable to attend meetings due to external commitments. The remaining nine came to an introductory meeting about the project where we discussed potential roles, requirements of being a research

group member and broad potential areas of research. All nine individuals approached signalled a desire to be engaged in the first phase of the project that we anticipated might last for between six and nine months. Table 4.1 describes the characteristics of the individuals who joined the group. Dates and employment status refer to the time of the first Research Group in January 2010.

Several members of the group knew each other prior to engaging in the research group. For example, Sarah and Barbara worked as volunteer facilitators at Connect's Drop-In sessions and were also members of the Women's Group.

Binda and Melanie had interacted previously as active members in the aphasia community though, living in different cities, they rarely spent time together. Katie, Tom and Priya had each been involved in training and fundraising initiatives at Connect. Binda, Barbara, Stephen and Sarah had contributed some years previously to the Department of Health Stroke Strategy. Initially I had anticipated that those invited to participate would not all wish to be involved but might nominate peers and colleagues with aphasia. This proved not to be the case as each was interested in participating him or herself. The commitment of this group of people to the project, to each other and to the aphasia community was agreed as a potential strength alongside the resource of expertise and diversity they brought to the group on account of age, ethnic background, marital status and range of stroke impairments.

I also had some pre-project connections with members of the group from my past work at Connect and presence in the world of aphasia. Two individuals were ex-colleagues and one an ex-Trustee of Connect. I had participated in training events with four individuals and sat on a research advisory panel with another. Two were unknown to me.

**Table 4.1.    Research Group participants**

| Name | Male/Female | Experience of aphasia | Roles with others with aphasia | Employment Previous (Current) | Base |
|---|---|---|---|---|---|
| **Katie \*\*** | F | Stroke - 5 years | Chaired local stroke service user group; Communication skills trainer with Connect | Deputy head teacher (Medically retired; unemployed) | SE England |
| **Melanie** | F | Stroke - 18 years | Set up and ran aphasia self-help service for 10 years Supports local SLT team | Policy Officer housing charity (medically retired; unemployed) | Midlands |
| **Sarah** | F | Stroke - 9 years | Co-facilitates music group, Drop-In activity at Connect | Lawyer (Medically retired; unemployed) | London |
| **Binda** | M | Stroke - 18 years | Ex-trustee of Connect Previously volunteer at local stroke support group | Deputy head teacher (Medically retired; unemployed) | Yorkshire |
| **Jeff** | M | Stroke - 4 years | Co-ordinator local stroke support group; volunteer at local stroke group; communication skills trainer at local Stroke Network | University lecturer (Medically retired; unemployed) | Midlands |
| **Priya** | F | Stroke - 2 years | Supports local stroke strategy activities | Optometrist (Currently unemployed) | Middlesex |
| **Stephen \*** | M | Stroke - 18 years | Employed as project worker at Connect. Secretary local aphasia group Previously co-ran aphasia support group | Charity worker (Project worker, Connect) | London |
| **Harry** | M | Stroke - 20 years | Employed as aphasia counsellor at Connect | Music industry (Counsellor, Connect) | London |
| **Barbara** | F | Stroke - 10 years | Co-facilitates womens group, Drop-In at Connect; supports local stroke implementation group | Council worker and trade union representative (Medically retired, unemployed) | London |
| **Carole** | F | Speech & Lang Therapist - 23 years | N/A | Previously Director of Innovation at Connect (Researcher) | London |
| **Debra (joined Jan 2011)** | F | (physical & communication disability) | Volunteers at Headway House; volunteers at Connect Drop-In | Disabled Arts organisation administrator (Currently Unemployed) | London |

*Withdrew after meeting 5 due to work pressures          ** Died in year 1 of project

A revisiting of membership occurred naturally towards the end of Phase 1 of the project. One member of the Research Group, Katie, died suddenly following a second stroke. A second member of the group, Stephen, had found attendance at the meetings increasingly difficult due to pressures of work and had stopped attending. Looking toward the innovation stage of the project, where we planned to create a series of 'friendship products', we reviewed whether current Research Group members wished to continue their involvement with the project or stand down. All seven remaining members were keen to continue. We discussed whether now was an appropriate time to recruit some new group members who might lend new skills and perspectives to the project. A suggestion was made to invite Debra, a disabled woman with personal experience of communication disability (though not aphasia) and professional experience of working with disabled artists. As a volunteer at Headway and at Connect, she brought both personal and organisational knowledge of communication disability and peer support and like others in the group shared activist tendencies. We agreed that whilst she didn't have aphasia she was sharply in tune with the lives of people with aphasia through her weekly commitment to listening to people with aphasia at Headway and Connect. Research Group members valued her thoughtful style and wide experience of disability issues, for example working in inclusive education projects. We felt her experience as a person disabled from birth might provide comparable or contrasting views on friendship. Finally we considered Debra would bring ideas and contacts to help us think about the content and outputs of Phase 2. Other than this one addition and the two departures from the group mentioned above, the Research Group has remained consistent throughout the three years of the project.

## 4.3 Research Group meetings

### 4.3.1 Practicalities

Research Group meetings ran from 11 am to 15.15 including approximately an hour break for lunch. Meeting for coffee prior to the meetings allowed individuals time to regroup after travelling, and catch up on social issues with each other. Those travelling longer distances frequently met up in the pub after meetings while they waited for the rush hour to pass and cheaper train fares to be available. I reimbursed all travel and refreshment costs drawing on a small allocation of bursary funding for personal travel and conference attendance and funds generated through teaching commitments.

The majority of meetings took place at the offices of Connect in central London where we had access to a large, airy meeting room free of charge. Group members sat around a large oval table where we could see each other, flipcharts and any projection of powerpoint slides. Three meetings took place at Brunel University though as most participants, particularly those travelling from further afield, were required to come via central London, Uxbridge was deemed a less favourable and less accessible meeting place.

We agreed to audio and video-record all meetings and from these recordings, flipchart notes, my meeting notes and fieldnotes created during and immediately after meetings I produced a set of summary meeting notes. Under agenda headings I described the issue under discussion, the range of views expressed and the decisions and actions agreed upon. In developing meeting notes I would also attempt to capture the breadth and diversity of discussions by including a selection of verbatim quotes transcribed from the audio recordings. I was careful in summarising the views of Research Group members with aphasia not to prioritise more eloquent or more confident voices but to capture the group consensus and highlight any dissonant voices. An example of Research Group meeting notes can be found in Appendix M. A full list of topics covered in Research Group meetings is included in Appendix L.

I also recorded methodological, interpretive or reflective insights arising from Research Group meetings in fieldnotes and my reflective journal. Typically these entries related to noticing my own physical and emotional responses, commenting on any instinctive reactions or unexpected responses from group members to discussions, and thoughts about strengths and weaknesses relating to facilitation of the group. For example, I would comment on the clarity of the questions we were asking, whether I perceived myself to have been over talkative, techniques that had facilitated (or not) group interaction, and the interplay of group dynamics with the topics under discussion.

### 4.3.2   Purpose and activities

The role of the Research Group was established in early meetings as directing the project throughout its courses through discussion and decision-making. Reviews of user involvement in health and social care research identify the different potential roles and functions of 'service users' as advisors and co-researchers (Staley, 2009). Beresford (2005) clarifies the difference between research where service users

perform a consultative role, commenting on proposals determined by academic researchers, research that is collaborative and research that is user-controlled. The intention here was to aim for maximum collaboration between Research Group members with aphasia and me as co-ordinator of the project and group member.

The first meeting introduced the range of ways in which different members of the group could potentially be involved, for example as peer interviewers, data analysts, product developers and disseminators. This was based on the assumption that different individuals may have different preferences for involvement and that not everyone would want to be involved in all aspects of the project.

I also clarified the requirements of a three-year programme of doctoral research, differentiating the research orientation of the project from more therapeutically oriented support groups that most group members were familiar with. We discussed previous involvement with research initiatives, what group members had enjoyed and, in some cases, their frustrations with these endeavours. For example, several individuals reported a frustration that having given up a lot of time to projects, the final reports did not seem to reflect or represent their views. Others criticised a lack of tangible progress from research to meaningful actions for people living with aphasia. One group member with aphasia voiced frustration and envy that she was unable to be the lead researcher due to the nature of her language impairments. This helped signal some of the pitfalls of tokenistic engagement and the possibility of harmful psycho-emotional emotional consequences where participants were unable to participate on equal terms.

In summary, people with aphasia who took part in the Research Group with me co-directed all aspects of the research cycle:

- prioritising the area of inquiry and shaping the primary research question
- creating and critiquing research design
- developing ethical materials and information
- advising on topic guide development
- recruiting participants
- planning, developing and delivering the Friendship Events
- participating in data analysis and interpretation

- taking part in a range of dissemination activities (e.g. setting up a website and developing / reviewing website material; writing articles for newsletters; co-producing and co-presenting conference presentations)

An overview of f Research Group participation in research processes over the three years of the project is provided in Table 4.2 (page 96).

## 4.4    Group process and group relationships

Principles of effective group process highlight the importance of attending to group objectives, group dynamics and group facilitation (Tuckman, 1964; Yalom, 1995; Elwyn et al, 2001). As a group, we established and agreed clear ground-rules for meetings that paid particular attention to issues of confidentiality, communication and inclusion. These were revisited at the start of all early meetings and wherever relevant. For example, when discussing interview data together we specifically revisited the need to keep discussions confidential and private to the research room. The focus and desired outcomes of the different stages of the study were revisited repeatedly at the start of meetings when we recapped on what had happened last meeting and outlined the anticipated focus of the meetings.

Adili et al (2012) critique the absence of accounts about how group process operates within the PAR group. These authors interpret the three-stage cycle of looking, thinking and acting in PAR learning circles (Koch and Kralik, 2006) in relation to Tuckman's four stages of group development: forming (looking), storming and norming (thinking) and performing (acting). An extended forming phase was not necessary in our PAR group where pre-existing relationships and the experience each of us brought as group participants and group facilitators fast-tracked group cohesion. The length of our study and individual's long-term commitment to the research process meant that our performing phase was long-lived as the group progressed through repeated cycles of looking, thinking, and acting.

Relationships necessarily represent the context of doing participatory action research (Maguire, 2006). PAR groups require regular sharing of personal stories and experiences as members build a safe, trusting and confidential climate (Koch and Kralik, 2006). From the first meeting rich, diverse personal stories of life with aphasia and experiences of relationships and friendships became a mainstay of our group dialogue. Listening and being heard was key to sharing stories and being open to learning from others. The rich weaving of personal and collective narratives of life

**Table 4.2    Overview of Research Group activities**

| Project | 0-6 months | 7-12 | 13-18 | 19-24 | 25-30 | 31-36 | Examples |
|---|---|---|---|---|---|---|---|
| **Design** | Articulate Research question Develop recruitment materials Topic guide | | Develop Event programme & materials | Develop Event programme & materials | | Generate ideas & questions for future research | Appendix B,I,M |
| **Data Generation** | Advise on recruitment for Phase 1 interviews | 6 group members participate in Phase 1 interviews | | Support recruitment for Friendship Events | Run & evaluate Friendship Events | Review of PAR process | Appendix F,I,K,M |
| **Data analysis/ Interpretation** | | Review Phase 1 interview data  Develop Friendship diagram v 1 | Develop Friendship diagram v 1  Co-develop presentations | | Review Phase 2 event and interview data  Develop Friendship diagram v 2 | Co-develop presentations | Appendix M,N,U,V |
| **Dissemination** | | | | Develop Feedback materials to Phase 1 interviewees Conference presentations | Develop website Conference presentations | Newsletter items Conference/informal presentations Plan post project communications | Appendix S,T,U,V |

with aphasia and disability inevitably forged new connections between individuals in the group and deepened pre-existing ones.

A fifth stage of group process noted by Tuckman and Jensen (1977) is the 'adjourning' stage as groups conclude and disband. Whilst a focus on the future and a post-inquiry commitment to sustaining action is characteristic of the PAR process, this dissolution can be associated with a sense of loss and mourning (Forsyth, 2006). As the group came to a formal end after 22 meetings we addressed the issue of endings with care and clear planning about preferences for future engagement with the research and each other. Consideration of endings is also addressed under ethical considerations and the findings relating to working together as a PAR group (Chapter 10).

## 4.5    Group facilitation and communication access

Stringer (2007) differentiates the resource person role of the participatory action researcher from researchers working within more conventional research paradigms. With expertise presumed as shared rather than being located with the person leading the research, the action researcher acts as a support person and catalyst, assisting participants to identify and clarify concerns, enabling participants to explore innovative rather than traditional methods of inquiry, supporting the group to take ownership of actions and the implementation of plans (Koch and Kralik, 2006; Stringer 2007).

Flattening of power structures to enable lay researchers to resist oppression by academic researchers and dominant academic discourses (Maguire, 2006) is of particular relevance when participants are disadvantaged by loss of language. Aside from me, and in Phase 2, Debra, Research Group members had impairments of spoken language, reading and writing. Several had difficulty following spoken conversation. Most had varying degrees of difficulty with memory as language difficulties interacted with their ability to store facts and information or retrieve information with ease. Stringer (2007) notes communication, participation and inclusion as three critical pillars of quality in PAR. As the only group participant with unimpaired language and memory

skills, my role as facilitator of the communication which underpinned participation and inclusion, was challenging and time-consuming.

Pragmatically I addressed this challenge by adhering closely to principles of good communication access which provide a 'way in' to equal participation and inclusion in conversations, meetings and services (Parr et al, 2008; Swinburn et al, 2007; Pound et al, 2007). Facilitating good communication access requires attending to interactions, documentation and environmental supports before, during and after all research interactions (Swinburn et al, 2007). Approximately one week ahead of sessions, group members were sent an agenda highlighting key areas for discussion and, where appropriate, questions to consider ahead of the meeting. All written communications were presented in an accessible or 'aphasia friendly' format, utilising, for example, enlarged font size, bullet points, clear headings and bolding to ensure text could be easily read (Brennan et al, 2005; Dalemans et al, 2009).

During meetings, accessible powerpoint slides were used to support communication and memory by:
- Presenting the meeting agenda
- Recapping and revisiting previous discussions and agreements
- Introducing areas for discussion and any questions central to the current meeting
- Presenting in an accessible format relevant new information
- Presenting diagrams summarising progress and next steps

An example of slides used to support the meetings is given in Appendix N. Written and visual records enabled group members to request rewinding or relocating to a particular slide to clarify points of discussion or support recall of an issue.

Another key aspect of communication and memory support was the use of visual material, particularly diagrams, which served to recap where we were in the overall project and any specific aspects of the project we were involved in.

For example, three key diagrams that were consistently available at meetings were:

- The overarching project diagram (fig 4.1, this chapter, page 86)
- The model of friendship (fig 7.2, Chapter 7 page 209)
- A diagram indicating how different friendship products, developed across the course of a year, fitted together within the overarching plan for the Friendship Events (Appendix N)

Within a week of meetings I would produce a full set of notes documenting discussions and decisions and send these to all members of the group. The problem with minutes being too long arose as an issue early on, specifically how to document a meeting of over three hours in a full but accessible way, e.g. using larger font, supporting pictures and sufficient explanatory context. Not everyone wanted to read the full notes, leading to a compromise to keep the notes as full as possible (since most group members with aphasia found a recap of context as well as decisions helpful), but also to produce a one page summary of key points and decisions (see example of meeting notes, Appendix M).

Within meetings I regularly summarized decisions, agreements and actions verbally and often visually on flipcharts or diagrams to ensure we shared the same understandings of the last meeting and were at the same start point for the meeting in hand. Inevitably some members of the Research Group with aphasia had stronger and more confident voices within discussions than others. Some members, like me, had more ready access to language. As individuals with experience of both participating in and facilitating groups, group members with aphasia quickly respected the differences of pace, language ability and contributory style of their peers. As an experienced facilitator of groups of people with communication disability, I was aware of the requirement to employ certain facilitatory strategies. For example, in early meetings, I would create space for quieter members of the group to have an input to discussions by asking both a general 'What do other people think?' question or specifically asking an individual if they had any particular thoughts on an issue.

I also had the role of bringing information to the group or, as one group member termed it, 'acting as a conduit' between the academic world and the world of group members. For example, I would occasionally summarise relevant academic literature on stroke and relationships or inform the group about the principles and processes of different research methodologies such as PAR.

## 4.6     Time

Time was a critical resource in relation to providing the communicative space to look, think and act together. It was always in short supply. In addition to the 22 Research Group meetings, I met with individuals from the group for one-to-one discussions as we prepared Friendship Event materials, developed presentations and worked on papers. These meetings were recorded with permission and notes created from the audio recording and my notes. These sessions provided a further audit trail of discussion and decision-making as well as a rich source of data for my research journals and personal reflexivity. Time spent together in the informal social moments over coffee before meetings, in the pub after meetings or, for example, travelling together to stations and conference presentations strengthened relationships, fuelled reflexivity and surfaced further contexts to consider power and relational ethics which are discussed further in the findings on doing PAR with people with aphasia in Chapter 10. A full list of project activities I undertook with research group members outside the 22 Research Group meetings is presented in Appendix L.

## 4.7     Ethical Issues

The iterative and unpredictable nature of PAR together with the prolonged and close relationships between researcher and co-researchers requires careful, ongoing attention to ethical matters (Hockley and Froggatt, 2006; Koch and Kralik, 2006). In this study formal ethical approval was sought and granted from Brunel University Research Ethics Committee for Phase 1 (June 2010) and Phase 2 (November 2011) data collection (Appendix A). This included, in Phase 1, attention to capturing and using data from the Research Group. Specific ethical considerations addressed in both applications related to

communication impairment and consent, distress, confidentiality and managing the potential presence of relatives and partners in interviews and events.

People with communication impairments are considered vulnerable adults and particular attention should be given to processes of informed consent and adapting interviewing procedures (Kagan and Kimmelman, 1995; Carlsson et al, 2007; Penn et al, 2009). For example, in a review of descriptions of informed consent procedures in research studies with people with aphasia, Penn et al (2009) critiqued inconsistent and poorly described procedures. These authors noted potential risks specific to people with aphasia in qualitative research such as anxiety, distress, exploitation, misunderstandings about research as therapy, loss of self identity, stereotyping and relative ease of identification in published papers.

Given the impact of language and memory impairments on participants' ability to retain and retrieve information, an ethic of ongoing consent (Dewing, 2007) was employed with multiple opportunities presented to revisit project aims, consent and the right to withdraw. Viewing the process of consent as an ongoing negotiation rather than a one off event (Holloway and Wheeler, 2010) is deemed good practice with people with dementia, learning disability and aphasia (Dewing, 2007; Cameron and Murphy, 2007; Penn et al, 2009).

For both Phase 1 and Phase 2, participant recruitment took place within established support groups under the leadership of Research Group members. In a review of research practice in relation to vulnerable participants, Nind (2008) has argued that utilising networks of support can minimise the risk of feeling coerced to participate in research.

Although the therapeutic and empowering benefits of telling personal narratives of illness and disability are well documented (Frank, 1995; Bruner, 1999), consent procedures also clarified that engagement in the Friendship and Aphasia research was not to be confused with therapy, a common issue

in health related research (Stark and Hedgecoe, 2010) and research with people with aphasia (Penn et al, 2009).

The principle of beneficence concerns maximising benefits to participants whilst minimising any potential harm caused through involvement in research. In this study ethical considerations concerned the possibility that research activities centred on friendship and friendship change post-stroke might cause distress. Operating with caution, care and compassion towards participants with aphasia was a guiding principle for all Research Group members (Rowan, 2006). Mindful of the potential for research activities to raise awareness of social isolation or negative changes in the quality and quantity of social relationships, we agreed the imperative not just for friendly, informative information sheets for both Phase 1 and Phase 2 of the project but also, where appropriate, easy access to follow-up information, peer support or emotional support. A member of the Research Group who is a trained counsellor was available to offer free counselling via a face-to-face or Skype service if required. In the event, the issue of participants requiring follow up emotional support did not arise.

Confidentiality was also an important consideration. In order to support communication and memory during interviews and research group discussions, photographic material, including photographs of individuals at events or graphic representations of individuals' social networks, served as an important method of supporting discussions. This required explicit consent procedures for photographic material as well as video recordings that were required to support transcribing material from people with minimal spoken output. A second issue of confidentiality was the discussion of respondents' stories within the Research Group. Coghlan and Casey (2001) question whether confidentiality within health related action research can ever be fully addressed. Whilst transcripts were immediately anonymised the style and content of material from Friendship Event and interviews meant that some respondents were easily identifiable by peers in the Research Group. I addressed this through frequent reiteration of the ground rules concerning confidentiality within the Research Group.

People with severe expressive language problems and/or their partner often request partners to be present during interviews and events to support communication. Presence of partners at interviews raises a series of methodological questions around the influence of proxy views. Collecting interview data via proxies is considered a second best approach to qualitative data collection (Koch et al, 2001; Philpin et al, 2005). Spouses of people with severe aphasia are known to engage in 'speaking for' behaviours (Croteau and Le Dorze, 2004) that may be distressing for the person with aphasia and compromise the credibility of the research data. Although we discouraged the presence of others during data collection the project group were mindful that this situation might arise. We developed supplementary information and consent sheets for relatives and plans to accommodate relatives at a discrete distance from partners with aphasia in the Phase 2 Friendship Events. I also employed a series of interviewing tactics in Phase 1 and 2 interviews to discourage participation of relatives in the interviews.

### 4.7.1   Relational ethics and the ethic of friendship

Action researchers frequently allude to the most prominent ethical dilemmas that arise during their inquiries as those that centre on relational ethics or the shared experience of human relationships (Koch and Kralik, 2006; McIntyre, 2008). Holloway and Wheeler (2010) caution qualitative healthcare researchers to be cognisant of both professional and research ethics, and the conflicts that may arise in carrying out a research role rather than prioritising therapeutic responses to participants.  In relation to action research inquiry, Rowan (2006) notes that 'In research where the researcher and the other participants come much closer, and are more deeply involved with one another, the personal and social implications become far more complex' (Rowan, 2006:115). This entails attending to the interpersonal and social ethics of doing research.  Interpersonal ethics refer to the care and concern with which equals treat each other. Social ethics relate to the difference that research can make to all those involved and with it, the duty to avoid making 'horrible mistakes' (Rowan 2006:115).

Tillmann-Healy (2003) progresses the discussion by describing the appropriateness of an 'ethic of friendship' or 'friendship as method' (Tillmann-Healy:729) for collaborative inquiries into issues such as friendship. Within the close collaborative relationships forged within our group we were exposed to the same potential risks and challenges of friendships. For example, what if individuals fell out or were unhappy with the way the research represented them (Sassi and Thomas, 2012)? What if the research failed to achieve meaningful, practical outcomes or we disappointed one another in some way?

Relational processes of trust, humour, mutual respect and reciprocity underpinned the working relationships within the Research Group. These issues have surfaced in Chapter 3 and will be explored in more depth in Chapter 10, which critically appraises the challenges and strengths of doing PAR with people with aphasia.

### 4.7.2   Disengagement

Leaving the field and disengaging from formal research processes, particularly where these have provided a context for the flourishing of social relationships, provokes ethical concerns about exploitation and power. These are familiar issues for participatory studies grounded within feminist values (Maguire, 2006; Huisman, 2008). Emancipatory disability research has also focussed research ethics on the need to avoid parasitical research relationships between researchers and those who are the objects of their research (Oliver, 1999). After a three-year process of working closely together, sharing ideas, food, humour and many intimate stories of disability and relationships the process of disengaging from the PhD research project was significant and attended to explicitly. Issues of endings and ways to manage ongoing connections between Research Group members are also addressed in Chapter 10.

### 4.8    Quality, rigour and trustworthiness

Ethical considerations relate centrally to whether research writing is trustworthy and does justice to the experiences of the participants (Holloway, 2005). There is an extensive literature on issues of rigour, quality and validity

in the evaluation of qualitative research. Criteria employed to judge the quality of quantitative research such as objectivity, reliability and generalisability are perceived as inappropriate for qualitative studies where researcher interpretation and subjectivity are integral to the processes and production of knowledge (Patton, 2002; Yardley, 2008).

Within the field of qualitative research *validity* refers to judgements that a study is sound, trustworthy and has been carried out in accordance with certain standards of good qualitative research practice (Yardley, 2008). However because qualitative research is not a 'unified field' some authors advocate caution in rigidly defining and applying criteria that may prioritise methods at the expensive of the creative, interpretative dimension of qualitative analysis (Dixon-Woods et al, 2004). Sandelowski (1993), whilst acknowledging the role of rigour, famously cautioned against confusing rigour with 'rigour mortis', where adhering to rigidly espoused methods risks stifling creativity and reducing the richness of human experience. Yardley (2008) suggests instead that quality should more flexibly combine principles of commitment and rigour, contextual sensitivity, and coherence across theory, research questions, methods and impact.

Trustworthiness within qualitative research requires demonstration of credibility, dependability, transferability and confirmability (Holloway and Wheeler, 2010). Credibility concerns the recognition of meanings by those who have contributed their experiences. A process of constant exploration and verification should ensure compatibility between the perceptions of the researcher and participants (Cresswell, 2003). Questions of transferability, ask whether findings are transferable from one research context to another (Holloway, 1997). Rather than principles of generalisibility associated with positivist paradigms, transferability relates to thoughtful, modest extrapolations from well-described cases to other contexts of inquiry (Patton, 2002). Transferability therefore depends upon adequate description of sampling methods and the profiles of participants.

Dependability reflects the reliability of a study (Guba and Lincoln, 1985). It demonstrates the detail, accuracy and consistency of a study by allowing readers to scrutinise the decision-making processes of researchers. Confirmability also helps make the research process transparent by enabling the reader to judge the way findings and conclusions have addressed the aims of the research and are not derived from biases of the researcher (Holloway, 1997). Confirmability ensures that data may be traced back to original sources through an audit trail.

Studies located within participatory action research methods are subject to forms of quality and validity that go beyond notions of trustworthiness (Herr and Anderson, 2005). Patton (2002) suggests that inquiry that aspires to be fully collaborative and participatory should abide by a set of principles. These include:

- Full involvement of the participants in all aspects of the research cycle and activities
- The ability of participants to claim ownership of the inquiry
- Participants work as a group with the researcher acting as facilitator, collaborator and equal
- Full recognition and valuing of participant's expertise and encouragement for participants to acknowledge and value what they bring to the research
- Recognition of power imbalances and actions taken to redress inequalities and imbalances
  (Patton, 2002:185)

These aspirations challenge most qualitative, participatory researchers but they pose additional dilemmas within PhD research studies where issues of originality and ownership are critical to academic criteria of evaluation (Herr and Anderson, 2005; Klocker, 2012).

The centrality of democratic, authentic engagement with lay researchers requires that questions about rigour and quality in PAR, must address whether the inquiry is accessible, whether it makes a difference and whether it is sustainable and of meaningful consequence (Koch and Kralik, 2006; Stringer

2007). The importance of relational processes and cycles of action and reflection with collaborators require transparent discussion of relational practice, personal values and epistemological assumptions (Kemmis and McTaggart, 2005; Bradbury and Reason 2006; Reason and Bradbury 2006).

Herr and Anderson (2005) call for action research to appraise dialogic validity to measure whether goals of generating new knowledge have been achieved and outcome validity to appraise achievement of action-oriented goals. Kemmis and McTaggart (2005) also relate quality of participatory research to pragmatic validity, or, in the case of this PAR project, how the inquiry had pragmatically impacted on participants' knowledge and experience of friendships. This links to Herr and Anderson's (2005) notion of catalytic validity, which highlights the transformative goals of PAR through ongoing education of both researcher and participants. Within this project, for example, the Research Group informally reviewed, at regular intervals, how our awareness and understandings of friendship had transformed across the course of the project.

## 4.9    Reflexivity

Reflexivity contributes to the integrity and quality of the research by interrogating the credibility of the researcher and the impact of the researcher's presence on the formation of meanings (Patton, 2002; Finlay, 2002). Through 'looking back and inward in a self-aware manner' (Fischer, 2009:584) the individual researcher can develop a greater mindfulness of personal issues and assumptions that may filter or obscure insights into and interpretations of data. Reflexivity therefore makes transparent the important role of the self (Fine, 1994), the biases brought to the research by the researcher and the impact of relationships on actions and knowledge generated by the research (Finlay, 2002).

Whilst the aims and value of reflexivity within qualitative research are commonly agreed, Mauthner and Doucet (2003) suggest there has been limited discussion of how to operationalise reflexivity in a theoretically and methodologically coherent way. They recommend that confidence in

qualitative work will be enhanced by attention to three key dimensions of reflective activity. Researchers should attend to social / emotional reactions to respondents in projects, to the institutional and interpersonal contexts which shape and house research activities and to ontological/ epistemological concepts of individual and relational accounts.

Patton (2002) asserts that reflexivity comes most strongly into play in analysing and reporting the data. Practitioners of participatory research however note the fundamental importance of positive working relationships and the impact of these relationships on the quality and trustworthiness of knowledge, action and learning (Stringer, 2007). Although reflexivity is an acknowledged component of much qualitative research, PAR inquiries tend to examine more closely the intrapersonal dynamics of power that operate between co-researchers within PAR groups. In doing so, it promotes the possibility of creating empowerment through self-awareness and the shared construction and ownership of knowledge (McFadden and McCamley, 2002; Maguire, 2006).

Finlay's (2002) five-part typology discusses reflexivity based in mutual collaboration, social critique and ironic deconstruction, in addition to more familiar introspective or intersubjective, phenomenological forms of reflexivity. Whilst mutual collaboration best suits principles of participatory research, Finlay suggests that reflexivity is rarely located exclusively within a single form of reflexivity. She also cautions against idealistic assumptions of equal relationships within the 'egalitarian rhetoric' of reflexivity based on mutual collaboration (Finlay, 2002:220).

Questions of reflexivity and relationship posed within this research included:
- How have my background, motivations and identities impacted on my relationship with research participants?
- How have my relationships with Research Group members and participants with aphasia affected the nature of the data and the findings?

- How has my relationship to research participants and collaborators evolved and what has been the impact for me, for them and for the research of these changes in relationship?

Methods of personal reflexivity have included journal accounts of responses to research meetings and Research Group relationships, and to conducting, listening to and analysing interviews. Fieldnotes of meetings, events and interviews have also been regularly reviewed for relevance to issues of positionality and power. At the end of the project we reflected individually and as a group on the changes in our interpersonal relationships and the impact of these changes on our evolved understandings of friendship.

## 4.10   Summary

This chapter has described the composition, formation and working relationships of the Research Group. The intrapersonal dynamics that existed between group members and myself represented a foundational component of the Friendship and Aphasia project. The spirals of reflecting and acting together on a continuous basis over three years have meant that the process of working together was not always neatly divisible into 'methods' and 'findings'. Rather these embedded, participatory processes left their mark in an evolutionary way on project actions, phases, interpretations and individuals. Careful reflection upon these collaborative acts of engagement contributed to processes of transparency and trustworthiness throughout the study. The chapter also highlighted the importance of heightened awareness of relationships and relational ethics as an essential thread of the fabric of PAR inquiries.

# Chapter 5
# Methods: Phase 1

### 5.0    Introduction

This chapter describes the methods of data collection and data analysis employed in the exploratory stage of the project. It focuses specifically on methods employed in conducting the 12 in-depth interviews in Phase 1. These were conducted and analysed between June 2010 and February 2011. They were designed to address the over arching research question:

- How do working-age adults with aphasia define, experience and understand friendship?

### 5.1    Recruitment

Ethical approval was granted from Brunel Research Ethics Committee in June 2010.  Overarching ethical issues, for example attending to issues of consent, vulnerability and confidentiality in the context of aphasia have been addressed in Chapter 4. Particular care was taken to make information and consent materials accessible to potential participants with reading and writing difficulties. Examples of these are provided in Appendix B. Adaptations including larger sans serif font, white space, emboldening and supportive pictures, as well as simplified sentences and language are well recognised aspects of making written material communicatively accessible (Brennan et al, 2005; Parr et al, 2008).

Inclusion criteria for all Phase 1 interviewees were:
- Self reported evidence of aphasia
- Aged 65 or under
- Ability to tolerate an interview of up to 90 minutes
- Sufficient auditory comprehension and cognitive ability to participate in a research interview with relevant supported conversation techniques.

A purposive sampling framework was developed which aimed to recruit a relevant and diverse group of adults with aphasia (Ritchie et al, 2003). The sampling framework aimed to include:

- Approximately equal numbers of males/females
- Individuals in their 20s, 30s, 40s, 50s and 60s
- people from majority and minority ethnic backgrounds
- various living circumstances (e.g. living alone / living with partners &/or family members)
- presence/absence of mobility difficulties
- individuals with under 5 years, 5-10 years and over 10 years experience of life with aphasia
- individuals with mild, moderate and severe levels of aphasia

This latter point led to interesting discussion about how the severity of aphasia is evidenced, perceived and measured. Research Group members with aphasia questioned whether severity should be defined by objective measurement of language ability and performance, or by respondents' subjective experience of confidence, emotional robustness, or perceived levels of social inclusion/exclusion. We therefore decided to ask all Phase 1 participants to self-rate their perception of the degree of their aphasia by using a five image pictorial scale from the Communication Disability Profile (Swinburn and Byng, 2006) (see Appendix C). Using the scale, interviewees were asked which figure best depicted how they were feeling today about their level of aphasia. A professional tool, the Boston Aphasia Severity Rating Scale (Goodglass et al, 2001) was also administered for all Phase 1 interviewees as a way to document for professional audiences the range of language impairment of study participants. This five-point rating scale is typically administered by a Speech and Language Therapist as part of a larger battery of language assessments, though only the scale was employed in this study. There was consensus among the Research Group about not subjecting any interviewees to formal language assessment that we deemed contrary to the values of the project. These data were not formally analysed but were intended as background information, which might help describe participants in future, presentations and discussions with professional audiences.

In discussing potential interviewees a suggestion arose that a sub-group of individuals from the Research Group would be apt candidates for a first wave

of interviews. Whilst individuals in the group recognised that as people with long-standing aphasia, and experience of activist roles such as trustees, group facilitators and trainers, they were not necessarily representative of people still isolated and disconnected by their communication disability, they were curious to experience the process of being interviewed at first hand. They talked about wanting to contribute their views as experienced people with aphasia. This experience related both to the process of reflecting as individuals on friendship and as experts in supporting and facilitating others with aphasia to share their views. They also articulated a sense of responsibility for other participants who would be interviewed about a potentially upsetting topic. They questioned how others with aphasia would participate and how they might feel. This was a way to check this out at first hand.

We determined to prioritise these interviews with those in the group who had more severe aphasia or a quieter voice within the group sessions. Six individuals from the group volunteered to be interviewed and completed consent forms for data collection.

We agreed that in recruiting the remaining six participants for Phase 1 interviews we should prioritise individuals who could be described more typically as 'service users' rather than engaged and active peer supporters, who had more severe aphasia or had aphasia of more recent (under 5 years) duration. Studies have noted the vulnerability of self-confidence when communication is impaired post-stroke (Lynch et al, 2008). People with more severe aphasia may experience a poorer quality of life post stroke (Hilari and Byng, 2009) than people with milder aphasia and are also likely to experience additional co-morbidities, such as mobility difficulties, which may impact on friendship experiences. Qualitative explorations of the impact of stroke suggest the diverse and interacting impacts of stroke and the ability to cope with them may vary significantly over time (McKevitt et al, 2004).

Snowballing techniques were chosen to eliminate professional gatekeeping, and because advisors were keen to involve peers in the project. Penrod et al (2003) suggest snowball sampling can be particularly relevant where people

are vulnerable or not easily visible and accessible. Snowballing can be useful in generating small population samples though they may run the risk of compromising the diversity of the sample (Ritchie et al, 2003). In order to minimise this risk, we developed a list of potential interviewees who met inclusion criteria and added diversity to our sample in some way e.g. time post-stroke, severity of aphasia and age. From a list of 15 people generated by Research Group members with aphasia we prioritised eight individuals whose characteristics fulfilled our sampling criteria. From these eight individuals whom we approached, six expressed an interest in being involved in the study. We provided these individuals with accessible, 'aphasia friendly' written information about the project (Brennan et al, 2005; Swinburn et al, 2007). For example information booklets were written in larger sans serif font with white space, bolding and pictures to support text (Appendix B). I arranged a time to meet potential participants to check their understanding of the project and project requirements and, if appropriate, gain their consent to being involved. This initial interaction also gave me the opportunity to document background information, establish a relationship and, importantly, learn about the communication needs of individuals and how best to support their communication. At this initial meeting we also established a time and date convenient to them for the research interview, typically two to four weeks later.

### 5.1.1   Participants

Details of all 12 interviewees recruited for Phase 1 interviews are presented in Table 5.1. Their biographies are presented in Appendix D. The sample included six men and six women, with an age range of 20-62. Four of the Phase 1 participants had severe aphasia, four moderate and four mild aphasia. Three individuals lived alone, three lived with parents, one lived with her son and the remaining five lived with a partner and /or children.

### 5.2   Conducting the interviews

In-depth interviews typically aim to explore and understand the respondent's world from their perspective (Legard et al, 2003). Successful in-depth interviews rely on skilled use of open questioning, reflecting on remarks made by respondents, and non-directive probing which encourages participants to

elaborate on responses (Taylor, 2005; Kvale and Brinkman, 2009). People with cognitive, learning and language difficulty are therefore at risk of being excluded from qualitative research that relies on traditional methods of depth interviewing (Taylor, 2005; Luck and Rose, 2007). Dalemans et al (2009) noted for example the high proportion of people with severe aphasia excluded from qualitative inquiry into life participation after stroke. Luck and Rose (2007) and Swinburn et al (2007) outline a range of ways in-depth interviews can be adapted to facilitate the involvement of people with aphasia. These include careful preparation of supporting communication props and materials, extending the time frame of an interview or scaling down the scope of interviews, and utilising silences creatively.  For example, in this study, in interviews with respondents with more severe language impairment, silences of more than 10 seconds were not uncommon while respondents searched for a word. In their work with people with learning difficulties Booth and Booth (1996) differentiated 'expressive silence', which may benefit from support from the interviewer and 'closed silence' which is less productive and is waiting to be passed over (Booth and Booth, 1996:63).

Silences in this study also created the space for participants with aphasia to begin a drawing or to review and respond non-verbally to written key words, drawings and diagrams that I developed independently or together with the participant. These paper-based artefacts served as an alternative method of probing or referring back to issues raised earlier in the interview. This is consistent with techniques of supporting conversation and research interviews with people with aphasia (Kagan et al, 2001; Luck and Rose, 2007). All paper artefacts co-constructed during the interview were stored and revisited in developing and checking transcriptions.

**Table 5.1    Phase 1 Interviewees**

| Name (Male/ Female) | Age now (years post stroke) | Employment pre stroke | Living arrangements | Level of aphasia – BDAE severity (self rating) | Physical impairment(s) |
|---|---|---|---|---|---|
| **Donna (F)** | Late 30s (4) | Dinner lady | Lives with 12 year old son (separated) | Severe (moderate) | Walks unaided, unsteady gait; limited use right arm |
| **David (M)** | Mid 50s (4) | Computer programmer | Lives with wife (2 adult children) | Moderate (moderate) | Walks with stick; right-sided paralysis |
| **Grant (M)** | Early 60s (20) | Engineer | Lives with wife (3 adult children) | Severe (moderate) | Walks unaided, some balance difficulties |
| **Sam (M)** | Early 40s (2) | Printer | Lives with mother | Severe (moderate) | Walks with stick; right-sided paralysis |
| **Emily (F)** | Early 20s (1.5) | Student | Lives with parents and older sister | Severe (moderate) | Some right-sided sensation changes |
| **Jack (M)** | Mid 40s (2) | Delivery driver | Lives with wife and 2 teenage children | Severe (moderate) | Epilepsy |
| **Sarah (F) *** | Early 60s (9) | Lawyer | Lives alone | Moderate (mild) | Walks unaided, right-sided weakness |
| **Jeff (M) *** | Early 40s (4) | University Lecturer | Lives with wife and 2 children (1 adult child) | Moderate (moderate) | Epilepsy |
| **Binda (M) *** | Late 40s (18) | Teacher | Lives alone (divorced) | Mild (mild) | Limited use of right arm Epilepsy |
| **Katie (F) *** | Mid 50s (5) | Teacher | Lives with partner (1 child still at home) | Mild (mild) | Walks with stick; right-sided weakness |
| **Melanie (F)*** | Mid 40s (18) | Charity worker | Lives alone | Mild (moderate) | Walks with stick; right-sided paralysis; visual scanning difficulties |
| **Priya (F) *** | Early 20s (2) | Optometrist | Lives with parents and sister | Mild (mild) | Limited use right hand |

* Research Group Member

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Another feature of interviews with people with aphasia is the use of closed questions, requiring a yes/no answer, and offering suggestions to reduce the burden of effort on individuals with word finding and expressive language difficulty (Luck and Rose, 2007; Dalemans et al, 2009). These techniques were used extensively as will become evident in transcript extracts. Verification of responses via observation of non-verbal reactions, summarising and key word checking or diagrams was also employed extensively. Taking stock of and summarising information that has been gleaned at regular intervals provided further opportunities for interviewees to verify or dispute my understanding of their comments.

A topic guide (Appendix E) shaped a series of open questions. After checking biographical details, the interview opened with a question exploring the overarching and important current impacts of aphasia on life, work and relationships. The topic of friendship was introduced by asking respondents to select coloured stones to represent people whom they would identify as friends (see below). The interview explored how they knew them, and what activities they did with them. Open-ended questions then explored what participants perceived to be important about these friendships and why. The interview also probed the nature of any friendship changes post-stroke, perceived barriers and facilitators to friendship post-onset of aphasia and respondents' advice and suggestions about friendship for others, for example ideas on what might help or what others could do to help maintain or extend their friendships.

All in-depth interviews were carried out in respondents' homes and lasted between 60 minutes and two hours. Interviewees received the broad questions covered by the topic guide in advance, in order to give them additional time to think and plan ahead how to answer the questions. They were also asked to bring to the interview any names, photos or other artefacts which they thought might help us converse about their friends and friendships.

The interviews were audio and video-recorded. A small camcorder was positioned and left freestanding, where possible to capture the interaction

between the researcher and respondent, particularly the use of gesture and facial expression. One participant declined to be video-recorded. Fieldnotes about context and researcher reflections were made immediately after the interview documenting details of context, researcher responses (cognitive and emotional) to the setting and respondent, and critical reflection on the process of conducting the interview. In particular I noted what had gone well or not so well in the interviews and any learning for future interviews. I also documented in fieldnotes substantive aspects of interview content, particularly any surprises or perceived ambiguities.

The project information sheet specified that the interview aimed to capture the views of the person with aphasia not those of relatives or partners they lived with. Typically, where relatives and partners were present in the home, they withdrew to a separate room after initial introductions or were encouraged to get on with their other activities. However three of the Phase 1 interviewees (all with relatively severe language impairment) chose to have other individuals present. One respondent asked for his partner to remain, one individual was happy that his mother came and went during the interview which took place in the living area of their small flat, and one participant chose to ask her mother and a visiting paid carer/friend to be present during the interview.

As discussed in Chapter 4, accepting contributions from family members where interviewees experience communication difficulties and avoiding 'speaking for' behaviours of partners and relatives (Croteau and Le Dorze, 2006) where participants have severe aphasia pose practical and methodological challenges (Philpin et al, 2005). In each of these interviews I reiterated clearly that the purpose of the interview was to hear the views and experiences of the person with aphasia and minimised verbal and non-verbal invitations to third parties to join in the conversation. Attention to physical positioning and avoiding eye contact with 'observers' were other techniques I employed to reinforce the focus on the views and opinions of the person with aphasia. Where third parties did intervene or offer opinions I sought to clarify

verbally and non-verbally whether the respondent shared views expressed or whether there was any indication of divergent opinions.

## 5.3 Interviewing and specific communication access techniques

The nature of each individual's difficulty with language, compounded with the anticipated difficulty of articulating views about a topic not generally discussed required that we gave advanced thought to ways of supporting conversations about friends and friendships. Four of the Research Group members with aphasia are experienced communication skills trainers and I also drew on my expertise as a Speech and Language therapist and communication access trainer. Prior to the interviews we determined a range of regular and more innovative ways to enable respondents to participate as equally as possible in conversation and the co-construction of knowledge. For example, the interviews drew on the use of coloured stones to externalise thoughts about friends, pre-prepared communication props and, resulting from the first six interviews with Research Group members, a series of 'some people say…' interview probes.

### 5.3.1 Stones

In the research interviews, after probing the general impact of stroke and aphasia I reiterated the main purpose of the interview to explore experiences of friendship and aphasia post-stroke.  At this point, I offered participants a selection of stones differing in shape, size, texture and colour and asked them to select one stone to represent themselves and various stones to represent people whom they thought of as their friends. Participants were asked to think about the characteristics of the different stones and where they might spatially position their friends in relation to themselves.  This is in line with use of creative and visual methods to support discussion of interpersonal issues within counselling and psychotherapeutic practice (Bradley, 2008). Visualization techniques are well recognised within PAR studies as providing opportunities for participants to initiate discussions about complex topics and explore and represent personal perspectives (Cornwall and Jewkes, 1995).

No guidance was given to interviewees concerning which people to include because the aim was to elicit personal and individual understandings. For example, if an individual asked for clarification about whether they were expected to select family or friends, I would say 'Whomever *you* think of as your friends'. I employed probe questions asking why interviewees had chosen specific individuals, what they perceived as important qualities of specific friendships, and reasons for suggesting more proximal or distant relationships by the way they located different stones.

Selections were placed on a piece of A4 paper on which were printed two faint concentric circles to convey a sense of increasing distance from the self-stone. The use of circles is similar to a technique used in social network analysis (Antonnuci and Akiyama, 1987) and adapted by Cruice et al (2006) for exploring the social network size of older adults. Unlike these studies however, no instruction was given regarding whether the circles represented particular categories of people, frequencies of contact or strengths of relationship. My intention was for respondents to determine how they defined friendship rather than impose pre-determined categorisation. With the permission of resondents, a digital photograph was taken at the end of the interview as a record of each individual's friendship circle.

During the interview the stones acted as a point of reference and as a tool for probing perceptions of different relationships and reactions of friends. For example, if a respondent located a friend stone very close to the stone representing themselves I might ask 'Can you tell me a little more about this person? What is it you like about them? How is this person different from this one? Sometimes the manner in which a person non-verbally manipulated or moved stones presented opportunities for follow up probes. For example, some respondents located a friend stone and then moved it closer or more distant from their own stone while talking about the friend. I would comment on this behaviour saying 'I notice you are moving that stone closer …why is that? Can you tell me more about how it is now? Has that changed?'

Another function of the stones was as a way to refer back to issues raised earlier in the interview. Referring back to topics when respondents have limited expressive language can be a particular challenge in interviews (Swinburn et al, 2007). The stones again provided a more concrete reference point. For example, I might say 'When you were talking about this person earlier (points to stone) you said … Can you tell me a little more about why you felt that way?'

### 5.3.2   Supported conversation and conversation props

The coloured stones represented a versatile communication prop to support the in-depth interviews. Other communication props used in interviews included pen and paper, on-line drawing (constructing drawing as part of the emergent conversation), writing of key words, use of photographs and artefacts within the person's home environment or notes which participants had selected to bring to the interview. Kagan and colleagues (Kagan,1998; Kagan et al, 2001) have pioneered the use of 'supported conversation' techniques aimed at revealing and acknowledging the competence of people with aphasia. A combination of the skills of the person with aphasia, techniques employed by their non-aphasic conversation partner and relevant communication props enable the person with aphasia to engage more meaningfully in conversation. Techniques used by the researcher included additional time and use of silence, frequent clarification and summarising, attending closely to the non-verbal aspects of communication (also captured on video) and occasional use of individual and co-generated diagrams and drawings.

For the second group of six interviewees, several of whom had marked expressive language difficulty, I developed a series of visual and verbal props to have available in case of struggle in the second wave of interviews. These materials reflected the ideas and insights shared by the first six interviewees and included:

- A diagram demonstrating types of people whom other respondents had selected as friends

- A list of barriers and facilitators to friendship mentioned by the first six interviewees
- A list of issues raised as important in friendship by the first six interviewees

Examples of these communication props are provided in Appendix C. Within interviews where respondents struggled to respond to open-ended questions I would frequently offer suggestions drawn from issues raised by the Research Group. For example I might tentatively offer a probe: 'Some people with aphasia say that …they feel closer to good friends now. Is that something that you have experienced?' These prompts were not aimed to shape or constrain new respondents' answers but to give them ideas to acknowledge, develop or reject, acting as a facilitative springboard to expressing their own thoughts and experiences. Importantly, in probing responses to what others with aphasia had mentioned in written format, there was always an item marked 'other' or a list backed up with question marks signalling that this was not an exhaustive list of possibilities. Chapter 10 will discuss further the strengths and limitations of using these methods to co-construct understandings with people with severe aphasia.

## 5.4    Member checking

After interviews were transcribed, I reviewed the transcripts to determine any areas where I was uncertain of respondents' responses and listed my questions and queries. I prepared an accessible summary of issues covered and returned to interviewees to feedback my understanding of our discussion and to check particular areas of ambiguity or lack of clarity. Digital photos taken at the initial interview were also used to support recall of our earlier discussion about individual friends and friendships. Some respondents asked for a copy of the transcript of their interview before this meeting, others were unable to read and/or expressed a preference to wait for face-to-face discussion. Member checking typically took place approximately three months after the research interview and therefore also gave respondents the opportunity to comment on any major changes in their circumstances and new

insights into their friendship experiences. In this way member checking enabled a further layer of confirming or questioning emergent findings.

## 5.5    Transcription

Interviews were transcribed verbatim. Digital audio recordings were transcribed as soon as possible after the interviews. Video recordings were not used as the primary source of transcribing but enabled audio transcriptions to be enhanced with additional notes describing non-verbal behaviours. Video data are notoriously time consuming and complex to transcribe and analyse (Silverman, 2010) and systems of describing visual data are contested (ten Have, 1999). However visual back up was particularly relevant for those respondents who had little speech or used extensive gesture to supplement spoken language.

Transcription is considered important both in making data available for analysis and in commencing the process of analysis (Wood and Kroger, 2000). The process of transcribing presents a number of questions and dilemmas. Minimally, decisions are required about orthography, the representation of pauses and systems of formatting (ten Have, 1999). Hammersley (2010) suggests that decisions about transcription should relate to the purpose of the study, the nature of research questions, the stage of investigation and the intended audience for the research.  As the purpose of the Phase 1 interviews was to elicit experiences and perceptions of friendship, rather than, for example, more focused conversational analysis of turn taking in friendship interactions, I chose to employ standard orthography rather than more fine-grained phonetic transcription. This also suited my intended thematic approach to data analysis.  At this stage I also intended to share transcripts and transcript segments with members of the Research Group and more detailed transcriptions can reduce accessibility to co-researchers unfamiliar with transcription conventions (Hammersley, 2010).

Transcription conventions broadly followed those of Jefferson (1984), capturing features such as silences, changes in volume, and aspects of non-verbal and paralinguistic behaviour that might differentiate meaning.  Pauses

and silences were obviously prevalent in much of the data. Most often, silences represented pauses for word finding, looking at visual material that supported interview conversations or moments where respondents worked independently or collaboratively with me to construct some supportive writing or drawing. These notes and comments were recorded in square brackets.  A full key to transcription conventions is included in Appendix 0.

A decision for the layout of talk to be double spaced, play script format, keeping line length short, was partly to reflect the fragmented nature of many respondents talk but also to allow adequate margin space for descriptive notes. Transcript examples are provided in Appendix P. Extracts used within the findings chapters retain the original continuous line numbering produced from this format, although, for purposes of accessibility and space, layout has been converted to a more continuous format.

## 5.6    Data analysis

Whereas interviewing to gather and explore participants' perspectives on friendship represented the 'look' phase of an action research process, the task of analysing and interpreting these descriptions and developing conceptual understandings concerned the 'thinking' stage of the action research cycle (Stringer, 2007).

Analysis of Phase 1 interview data took an inductive or bottom-up approach (Silverman, 2010).  A broad thematic analysis was used to organise and describe data and relate patterns of the data to the research topic and questions (Boyatzis, 1998; Stringer, 2007). An acknowledged advantage of thematic analysis is its greater accessibility to co-researchers (Braun and Clarke, 2006) and therefore it is well suited to a participatory, emancipatory inquiry.  As a flexible and foundational tool for qualitative data analysis, thematic analysis is also a popular tool for novice researchers.  Sandelowski and Leeman (2012) highlight the usefulness of themes as an accessible tool for disseminating and actioning findings and facilitating their usability in health contexts.

Critiques of thematic analysis include lack of any strong alignment with theoretical and philosophical positions, unlike for example grounded theory, discourse analysis or Interpretative Phenomenological Analysis (Braun and Clarke, 2006).  In the study I intended to explore methods of data analysis, which might engage in an accessible, meaningful way Research Group members with aphasia who had impairments of reading as well as no formal training in qualitative data analysis. For these reasons, I anticipated that thematic analysis would offer a more accessible, collaborative tool than, for example, Interpretative Phenomenological Analysis.

A process of data review, identification and description of key units or features of data, and identification of overarching themes represent basic processes in the analysis of qualitative data (Patton, 2002; Boyatzis, 1998; Stringer, 2007). My analysis of interview data broadly followed the six phases of thematic analysis identified by Braun and Clarke (2006) and I use their terminology relating to codes, categories and themes. The cyclical sharing of emergent description and analysis of the data with colleagues in the Research Group and incorporating their views in analysis and interpretation followed processes described by Stringer (2007) as emerging analysis.

Below, I describe the stages of data analysis of the Phase 1 interviews as I analysed these raw data and brought thoughts and patterns to the Research Group. This description necessarily imposes a linearity and neatness on a process that was cyclical and messy. It required revisiting of earlier stages or plunging again into original data as I and/or we, as a Research Group, reflected iteratively on emerging categories, meanings and accounts. In this sense the approach to data analysis resembled more fluid, back and forth movement between a series of viewing platforms (Spencer et al, 2003).  The extent to which I shared the viewing platform with my collaborators varied and I discuss and reflect on this in more detail in Chapter 10.

### 5.6.1   Analysis of the interview data

*1. Familiarisation with data*

I listened repeatedly to audio recordings of the interviews, both during and after the transcription process to familiarise myself with the data. I viewed all video recordings once or more often where video recordings were required to develop or complete transcriptions. When transcriptions were complete I read the interview transcripts multiple times while I generated reflective notes in the margins. These notes documented personal reactions to what participants talked about, methodological notes, such as critical evaluation of interviewing skills and communication support techniques, and reflections about interesting or surprising data.

*2. Generation of initial codes*

The process of monitoring for patterns and recurrent categories began by detailed review of two transcripts, chosen for their contrasting use of language and styles of expression. One person with markedly impaired spoken output expressed herself in sparse, direct language, the other, while hesitant, used language rich in metaphor. Each transcript was scrutinised line by line and data were manually coded employing a range of initial coding techniques (Strauss and Corbin, 1998; Saldana, 2009). Codes were identified as 'a word or short phrase that symbolically assigns a summative, salient, essence capturing, and /or evocative attribute for a portion of language-based or visual data' (Saldana, 2009:3). Types of codes described by Saldana and prominent in this initial cycle of coding were:

- *Descriptive codes* – for example describing and categorising the various impacts of aphasia
- *In Vivo codes* – utilising participant's own form of words (and own aphasic language) to describe experiences and reactions related to friendship
- *Affective codes* - for example referring to emotions expressed by participants and values they ascribed to friendship
- *Process codes* - referring, for example to participants' actions and strategies in maintaining friendship
- *Versus codes* (Wolcott, 2003) as participants defined, for example, qualities of friends who stayed in touch versus those who drifted away or differences between friends and family members

During coding, I also added analytic memos to transcripts noting for example recurring themes, points of theoretical interest, surprises and convergence or divergence from both relevant literature and previous Research Group discussions.

I created shorthand codes in the margins of interview transcripts and marked the text using coloured post-it notes, highlighting and word processing review tools. I documented the different codes from each of the interviews and these lists formed the basis for a very preliminary grouping of data into some broader categories of codes (Silverman, 2010; Patton, 2002).

This line by line coding process was then repeated for each of the six first wave transcripts before I began a second cycle of pattern coding (Miles and Huberman, 1994) across the six interviews to identify patterns which pulled together groups of codes into some tentative overarching themes from the data to share with the Research Group interviewees.

The second wave of interviews took place concurrently with the early analysis described below, with generation of transcripts and initial coding following a similar process. First and second cycle coding of this second set of interviews were informed but not constrained by this first wave of data coding and analysis. Throughout this second cycle of coding I assigned outlying or idiographic codes to a category of 'other' for a further cycle of review after the Phase 2 interviews.

*3. Generation of initial themes – first attempts at co-analysis*

Timing of sharing preliminary data analysis from the first set of interviews with respondents who were also members of the Research Group posed a dilemma. Having immersed myself in pages and pages of verbal data, large quantities of verbally labelled codes and multiple piles of paper and post-it notes what was a manageable and accessible way of sharing data with this subgroup of individuals from the Research Group? How could I authentically engage Research Group members with aphasia who had no training and

experience with qualitative data analysis in working alongside me to make sense of the data?

I convened a group meeting with the six respondents whom I had interviewed in order to probe their first thoughts on the data and to problem-solve next steps with the analysis. This meeting prompted three members of the group to signal their distress on reviewing the content (e.g. revisiting the early trauma of stroke) and the style (e.g. the perceived inarticulate nature of their description of experiences in their interview transcripts). This was despite extensive briefing about the nature of representing talk in interview transcripts which can shock and upset interviewees when they view their transcripts (Kvale and Brinkman, 2009). We agreed at this point that, rather than probe individual stories together, I would return to the data for more detailed analysis and bring common themes and categories of experiences to a full meeting of the Research Group.

*4.  Generation of initial themes*

I returned to the data set of six Research Group member interviews and, moving back and forth multiple times between individual transcripts, the lists and patterns of grouped codes I generated an initial candidate thematic map (Braun and Clarke, 2006). This consisted of six overarching themes:

- Aphasia and exile
- Friendship and hard work
- Communication and non-communication dimensions of friendship
- Reciprocity and the two way process of friendship
- Friendship as a dynamic process
- Impacts and identity

I developed this set of themes with related patterns and categories of subsidiary codes as a visual mind map (Buzan, 2010) to take to a full meeting of the Research Group. Zuber-Skerrit and Fletcher (2007) note the relevance of non-linear, graphic representations of concepts in mind mapping as particularly relevant to an action research orientation to reflection on practice.

I created a brief summary of each theme with illustrative stories and vignettes selected from interview transcripts and presented this to the Research Group for individuals to question, clarify or confirm.  This interactive session acted in many ways as an accessible interim case summary (Miles and Huberman, 1994) enabling commentary on data gathered and synthesised thus far. Interim case summaries may also provide researchers with an opportunity to critique the quality of the data and identify any blind spots (Miles and Huberman, 1994).  Following this session to pause and reflect on the data from the first six interviews, I repeated steps one to four with the remaining six interviews from Phase 1.

*5. Reviewing the themes against the entire data* set

Once all interviews had been analysed I reviewed the six major themes for internal homogeneity and external heterogeneity. Internal homogeneity refers to whether data hold together or 'dovetail' while external heterogeneity concerns whether individual themes are sufficiently clear and differentiated (Patton, 2002). This led to development of a refined overview mind map, which I again presented to the Research Group for discussion, questioning and pruning.  We explored and discussed perceived anomalies and omissions and debated possible reasons for the presence or absence of particular issues within the interview data. We did this by referring to stories and experiences that had surfaced in the interviews of the six Research Group members and which they chose to share with the whole group. I also relayed to the Research Group examples, descriptions and stories from the other six interviews.

*6. Defining and naming themes*

Names and definitions of themes happened partly in the review process within Research Group meetings and partly in the process of my writing up of themes and sharing this writing with Research Group members with aphasia. Several theme names were altered to reflect the terminology used by participants. After some final discussion regarding the naming and (re)positioning of themes and sub-themes we verified that the revised mind map felt sufficiently clear and wide-ranging to provide distinct, visual pegs on

which to hang stories from the research interviews, and to group participants' personal experiences of friendship. We agreed the final version of our visual model of friendship and aphasia as a working model to support Phase 2 of the project.

*7. Writing up themes*

There is widespread consensus that writing for qualitative research represents an on-going process of analysis (Holloway, 2005; Wolcott, 2009). Collaborative writing is recognised as one of the more challenging aspects of participatory research where people have communication or learning difficulties (Nind, 2008). The process of writing up themes required a revisiting of stages 5 and 6 and enabled several further refining tweaks to theme names and terms chosen for sub-themes. In practice, I took charge of writing the first draft summary of Phase 1 Findings that became a working document for Phase 2 of the project. However in Research Group meetings, we continued to interact closely with the names, definitions and concepts of Phase 1 data themes throughout the innovation phase of the project. Core data themes were revisited as we developed materials for the Friendship Events and when we worked collaboratively on developing academic presentations that presented findings relating to major themes during year two of the project.

Due to the relatively small number of interviews and the nature of the data, where very long extended sequences of elicitation and verification over several pages sometimes represented a single coded item, I determined not to use CAQDAS software. Although keen to share data with co-researchers in the Research Group I was aware that CAQDAS software such as N-Vivo would be inaccessible to them. Early ventures with system crashes on uploading photographic, video and audio material were not encouraging and ultimately I recognised a personal preference for manual handling of data (Patton, 2002).

**5.7    Summary**

This chapter has described the range of methods employed during Phase 1 of the project. The practices and processes of participatory data collection and

analysis have been described though, as these are challenging to disentangle from the iterative learning and reflection that fuelled our research journey, these will be illustrated and discussed more fully in Chapter 10. The chapter has also highlighted the range of ways in which interview techniques were adapted in order to address issues of inclusion when participants have impairments of spoken and written language. These were set in the context of maintaining standards of quality, rigour and transparency required by qualitative research.

# Chapter 6

# Contextualising Findings on Friendship and Aphasia

## 6.0    Introduction

In both Phase 1 and Phase 2 interviews respondents tended to talk about experiences of friendship within the broader context of life with aphasia. Both groups made similar comments on this background context. This chapter therefore sets the scene for the Phase 1 and Phase 2 findings which will be described fully in Chapter 7 and Chapter 9 respectively. In order to avoid later repetition, and because contextual findings were so similar across all 28 participants, this chapter combines data from both Phase 1 and Phase 2 interviewees. The chapter presents:

- Findings relating to the diverse consequences of aphasia and their impacts on relationships and social participation in general
- An introduction to the people whom research participants identified as friends

These contextual findings are also an opportunity to get to know some of the respondents in both Phase 1 and Phase 2 of the project. Brief biographies of all participants are also provided in Appendix D.

Many of the impacts that participants described on everyday life, activities and relationships are consistent with those described elsewhere in the aphasia literature (Le Dorze and Brassard, 1995; Parr et al, 1997; Parr, 2007). Key issues that participants described and that are critical to understanding the rich psychosocial context in which respondents experienced friendship, included:

- The impact of stroke and aphasia on life and expectations
- Aphasia as exile
- Spoken communication changes
- Written and electronic communication
- Managing other impairments
- Infrastructural barriers
- Experiences of rehabilitation

- Impacts on family relationships
- Recovery and change

## 6.1    The impact of stroke and aphasia on life and expectations

Participants described their experiences of life with aphasia in vivid terms, which were accentuated by the stark and dramatic expression of their changed language. Individual narratives illustrated not just the life-changing initial impact of stroke and aphasia but struggles with impairments, and experiences of social exclusion that persisted many years after the event and well beyond the ending of formal interactions with rehabilitation.

> 'This I can't (...) erm [*points to lips*] speak I can't (...) I can't, erm (...) talk [*back and forth hand gesture*] to each other, yeah, yeah, yeah. And the erm (...) leg is not working [*shakes head*] yeah (...) The erm (...) [*lifts and drops paralysed arm*] (...) ch- (...) wheelchair, yeah, yeah, yeah ' (Sarah, line 49) [2]

> 'I couldn't, I couldn't, I can't, I can't get a *job*! You know I can't get a job, you know' (Melanie, line 652)

Most participants reported a major impact of loss of work on relationships, identity and financial circumstances. Only three of the 28 respondents had managed to return to part-time work, one stacking supermarket shelves, one in a stroke support agency and one in a reduced capacity as an optometrist. For several participants, altered ambitions and expectations continued to dominate their lives even many years later. Melanie, for example, had worked as a policy advisor in a housing charity. Her life changed dramatically after her brain haemorrhage in her late 20s, since which time she had been unable to work. Realisations were still hitting home eighteen years later and she continued to paint a painful contrast to mourned life expectations.

> 'My life is very, very narrow. And I thought it was going to be so, so much different and you know, I had you know a career, you know

---

[2] Line numbers refer to continuous line numbering, and play script format of utterances in the original transcripts.

holidays and everything like that, just doing something with my life and everything like that, and so great deal of sadness.'

(Melanie, line 2116)

Alongside acquiring aphasia most participants had experienced one or more other neurological consequences of stroke such as right-sided paralysis, altered vision and balance, epilepsy, post-stroke fatigue and depression. For a majority of participants, initial changes were accompanied by strong emotions – anger, anxiety and in some instances wanting to die. For others, curiosity or a hazy 'cognitive fog' filtered and in some cases buffered early experiences. Metaphors of fog, mist, masks, and exile were all commonly employed to depict a strange detachment from self and from others in the new land of aphasia.

## 6.2    Aphasia as exile

'And we as a group are *exiled*. You know, that's erm, we are '*other*', we are '*other',* not the same'.

(Binda, line 705)

Binda worked as a deputy head teacher before experiencing a stroke as he turned 30. He made reference throughout his interview to an experience of exile from family, friends and society in the early years after the onset of his aphasia. This sense of being suddenly thrust into strange and unfamiliar territory, where language, culture and ways of being were no longer the same was echoed by a majority of respondents. David, a former project manager, living with a new partner whom he married a few years after his stroke, described the ordinariness of everyday life, which suddenly changed irrevocably.

David:    and I was, so I was just putting the potatoes on [*laughs*]

CP:    Gosh. All very vivid still

David:    Yeah, yeah. And suddenly I just went pfft, like that. I don't know what happened.

(David, line 108)

For some, alienation and disconnection were perceived as immediate, for others transition to a different existence was a slowly dawning realization. Many people described a hectic whirl of visits from friends and work colleagues in the initial hospital days. Familiar presences, structured hospital routines or a cocktail of fatigue and cognitive fog contributed, for some respondents, to a period where emotions and expectations were put on hold. As the acute drama subsided, many respondents recalled a lingering uncertainty, exacerbated in some cases by the strangely disorienting reactions from those around them.  For many, perceptions of existing in a world apart set in early and could last for weeks, months or, most often, for years. Ron had previously worked long hours as a gas fitter. He lived alone in small cul de sac in a semi-rural location. Three years into his life with stroke, he referred to himself as living in a 'zombie' like state (fieldnotes, interview with Ron), and still described days when he felt set apart from those around him:

> 'Some days you do have an (...) I'm having like my, my own, my own world.'
>
> (Ron, line 168)

Gary was congenitally deaf but reported managing communication well until he had a stroke in his early thirties. As a consequence of the combined impairments of deafness and aphasia he developed significant word-finding difficulties and speech distortions. To follow his speech required considerable effort on the part of the listener, not well illustrated within the broad transcription employed in this study (see page 121).  Although well supported by his parents he also reported his frustration at losing his job, as a delivery driver, his financial independence and his girlfriend as a consequence of his aphasia.

> CP:    I think Jeff says he's behind a mist. Is that, is that something that you (…)
>
> Gary:    Same, yeah [*touches chest and nods*]
>
> CP:    Yeah. So you feel that you're, you don't lose the sense of yourself. You are the same Gary inside?
>
> Gary:    Yes, same. [*mimes holding two hands up ? to represent*

| | *barrier*] |
|---|---|
| CP: | But you're behind a (...) |
| Gary: | Behind wall, wall. |
| CP: | Behind a wall, yeah, yeah. |
| Gary: | Like wall. Me. [*mimes one hand repeatedly running into wall*] |
| CP: | Yes, so you keep bashing into the wall, yeah. |
| Gary: | Yeah. |
| CP: | Yeah. |
| Gary: | All the time. I can't climb over it. |
| | (Gary, line 1340) |

A perception of separation from the non-aphasia world was heightened by the impossibility of people without aphasia understanding the experience. Interviewees described that not only strangers but also close family and friends struggled to understand the impacts of aphasia.

| Gary: | Like I said before, understanding, yeah, but they think like they know everything. |
|---|---|
| CP: | So they think they know everything, so it's not quite the same as *really* understanding what it is for you. |
| Gary: | No. I try to tell them, tell them, they (...) [*mimes nodding in agreement, laughs*] |
| CP: | So they nod their heads as if they're saying yes, yes. But they don't *quite* understand what the situation is? |
| Gary: | True. |
| | (Gary line 2135) |

For some participants, lack of understanding was a recurrent source of frustration. Others like Trisha had developed a more relaxed attitude to the enigma of aphasia. Trisha also experienced a stroke in her thirties. A former mechanic, she took a pragmatic view of poor awareness of aphasia, voicing a lack of expectation that friends and family could ever hope to appreciate what aphasia was like. She described how aphasia defied clear verbal explanation:

'Erm, well, I don't think really other people really know.

Because erm, you can't ex-, you can't explain aphasia and, and how how, how you explain it, doesn't sound like, does it!'

(Trisha, line 1174)

## 6.3    Spoken communication changes

Many participants perceived that a reason for this poor appreciation of the impact of aphasia was that communication infiltrated so many aspects of selfhood and social interaction, yet was invisible and intangible. They described how they perceived communication changes had affected their social interactions and relationships.

'I, I  (3) as-pha-si-a is (..) difficult to (..)

no, I *can't* [*points to lip*s]

speak out but [*looks down to stones then hovers hand over stones representing close friends*]

but (3) my, (2) my (..) [*tuts turns head to left*] (3) I (3)

[*opens palm, staring to distance*]

My (...) ffff- (3) The k- (…) *God!* .Erm, (3)

[*drops shoulders, sighs*] [*starts fingering stones*]

Sss - speaking out (..)  is (..) so- (..)  im- (...)

so (..) *natural* before the stroke [*rapid to and fro gesture*]

(...)  And (..) w- words [*pointing to individual stones*]

(...) No, erm, [*drops shoulders*] (7)

(Sarah, line 821)

The difficulty finding and using words, changes in fluency and flow, and altered requirements of time and effort featured strongly in the accounts of respondents such as Sarah. Previously a lawyer who described herself as having enjoyed the sharp cut and thrust of conversation and humour with a close circle of friends, Sarah provided many rich examples of friendship maintenance in the context of her dramatically altered language. Her transcript was punctuated with rich peals of hearty laughter as well as paralinguistic displays of intense silent word searches. These sometimes resulted in a frustrated abortion of a topic or sometimes, by means of second (or third) best word selection, slowly advanced a conversation.

David was in his early fifties when he experienced a stroke affecting both speech and mobility. Previously an I.T. project manager he described a sense of relief when he was medically retired and drew on a critical illness insurance policy. In his interview he suggested a pre-stroke interest in language and archaeology might have been part of his curiosity about aphasia. He expanded on the time it now took to put his thoughts into written or spoken words. In both cases what is distilled from thought to language is described as a reductive 'drip in the ocean':

David:   Erm, (15)I , I don't know really. I suppose one of the things that I do (..) wish, (..) erm, you know, I can say, I, I, erm, (…) I, I erm, (4) all the things that erm, the things I,

my, ideas and my (..) ex-experience is probably erm, I can't ex- explain what is going on. You know, because it takes, (..) writing takes, it's just a, just a, just a, (..) erm, ocean in the (..) ocean in the (2)

What's the (..) drip in the ocean because

CP:     Yeah, erm what you get out is a drop in the ocean compared to what's going on in there [*points to head*]?

David:   Oh, I am thinking, I feel I've got an idea, I *can't* (..)

Lot of the time I can't write it down so forget about it, you know. I k- k- can't explain to other people about it.

(David, line 2351)

Like Sarah and David many participants experienced dysfluency and the transformation of something Sarah called 'so natural' to something more alien and unnatural. The written transcripts of their language, even with a broad rather than detailed transcription of phonetic changes, highlight the transformation of spoken language to a more cumbersome, faltering tool for conversation and relationship.

Difficulty retrieving words in a timely, efficient manner could lead to troubles interjecting, holding the floor or remembering topics. A former soldier, Derek experienced a stroke in his late forties and had lived alone since this time. In addition to mobility and visual difficulties he reported experiencing mental

health issues as a result of his stroke and separation from his wife. He reported that support group meetings were a friendly and reassuring space to see the funny side of aphasia conversations:

> 'we just talk amongst ourselves because talking to somebody
>
> takes just so flipping long, and after two minutes we've all forgotten
>
> what the flip we're talking about anyway, so [*laughs*], so yeah.'
>
> (Derek, line 763)

Both Shana and Emily, who was sitting A levels at the time of her stroke, reported difficulties following conversations at speed and retrieving words on cue. Emily perceived a combination of a less active social life and a tendency to muddle other friends' names as damaging to everyday social conversation with her best friend Geraldine:

> 'Geraldine lots of talking about erm friends and erm (…)
>
>  I cant remember the names of people and some (…) sometimes it's
>
> hard and also like (…) [*writes 'gossip'*] '
>
> (Emily, line 561)

Many respondents cited humour as an important feature of relationships. Laughter and shared humour were commonplace in the interactions I witnessed during the study. However, several respondents highlighted the challenge of timing, word retrieval and reduced verbal flexibility in social interaction. Shana demonstrated vividly the impact of slower processing and auditory comprehension difficulties on following jokes and 'getting', or as she mimes, missing, the punch-line:

> CP:     So sense of humour was important.
>
> Shana:   Yeah. Or sometimes the humour, ha ha, what?
>
>          [*mimes bewilderment*]
>
> CP:     So it's important but sometimes it's hard for you to
>
>          understand the joke?
>
> Shana:   Yes. Oh yeah.
>
> CP:     Yeah, yeah. So it's not about telling the joke.
>
> Shana:   The drum roll (…) *Tada!* (…) I don't get it [*mimes blank, I*

*don't understand expression*].

(Shana, line 1434)

Another feature of changed language and tone which participants commented on, in relation to friends and family, was the way aphasia imposed a more blunt, direct style of language. Shana for example reflected that other people did not always appreciate her friendly manner behind what could be a quite confronting, direct style of questioning:

Shana:    I'm *friendly*.

CP:        Yeah, yeah, you are. Yeah. You're quite blunt as well.

Shana:    Yes. Because of my speech, you know. That's it and that's it.

CP:        Kind of quite black and white. Boomp, boomp.

Shana:    Yes.

            (Shana, line 1416)

Joan, in contrast, noted that since the onset of aphasia she enjoyed being clear and direct with her friends and family and viewed it as an asset. Prior to a stroke in her 40s she had worked as a manager in the car industry. She described herself as always straight talking. However she also recalled early on the unintentional use of expletives, leading us to question, in later discussion, the potential impact of this on nervous visitors:

Joan:      …because with my speak when I first come out whatever come out of my mouth was terrible, terrible.

CP:        Yeah. In what way terrible?

Joan:      Oh, (..) terrible, fuck off. If anybody said to me, 'hello, Joan, how are you?' and it was me, in my head it was I'm lovely, thank you, love. My head it was going all lovely, I'm lovely. But when I opened my mouth it would be '*fuck off! fuck off you'*. But I didn't know what I was doing.

            (Joan, line 123)

Inevitably these communication changes affected the ability and ease of taking part in friendship based conversations whether at the level of exchanging information or the social connectedness of interaction.

Some respondents perceived the real challenge was not so much the ability to interact but the 'blankness' of having nothing to say. For these individuals, diminished communicative ability interacted with subtle cognitive impairment and a narrowing of life to engage in the depth and flow of conversation perceived as important to relational exchange:

CP:     So can you think of any other suggestions you've got for people?

Shana:  Hhhh. See, this is the thing. *A blank.*

CP:     Blank, right.

Shana:  And then (…)

CP:     It's hard to think of (…)

Shana:  Yeah.

CP:     Yeah, yeah. You were saying in the, on the day [the Friendship Event] that that's one of the things for you that's really *hard*. You feel like there's a blank in your head.

Shana:  Djuggestions oh, duhdeduhdeduh. But I can't because *blank*, erm, what to say next.

CP**:**    Right. And that's something that gets in the way with kind of developing relationships, is it?

Shana:  Yeah.

        (Shana, line 2007)

Shana, Emily and Cherry perceived that constrained lives and the limitations imposed by language impairment made them appear less interesting as well as having less to say. For example, Cherry had managed a busy life juggling her work in a charity and sharing the parenting of her two young children with her partner. She had a stroke aged 40 after giving birth to her second child. She described how not being able to work diminished conversations about office politics with former work-based friends. She also pointed to the stuffed shelves of her bookcases. Unable to read since her stroke, she described the loss of conversations with her friends about books which she previously read at the rate of one every week:

'Hmm, erm, erm, erm, well, erm, me erm, book, one (...) erm,

one (...) week's no, one week every time and I, I, *massive* stroke, erm, and (...) books no good.'

(Cherry, line 830)

## 6.4    Written and electronic communication

Many respondents referred to ongoing difficulties using the phone, writing, spelling, emailing, texting, and using numbers.  As well as affecting staying in touch with friends, participants regarded impairments of reading, writing and using electronic communications as impacting considerably on the logistics of getting in touch. The relative of one interviewee cited this as a major barrier to friendship maintenance. Three examples below illustrate the complexities of getting and staying in touch when communication is altered and when friends may not understand that so many forms of communication are more complex, arduous and time-consuming with aphasia.

Jeff juggled four part time academic jobs in three cities before he acquired aphasia whilst at work in his early forties. He described how contact with former work colleagues, typically via email, slowly dwindled as they failed to appreciate the nature of his writing difficulties and he struggled to expand on the content of exchanges.

Jeff:    Emails [*gestures back and forth*] all the time. Erm, and slowly, slowly, slowly [*back and forth gesture slows down to a stop*] not, not stopping [*chopping gesture*] (…)

CP:    Gradually tailed off?

Jeff:    Yes. Only one way!

CP:    Only one-way? What because she was Emailing you and you weren't able to Email back.

Jeff:    Yes. Is ob- obviously, it's, it's, it's, it's okay. Erm, no, no idea that erm, no idea that I forgot the Emails. I don't understand. Erm, later on, *much* later on (…) How many (...) months, little bit (...) Emails. Erm, and sh- very short and very bad writing. [*laughs*] And, and not much, [*gestures small*] no, no (…)

CP:    Not much content?

Jeff:        No. [*laughs*]

                 (Jeff, line 830)

Cherry, described problems using the phone and other forms of communication where she and communication partners missed out on face-to-face cues.

Cherry:   And phone erm, talking sort of very slowly. [*laughs*]

CP:       So that one [*points to list*] is a little bit better.

Cherry:   Yeah.

CP:       Yeah. And do you do anything like Skype with your friends?

Cherry:   Erm, erm, little bit.

CP:       Yeah, so a little, a little bit.

Cherry:   Yeah, yeah

CP:       Yeah, yeah. But really it sounds like you're saying one of the changes maybe is that it's better face-to-face and seeing people.

Cherry:   Yeah, yeah. [*laughs*]

                 (Cherry, line 862)

Emily, aged 20 at the time of her interview and still living at home with her parents, sometimes required her mother to correct and mediate language in her text exchanges with friends.

Emily:   Sometimes like (..) I'm I like, I, I text. I don't know if it's (..) like (…) Like [*laughs*] right or anything. But yeah.

CP:       So you text Tim?

Emily:   Some, yeah. Erm.

CP:       And he texts you back.

Emily:   Yeah, but (2)

CP:       But (..) it's all a bit hit and miss? [*laughs*]

Whilst experiences of and reactions to changed communication were diverse and individual, for those who lived alone or experienced very severe language impairment, the impacts illustrated above could be thrown into sharper relief.

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## 6.5    Managing other impairments

In addition to communication difficulties, most respondents were also dealing with a range of other stroke-related impairments. Many lived with right-sided weakness or paralysis affecting mobility, balance and hand and arm function. Others managed epilepsy, fatigue, depression, and the day-to-day anxieties, uncertainties and effort that accompanied these impairments.

> ' I find that aphasia and I think you know, erm, my physical disabilities and everything, you know, and it means that everything, you know and because I can't drive and everything (..) it's, it's just such a *struggle.'*
> (Melanie, line 2100)

Participants mentioned fatigue not only as a consequence of the hard work of walking, talking and participating but also as an impairment in its own right. Chris was in his early forties at the onset of his aphasia. He had previously worked long sessions of shift work but his energy levels had dramatically changed as a result of post-stroke fatigue, medication for epilepsy and significant impairments of language and mobility. He repeatedly talked about and mimed the daily impact of fatigue two years into his post-stroke life. Now, he reported, he looked forward to his wife taking time out with her friends so that he could get a break from home-based rehabilitation or the packed social diary that she promoted as integral to his recovery:

> CP:      So do, do you you get bored? Or it looks like you're quite busy.
>
> Chris:   Yes. Tired. Tired. Tired.
>          But erm, erm, (? unclear) fucking hell, man, finished.
>          Good! No. Erm, erm, erm, (5) No, no. No. No. No. Tired. (3)
>          Yeah.
>          (Chris line 1809)

Participants also raised depression as an impairment experienced or requiring pre-emptive action to keep at bay. In three interviews (Karen, Derek, Melanie) where respondents talked openly of mental health difficulties it was unclear whether depression resulted from neurological impairment or was the reactive consequence of living with a range of stroke impairments. All of these

individuals lived alone.  A fourth participant, who also lived alone, compared her situation unfavourably to people with aphasia who lived within a family. She shared her perception that the effort required to avoid isolation and low mood could be more challenging for those who lived alone:

> I *try* to go, you know, but it's isolated, you know. It's *hard* for me*.
>
> (Shana, line 976)

Ron, who also lived alone, and was unable to drive after his stroke described the importance of investing energy in getting out. He articulated a belief that connecting with friends at his stroke support group acted as a proactive strategy to avoid the onset of depression and its consequences:

> 'You know, it's probably there for life and you've just got to *grin* and *bear it*. You know, you can't be one thing I would not have, I did not want to have any depression or things like that.  Because you would just go into your shell and go, you know, so I might as well *shoot* myself or go over the first bridge I can find, you know.'
>
> (Ron, line 392)

## 6.6    Infrastructural barriers

The lack of awareness of aphasia by people in the wider world naturally reinforced an experience of exclusion. Respondents cited many of the day-to-day barriers which made engagement in life generally more complicated, but getting out and about with friends particularly so. Many participants mentioned inaccessible public transport as a barrier to accessing activity and friendship. No longer able to drive, and with reduced confidence in getting out and about, Ron, for example found the impatience of local bus drivers a further source of anxiety:

> Ron:    And so about the buses itself, erm, the drivers there I thought they were, well, they're not, they were erm. Hhhh [*clicks tongue*]. What am I trying to say. That they have to be actually very (…) *more than patient* on there. They were (...) I can see myself like when I was going round the cities and bits and pieces and different towns that they were getting

> very, not, not annoyed but …
>
> CP:      A bit het up?
>
> Ron:     Het up, yes.

Infrastructural barriers compounded physical and communication difficulties. Neither Cherry nor her partner drove a car. She had a right-sided hemiplegia in addition to aphasia. She alluded to the ingenuity and effort required in undertaking trips to friends, her son's school or support groups:

> Cherry:   Erm, erm, erm, and erm, escala (...) esala .Oh God.
>
> CP:       Yeah, I know what you mean. Escalator. So that, you can't do that. Yeah.
>
> Cherry:   And Sarah (participant at the Friendship Event) erm, zzz escalator.
>
> CP:       She had the same issue.
>
> Cherry:   Yeah. Yeah.
>
> CP:       Yeah, yeah, yeah.
>
> Cherry:   Well, erm, bus (...) erm, and erm, and erm and tube and zzz, and erm erm, lift, erm, yeah. And (...)
>
> CP:       That's better, the lift. But if there's an escalator that's a bit [*imitates someone being frightened*]
>
> Cherry:   Yeah. What's it called? Earls Court and then bus, s- s- Hammersmith, yes. Lift. And erm, (...) and erm, Covent Garden, yes.
>
> CP:       Yes. Gosh, so you know all of the tube stations that have lifts.
>
> Cherry:   Yes. [*laughs*]
>
> CP:       That must make it more tricky meeting up with your friends or kind of getting to see them so much.
>
> Cherry:   Yeah. Yeah.
>
> (Cherry, line 968)

Other participants talked of difficulties with benefits and other welfare systems. Frank, in his mid fifties, had significant reading and writing difficulties but no visible signs of any stroke impairments. He lived alone and, at the time of our

interview, talked about his anxiety at being told he had been placed in a 'ready for work' category after misunderstanding a recent letter from the Department for Work and Pensions. Formerly a hospital porter he expressed frustration at the invisibility of his on-going reading and writing difficulties and exasperation at the perceived lack of acknowledgement of his impairments and the stress induced by interactions with administrative systems. Jack had no obvious physical disabilities but had severe aphasia affecting reading and writing in addition to expressive language. He made repeated references to money and the impact on finances of being unable to resume his work as a delivery driver. He lived at home with his wife and two teenage children. As his interview concluded, his partner, Dawn, spoke of the additional frustration and stresses of being sent another '46 page form' (fieldnotes, Jack) with respect to his latest reassessment for disability benefit.

## 6.7 Experiences of rehabilitation

Health and social care workers featured prominently in many narratives of the early months of rehabilitation as participants struggled to regain communication and direction. Participants often praised these workers for their privileged knowledge and special powers, enabling them to act as guides and mentors, facilitating and helpfully charting a course through the unmarked territory of stroke and aphasia.

Feeling 'at sea', a number of respondents regarded the guiding hand of confident, well-informed therapists highly. Binda, for example, recalled his Speech and Language Therapist as a connector and conduit between the before and after aphasia worlds:

> She was absolutely excellent. She was well grounded. And erm (..) took me (..) step by step (...) her (…) it was as if she was a (…) conduit (…) to )...) the outside world. And erm (...) it was (…) almost as if I spoke a different language and erm she could (…) understand and (…) bring on the rest of the world.
>
> (Binda, line 477)

Others enjoyed the focus on rehabilitation activities. For example, Cherry viewed work on verbs as important to recovering speech and communication. Frank worked as a hospital porter prior to onset of aphasia through a heart condition in his mid-fifties. He reported valuing aspects of the therapeutic relationship as well as the practical support to access the a community of people with aphasia:

> Frank:   I've got all the time in the world for speech therapists, yeah. Yeah.
>
> CP:   So what is it about them that (…)?
>
> Frank:   See I've not been going for physio because I had all my faculties so you know. But yeah, problems with (…)
>
> CP:   What was helpful from the, that you got from the speech therapy then?
>
> Frank:   Erm, well, you know, time, understanding. And also she, she said to me, erm, we could refer you to a stroke group, she said try it, she said but I know you won't enjoy it because they're too old, you know, they're old people. So she said I'll write you a reference to come to Connect and I never look back.
>
> (Frank, line 1459)

Many participants were vocal however in their criticism of absent long-term support and inadequate practical help beyond the 'basics' of walking, talking and dressing. Terry, a former salesman, had experienced a stroke 13 years previously in his mid-thirties. He recalled how his therapist had quietly kept him on the books, below the 'radar' of her manager, so that she could keep him on for an unusually extended period of therapy. Others contrasted the abandonment by statutory healthcare services to the warmth and welcome of third sector support agencies that offered reassuring support and friendship in the longer term.

Whether respondents evaluated the health and social care support they had encountered positively or less favourably, very few participants recalled any

involvement or prioritization of friends in rehabilitation. Many individuals also reported a perceived lack of support for family members.

> CP**:**   I mean, out of interest, did the hospital give any support or advice to Judith [*wife*]
>
> John:   Pff. No, no, no.
>
> CP:   Give any support or advice to your friends?
>
> John:   Erm, no. No. [*laughs*]
>
> (John, line 2531)

> CP:   And out of interest did any therapist or the rehabilitation people, did they offer any information or advice to your husband or your friends?
>
> Joan:   *No*. Absolutely *nothing.*
>
> (Joan, line 1678)

Chris's wife, Tina, reported a similar experience. She recalled with some frustration the absence of longer-term support for her partner and herself:

> 'I've struggled for everything and I've fought for everything. And I've just been exhausted. We probably did need more support than what we were getting but it's only because I've been through it now and I found out afterwards, I'm not negative because I can't spend anymore, I haven't got, I've only got so many resources so what's the point wasting it on the negativity, you've got to turn it to what's happening today, forget what's happened yesterday. But there needs an awful lot of more support out there.'
>
> (Chris's partner, Tina, line 2955)

A number of participants described experiencing a more intense presence of family members during their rehabilitation. This tightening of family relationships, the emphasis on important new relationships forged with rehabilitation staff, and the absence of work routines and regular friendship activities could all add up to the perception of different priorities in a different world. Many participants suggested that family and rehabilitation priorities, particularly early on, could unintentionally exclude friends. Priya, a recently

graduated optometrist when she experienced her stroke, was someone who reported retaining most of her many friendships. She reported however that friendships were not her top priority during the acute phase of her rehabilitation:

> 'So I had so much to do, erm, like my, erm, SLT therapy and my, erm, OT and like my physio and I had to do, erm, I [*clears throat*] (…) Erm, erm, I had so many family things as well like, erm, I had too much to do to think about her (close friend) in effect.'
>
> (Priya, line 1509)

Anthea, was working as a nurse when she had a stroke in her mid-forties. She recalled a strong presence of friends during the acute phase of her illness though it was family who became more present as the work of rehabilitation continued:

> 'Because what, when at first erm, I was in erm, the hospital
>
> most of my friends were there. But when I went into erm, what do you call it … the rehabilitation that most times it was my family who was there.'
>
> (Anthea, line 810)

It was only on returning home that her long-term partner left her, because, as she described it, he was unable to cope with her physical and communication disabilities. Shortly after she moved into a residential home where she still lives 11 years later.

## 6.8    The impact of stroke and aphasia on family relationships

Families were an important aspect of the psychosocial context for the experience of friendship. Participants portrayed relationships with close family and partners as diverse and complex. Often perceived as a source of great support, families and changed family dynamics could also fuel a vortex of emotions and clashing priorities. Participants who experienced strokes in their twenties and thirties reported that parents could become a dominant presence in mediating and facilitating their social lives and activities. Six of the 28 participants ascribed the break-up of intimate relationships to post-stroke

stresses. One interviewee described leaving his partner as preferable to seeing the fear and pity reflected in her eyes every time she looked at him. Another respondent described weathering the storm of her partner's psychiatric difficulties and hospital admissions, which were assumed to have arisen in response to the challenge of coping with massive changes at home.

Children were affected in different ways too. One father described his daughter Rosie's unhealthy concern that his every minor headache and illness signalled another potential stroke:

> Jeff:   And erm, Rosie concerned is little bit scary. Erm, and Rosie and Jane talking [*gestures two-way talking*] and no, sorry, not me, not, not a stroke, a headache and asleep. I think, I think, not a, not a- attached the stroke, separated (...) a headache and (…)
>
> CP:   But they both worry about you?
>
> Jeff:   Yes
>
> (Jeff, line 1102)

Katie was in a same sex relationship and had two teenage children living at home. She described the challenge of watching her children cope by directing all their talk and requests for help to her partner:

> Katie:   It was pretty horrendous.
>
> CP:   How did your relationship change with them? Or did it change?
>
> Katie:   Yeah, they didn't talk to me.
>
> (Katie, line 81)

Other interviewees described the recognition of on-going love and support from parents and extended family as a rock of stability in uncertain times. Approximately half of the participants perceived that relationships with close family members either remained unchanged or, had grown closer. Sarah, an only child of elderly parents, was adamant in her perception of positive, if not improved, ongoing relationships:

CP:      And that's okay. That's closer in a *good* way?

Sarah:   Exactly, yeah, yeah, yeah

CP:      Because again some people say that, you know, relationships with family or parents can become a bit complicated.

Sarah:   No, no. It's (…) *Me* [*touches chest*] its good, yeah, yeah. Yeah, yeah.

CP:      And that's good for them as far as you know?

Sarah:   Yes, yeah, yeah, yeah, yeah.

(Sarah, line 2001)

Chris, who had very severe aphasia, and his partner Tina both perceived their marriage as strengthened rather than weakened by aphasia. Richard and Shirley had also stuck together as a committed couple in the context of Richard's very severe aphasia and physical disabilities. Richard had worked as a musician prior to a stroke in his fifties. He and his wife continued to maintain strong friendships with a circle of friends connected to his family and love of music.

## 6.9    Recovery and change

Perceptions of 'recovery' were diverse and multi-faceted. Stories suggested reaching more stable ground was the consequence of hard graft, physical and psychological recovery and the passage of time.  Whilst most participants reported a gradual lifting of the 'fog' as internal and external realities reconnected, many also reported days when fatigue, low mood or adverse events could trigger return to a mist of confusion, uncertainty or self-doubt, even many years into life with aphasia.

Stories were not all about change and loss. Moments of hilarity, laughter and positive personal philosophising punctuated interviews. Research Group sessions and the tone of the Friendship Events reaffirmed the danger of perceiving all changes through the lens of tragedy and victimhood.  Many respondents reflected on experiencing a new depth of relationship and appreciation of friends and family. Similarly, participants reported being

exposed to and enjoying new activities such as theatre, neighbourly socialising and volunteering which they had not previously had the time to participate in. 'Feeling lucky' was a thread running through several interviews, and many accounts contained features of Arthur Frank's quest narrative (Frank, 1995) as interviewees reflected on personal transformations, and of finding altered meaning within their changed lives.

> 'It's not like as bad now. Because I have grown into a lovely person [*laughs*]. I mean, I know that'. (Katie, line 158)

> 'I feel really good, erm (...) yeah (...) erm (...) *so* fucking fortunate [*hovers hand over stones*]' (Binda, line 926)

Unsurprisingly, participants in this study, two thirds of whom regularly interacted with stroke and aphasia support agencies, identified the powerful role played by others living with aphasia. Several individuals considered that meeting peers, particularly younger people with stroke and aphasia, represented a major turning point in their recovery and wellbeing. Support groups provided participants with new opportunities to observe, learn, laugh and contribute.

### 6.10    Who are your friends?

As discussed in the Methods chapter (see Chapter 5, page 118) in the Phase 1 interviews participants were asked to select coloured stones and pebbles to represent people they identified as friends. The success of this technique in facilitating descriptions of friendship led to its use as an activity in the Friendship Events also. These stone selections (and photo images of their stones) then served as a tool for questioning experiences of friendship and probing similarities and differences between people identified and the relationships that interviewees in Phase 2 shared with them. The selection of stones was therefore a route into discussion of friends and friendships in both Phase 1 and Phase 2 of the study. Again there were strong similarities between the way Phase 1 and Phase 2 participants responded to this task and therefore findings from both groups of interviewees are collapsed here.

Two illustrations of the friendship stones are presented below. Grant worked as an engineer before his stroke in his forties. He was of African origin and had travelled extensively in his work as Director of the company he founded. He had very severe aphasia. Drawing on a list of people that his wife had written prior to the interview, and various personal artefacts retrieved during the interview, we pieced together a picture of people he currently described as friends. His selections included his wife, his ex-business partner who still lived in East Africa, and the leader of a local gardening group where he volunteered weekly. He talked about two friends with aphasia who worked with him on the gardening project but declined to choose stones for them. He did however select a stone for a much-loved colleague with aphasia who had passed away some months previously.

Donna, a single parent living at home with her young son, previously worked as a dinner lady. Her selection of friends consisted predominantly of family members, most of whom lived locally and visited her on a regular basis. She also chose the local co-ordinator of her stroke group and two others she had met through attending this stroke support group. Another member of her circle was a neighbour and former acquaintance at the school where she worked. She was described as a friend because she took the time to say hello and didn't avoid or patronise her.

**Fig 6.1  Grant's friends**



Peter (leader of volunteer gardening group)

Grant

Friend with aphasia from support group (recently deceased)

Wife

George (former work partner, lives in East Africa)
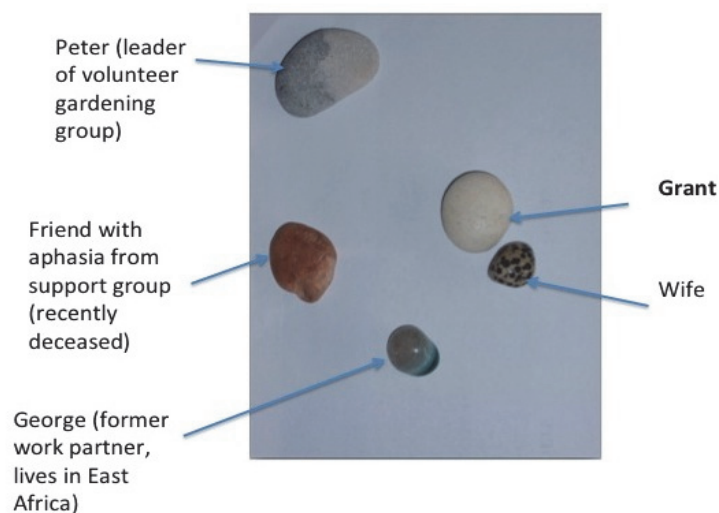
**Fig 6.2   Donna's friends**
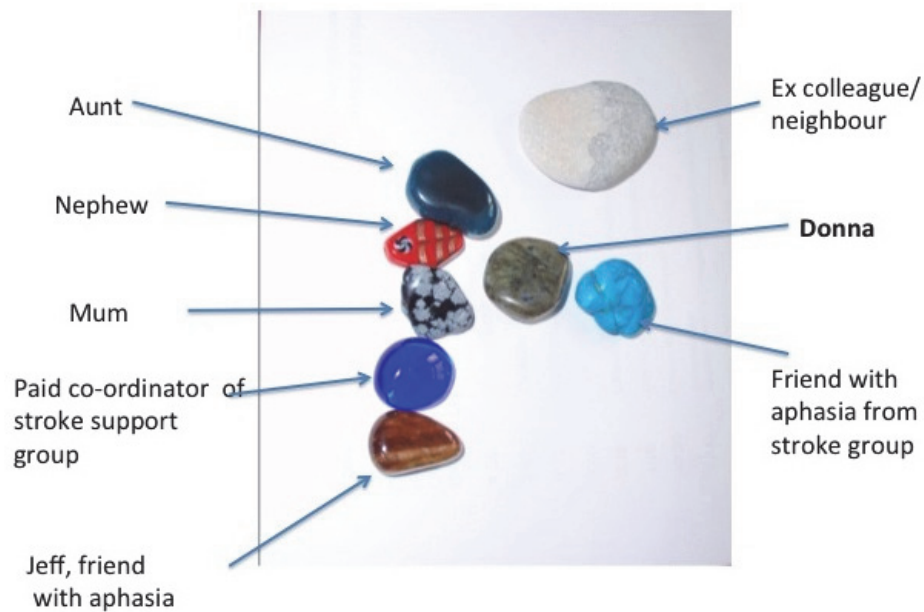


Across participants, selections reflected a wide range of people and diverse types of relationship that frequently overlapped.  These included:

- Friends associated with social activities - people who participants regularly socialised with (cinema, museums, eating out, coffee and chat), co-participants in leisure group activities (swimming, Pilates, watching sport, holidaying), people with shared political interests

- Friends associated with work and education – former colleagues, people known from school and university, new colleagues involved in volunteering activities

- Friends with whom they had a shared history – old family friends, friends from parenting days, ex-colleagues and school mates

- Individuals who were neighbours, fellow tenants or fellow residents within council estates, housing communities or, in one case, a residential care home

- Family members who counted as friends – partners, parents, children, siblings and members of the extended family such as sisters, cousins, nephews and nieces. Friends of the family and friends associated with partners.

- Friends associated with caring and therapeutic roles – paid carers, current or former therapists, alternative/complementary therapists, support group coordinators

- Friends with experience of aphasia and living with disability – colleagues in stroke support groups, family members of people with stroke, people with experience of other disabling conditions such as dyslexia and diabetes

The process of selecting and positioning stones and groups of stones provided further insights into perceptions of different relationships. For example, many respondents represented degrees of proximity by positioning stones/friends closer or more distant from the stone representing themselves. Some respondents across the course of the interview moved 'friends' closer or further away. One respondent instantly divided his selected stones into two equal groups, identifying one set as friends he perceived as still friends and a second group as those whom he now considered ex-friends post-stroke.

A majority of interviewees clearly differentiated a small but important group of 'friends' from a wider and more numerous circle of 'acquaintances' who were on the periphery but did not warrant or were too numerous to select and be represented by stones. Participants' reasons for selecting friends and the wide range of roles and functions friends played in their lives are incorporated into the findings and themes reported in Chapter 7 and Chapter 9.

## 6.11   Summary

This chapter has described the context within which the individuals with aphasia in this project experienced aphasia, social interaction and friendship. Participants in both Phase 1 and Phase 2 of the project reported wide-ranging, dynamic impacts of language and communication changes which operated at personal, interpersonal and structural levels. Some changes were profound,

others more subtle. Awareness, understanding and the skills of others could exacerbate alienation or facilitate engagement.

Asked to identify their 'friends now' research participants selected a diverse range of people and relationships, including family members, paid carers, leisure friends, former work colleagues, friends of long-standing and new friends with and without aphasia. The next chapter focuses more sharply on the experiences of friendship described in the in-depth interviews of Phase 1. These interviews constituted the exploratory phase of the study and led to the preliminary model of friendship and aphasia.

# Chapter 7
# Phase 1 Findings: Experiences of Friendship and Aphasia

## 7.0      Introduction

This chapter focuses on findings from the exploratory phase of the project undertaken in year 1. Findings are drawn from analysis of the 12 in-depth Phase 1 interviews and interpretations shaped through thematic analysis and iterative discussion within the Research Group.  The six interacting themes that emerged underpin our preliminary model of friendship, which is presented at the end of the chapter in Figure 7.2.

The findings presented here focus on the overarching research question:

- How do working-age adults with aphasia define, experience and understand friendship?

In this section, the focus is on what respondents perceived as important within their friendships, the nature of any changes to their relationships with friends and the ways participants made sense of these changes. The six themes that will be described are:

1. My friends are 'my anchors'
2. Communication is only 'one dimension of friendship'
3. Friendship is 'really, really hard work'
4. 'More than me': friendship is two-way
5. Constantly changing: the friendship kaleidoscope
6. Friendship and identity

**Table 7.1**     **Summary of Phase 1 themes**

| Theme heading | Summary of theme |
|---|---|
| **1. My friends are 'my anchors'** | Perceptions of friends who perform a grounding, anchoring role in this period of exile, by exhibiting loyalty, constancy and a firm belief in their friends |
| **2. Communication is 'only one dimension of friendship'** | Impacts of language loss and changes in communication as they impact on friendships<br>Aspects of friendship which are less related to communication or that transcend it |
| **3. Friendship is 'really, really hard work'** | Struggles and effort required to maintain and develop friendships in the context of physical and communication disabilities<br>Managing emotional responses to aphasia and the unpredictable reactions of others |
| **4. 'More than me': friendship is two way** | Imbalances in power and the social exchanges of friendship<br>Importance of acts of reciprocity and altruism in friendship |
| **5. Constantly changing: the friendship kaleidoscope** | Ways friends fade in and out as some are lost and some are gained<br>Perceptions of falling behind<br>Changes due to recovery over time |
| **6. Friendship and identity** | Impacts of aphasia on perceptions of self and identity<br>Identities imposed by families<br>Peer support as a space to affirm and reconfigure identity |

**7.1     Experiences of friendship and aphasia: themes**

**1. My friends are 'my anchors'**

The description of friends as 'anchors' first arose in Binda's interview as he was selecting people he regarded as close and important.  Hovering his hand over the stones he had selected, he asserted:

> 'I think of my friends as my anchor (…). My anchors'
>
> (Binda, line 690)

Friends whom he described as anchors were associated with high levels of trust and respect, shared values, and a closeness shaped, for him, not by length of time known but a 'click' of connection:

> 'we are very very close'
>
> (Binda, line 731)
>
> 'its not a matter of time just a matter of clicking'
>
> (Binda, line 802)

Anchor-like friends had a constancy and reassuring presence which meant he could summon them at times of uncertainty, still reported as a regular occurrence almost 20 years into his life with aphasia:

> CP:    Could you say a bit more why these friendships are important?
>
> Binda:    Erm, [*clears throat*], erm, okay I told you about erm, (...) they are an anchor [*hand on chest*] for me, erm, when something (...) .erm, kind of disturbing happens to me erm, that I (…) erm, erm, my confidence goes [*holds chest*] or erm ooh [*flutters fingers on chest*] erm, erm, erm, feel unsteady. Then I think of erm, them [*laughs*] and [*laughs*] their voices saying okay, if I told them this what would they say back? Okay. [*sits back*] Hhhh. Like that.
>
> (Binda, line 829)

Participants described close, anchor-like friends as people who were steady, loyal and stabilising, who were a source of confidence and courage when some new trial presented itself or a partner to offer familiarity and reassurance when the external world felt strange and threatening.

Four men Jeff, Grant, Jack and David each identified their partner as the person who was their closest friend. In addition to fulfilling roles as wives and partners, these women were described as being key to facilitating rehabilitation (where it was still ongoing), access to welfare and the day-to-day administration of life. For Grant and Jack, their partners also managed the logistics of communication with friends. Despite the complex dynamics of

'caring' relationships these individuals were most often described as enabling companions, assistants and friends.

Jack's response was typical of the reaction of this group in the stones activity. He picked a large stone to represent his wife, Dawn, and located this adjacent to his own stone:

> CP:     So you'd put Dawn in there.
>
> Jack:   Yes.
>
> CP:     Right, in there, very close, yeah. … …
>
> Jack:   Yes, yes, yes, yes. [*nods*]
>
> (Jack, line 1792)

Participants described these close friends as combining instrumental support with more emotional contributions to relationship. Some respondents, particularly women and those living alone, tended to select a small network of diverse, relatively long-standing friends who played these anchoring roles.  In some cases participants identified people new to their circle post-stroke who played a stabilising role, or, as described in the advisory group, a 'grounding' in the experience of exile and confusion. These new but sturdy friendships included friends encountered at support groups and volunteer activities.

Emily, Katie and Sarah described very close, anchoring friendships with paid support workers. Katie contrasted honest conversations about difficult topics with her carer, to her perceived need to present an upbeat but sometimes deceptive exterior with others:

> Katie:   I have a carer on Tuesday and she is a really good friend because I see her every single Tuesday. Erm, and because I see her every Tuesday she is a very good friend to me I think I talked to her about the kind of things that may be upset me all, I am confused me a bit. She's very good.
>
> CP:      So you share lots of information, you check things out with her.
>
> Katie:   Yeah. Yeah. (Katie, line 287)

These new relationships were built on regular meeting time, understanding of the condition (which could contrast with a perception of the limited understanding of some friends and family) and a space where people could be honest and vulnerable. Emily, an A-level student at the time of her stroke, contrasted the understanding of Hetty (her paid carer) with her former best friend, Geraldine.

> CP: But they've [*friends from school*] started acting a bit weird?
>
> Emily: Yeah. I think it's the stroke what (…) Because it, it's hard like (5)
> I don't know. Cos  Hetty,  you know (...) understand exactly like, like but I don't know. Like erm, Geraldine (...)  I think don't understand exactly
>
> CP: (…)  Mmm
>
> Emily: I think (…)
>
> CP: It's just like it's beyond her sphere of understanding?
>
> Emily: Yeah.
> (Emily, line 1760)

Hetty now accompanied Emily on trips to nightclubs. She understood the demands of ordering drinks at a noisy bar and Emily perceived her as a willing conversation partner about the highs and lows of aphasia, a topic Emily chose to avoid with Geraldine.

**Qualities and functions of 'anchoring' friends**

Close friends, those located in the inner circle of personal communities, varied in age, background and the history and context of their friendship connections. However respondents in the study consistently highlighted a core set of qualities that they regarded as singling out close and trusted friends. These qualities were often drawn out and articulated through comparison with those who had perhaps been less constant or sure-footed in their friendship. Friends considered as anchors were described as loyal, constant, and trustworthy. They did not abandon or write friends off when the extent of their aphasia or changed life circumstances became apparent.  Rather they stood firm and in

many cases offered both practical and emotional support whilst persisting in a belief that their friend with aphasia would recover and improve. They were perceived to offer a reassuring grounding at a time when many respondents described feeling confused and lost.

**(a) Loyalty and constancy**

'Being there', staying in touch, and not running away were all identified as important features of friends as 'anchors'. Although most respondents received a rush of hospital visitors immediately after their stroke it was the people who maintained a presence in the short, medium and longer term that marked them out as good friends. Regardless of busy lives, or personal fears and insecurities around communication, they were perceived as constant and loyal presences - they kept coming, caring, texting, phoning, and 'being there'.

> 'like one of my, my *best* friends has been there through thick and thin,
> through everything. And erm, she, she [*clears throat*] erm,
> we always, once a week we always go for a walk and erm, we go to
> the cinema or erm, we talk on the phone or erm,
> we text and everything like that'
> (Priya, line 830)

Donna's relative paucity of speech and deprived social circumstances emphasised the power and appreciation of friends who were perceived as reliable and constant. Here she describes what she likes about her nephew Angelo:

> CP:      And any things, any qualities that you particularly like about
>             Angelo?
> Donna:   (10) And always there.
> CP:      Always there.
> Donna:   Yeah.
> CP:      Okay. Always there. Very steady for you
> Donna:   Yeah
>             (Donna, line 811)

**(b) Trust and belief**

Trust was a word that surfaced regularly in narrative descriptions of close and enduring friendships. For Katie and for Sarah this trust was embodied in the fact that these friends were the executors of their wills. Sarah spoke of this as the ultimate accolade in trust. She seemed to metaphorically gesture the weighing of her friends Sandra and Mark as she spoke of them being executors of her will:

> CP: So can you just sort of say (..) a  bit more about what's important to you about them?
>
> Sarah: Executi-, execu- to, executive [*hand hovers over 2 stones*].
>
> To me (…) erm of the *will,* [*points to head*] yeah.
>
> [*open hand gesture up and down as if weighing*]
>
> And close, close friends. Yeah, yeah.
>
> (Sarah, line 247)

Binda experienced trust as a resource that enabled him to delve below the surface and explore vulnerability and hidden aspects of self:

> 'Erm, [*pauses*] oh, erm, erm, you need a lot of trust. And trust entails erm, (3) er, (...) erm, (3) trust entails erm, erm, (...) entails vulnerability. And erm, and, er (3), people are carrying, I carried *lots* of vulnerability with me. … … But I want to, I feel that if I wanted to (..) erm, to develop I need (..) er, (...) communication with my friend to (...) to (...) erm, talk to er, about my (...) smelly bits or my (...) erm, erm, (3) erm, darker [*jokey voice*] side.'
>
> (Binda, line 1258)

Several respondents shared this view that lack of language could make people with aphasia feel more exposed and vulnerable. Trust was an important companion to vulnerability if friends were to be invited below the surface of sparse language where they might encounter private thoughts and emotions or the 'smelly bits' that were rarely on public display.

Good friends were also perceived to display a constancy of belief in their friend with aphasia. Despite the uncertain course of recovery and perhaps

unspoken doubts about the future, anchoring friends could be key to instilling confidence and a sense of forward momentum. Sarah recounted how she regarded the dogged belief and motivational 'nagging' of an old university friend over a period of five years as being responsible for a successful return to driving.

> CP: So what did she do?
>
> Sarah: Keep *on* dr-, erm keep *on!* [*laughs*]
>
> Erm, (..) the car,(..) the car is (..) erm,(3) the car [*looks at hand*]…No.(3) The (…) No. Go-! (3) Con- stant- ly, (2) con- stant- ly erm, [*rapid to and fro gesture*](2) Joan (..) is (..) [*staring at outstretched arm*] con- stant- ly re- min- ding me. [*laughs*] (2) hhh to erm, (3) five years ago (..) erm, course of, (..) [*marking gestures on table*] course of erm (..) instructions. [*staring down at stones and outstretched hand throughout*]
>
> CP: So she didn't let that rest, she kept saying to you well, what about driving, what about driving.
>
> Sarah: Yes, yeah, yeah, yeah, yeah, yeah
>
> CP: So being quite persistent?
>
> Sarah: Yes, yeah, yeah, yeah. [*nodding*]
>
> (Sarah, line 1392)

Joan, was one of a trio of old university friends, whom Sarah met up with weekly. She had refused to let Sarah's reluctance and initial low confidence get in the way of a return to driving. Sarah described how eventually, accompanied by Joan, she took a driving assessment, bought a car and resumed driving. This, she perceived, was an achievement that would not have been possible without her friend's persistence over a period of years.

**(c) Grounding**

A key function highlighted by participants of these solid, close friends (including family as close friends) was their ability to anchor a person in familiar, albeit changed, landscapes of self and everyday life. This was sometimes against the backdrop of chaos, alienation and the existential

intangibility of the aphasia experience described above and in Chapter 6. Several participants described the way that certain friends, by listening, by acknowledging their aphasia, and by affirming them in familiar roles and identities, gave them a precious space to check things out more precisely, as described above by Katie in her relationship with her carer.

For some participants, friends were described quite literally as someone to hold onto and steady themselves. For Melanie, new friends with aphasia at the support group she had established played this role:

> 'And I think you *latch* onto things, you know.
>
> And you want to, you know, hold on to something.
>
> And so, yeah, they were my friends because we were all in the same situation.'
>
> (Melanie, line 2384)

Donna, Priya, Jeff, Grant, Binda and Katie also gave examples of feeling relaxed and stabilised by friends with aphasia. For some individuals, like Melanie, this grounding amongst peers was an important pre-requisite to further exploration of self and identity.

## 2. Communication is only one dimension of friendship

> 'I *can't* describe it (...) but erm, (4) [*staring ahead, outstretched, open palm*] friendship is, (2) is, (...) is, erm, erm, one, two, three, four, five, (…) *six* dimensions [*looks at CP*]. Yeah? (...) Con-ver-sa-tion is (...) *one dimension*.'
>
> (Sarah, line 1596)

This theme originated in response to the first wave of interview data and Sarah's evaluation that whilst communication and conversation were very important, she experienced it as only one dimension of friendship. This theme concerns the way language changes and communication barriers were perceived to contribute to friendship experiences. It also explores the different ways participants viewed and made sense of communication access, from the interactional skills required of friends, to more infrastructural elements of

communication access required to render public and social environments accessible.

It is important to mention that for two respondents, Grant and Donna, any talk of relationship was overwhelmingly filtered through the prism of communication loss.

> CP: Why do you think they (friends) didn't come and visit that much?
>
> Donna: Speech.
>
> CP: Speech, yeah
>
> Donna: Yeah.
>
> CP: So that kind of got in the way of understanding
>
> Donna: Yeah.
>
> (Donna, line 442)

Grant, experienced the severity of his aphasia as an incarcerating enclosure, inhibiting social possibility and connection. After a long sequence exploring Grant's perception of his aphasia, this extract was my verbal and diagrammatic verification of what I had understood:

> CP: So it's almost like (...) If there's you (3) [*writes Grant and encircles with communication barrier – paper artefact 13*] and this is this is *communication*
>
> Grant: Yes
>
> CP: You can't, can't get through to your friends
>
> Grant: Yes yes *exactly* yes [*smiles*]
>
> CP: Because this keeps you, your friends are *here* [*indicates beyond outside circle*] and you're *here* [*indicates inside circle*]
>
> Grant: *Exactly* [*smiles, sits back*]
>
> CP: Is that it?
>
> Grant: Yes
>
> CP: So is that what you're trying to say to me?
>
> Grant: Yes exactly yes
>
> CP: So the other things are kind of irrelevant

> Grant:  Yeah exactly
>
> (Grant, line 3127)

Whilst no one minimised the seismic changes to relationships brought about by altered language, most respondents, however, contextualised communication as just one dimension of friendship, taking its place amongst a broader mesh of issues and impairments such as depression, epilepsy, fatigue, mobility restriction, loss of work, difficulty travelling. Many of these topics are addressed in more detail under theme three, Friendship is really, really hard work.

**(a) Communication changes and challenges**

The multiple impacts of aphasia on language and communication have been outlined in Chapter 6. These examples have highlighted perceptions of the impacts on interpersonal relationships. Participants talked of the range of ways in which close friends adapted more or less well to interactions in the context of aphasia. Like other conversation partners, many friends were reported as speaking too fast, too loud and too much. Participants with aphasia described how friends, and indeed family, just didn't know what to do. Furthermore they felt powerless to coach them into more enabling communication behaviours:

> Emily**:**  Because like I *can't talk*. Well, but (..)  I can but (…)
>
> CP:  So because of the talking, I'm just not quite clear, because of the talking is it that *they* don't know what to do?
>
> Emily:  Yeah.
>
> CP:  *They* don't know what to do. And when you say what am *I* supposed to *do* is it (…)
>
> Emily:  Oh, no, no. No.
>
> CP:  That's not to do with <u>*you,*</u> that's to do with <u>*them.*</u>
>
> Emily:  Yeah.
>
> CP:  So it's more about *them, they* don't know what to do.
>
> Emily:  Yeah.
>
> (Emily, line 1738)

Stories of friends who struggled to slow the tempo of conversation and the significant challenge many participants experienced in the noise and speed of group conversations were commonplace. Taking part in these different conversations required effort on both sides, the person with aphasia and their friends. Jack spoke German and English prior to his stroke. He and his partner Dawn perceived that some of his old friends hadn't been prepared to put in the effort to learn to communicate with him after he acquired aphasia. Summarising towards the end of his interview what might be useful advice to people whose friends acquire aphasia, Jack and Dawn revisited earlier themes:

CP: Do you think they work, do you think they work hard enough at learning to understand?

Jack: No.

Dawn: No.

Jack: No. No.[*shakes head*]

CP: They don't sort of (…) I think we've agreed they don't know what to do.

Jack: Yes.

CP: But they don't maybe put the effort into it?

Jack: Look, look. Pscht.[*moves friends stones away from self-stone and waves to indicate 'bye bye'*]

CP: Yeah.

Dawn: They don't put in the effort to try sometimes.

(Jack, line 3251)

Other respondents noted that it was not so much effort but tone that could be problematic. Donna appreciated friends who used the same tone, and equal, respectful style of speech, but perhaps with an enhanced manner of listening. This was important in the context of Donna's distorted speech and reduced language. In this extract she demonstrates through a series of gestures touching her head, ears and chest, the way her aunt manages this where others fail:

CP: Sort of listening to the speech and sort of listening to the

person?

Donna: Yeah. Where [*gestures - hands to ears then chest*]

CP: So a bit beyond the speech is that what you're, I'm kind of following your gestures a bit that it, the way you're, you're, (..) [*echoes Donna's gesture*] what listening means to you it's more than just using your ears?

Donna: Yeah, yeah. <u>*Yeah*</u>! *Yeah*.

(Donna, line 1641)

Descriptions of communication with friends tended to emphasise sensitivity to affective components of communication rather than the practical dynamics of interaction. Participants spoke more frequently about requirements for friends to participate in quiet empathy, an 'authentic patience' and 'being there'. Probed as to why particular people stood out as close and ongoing friends there was a directness and simplicity to the way many respondents described the quality of friendship interactions. It is possible that this reflects the severely limited vocabulary of many participants. But explanatory expressions about good friends who were 'just there' and just 'nice' seemed most often to reflect a quality about a friend rather than a specific communication skill or strategy. Sarah's explanation was echoed again and again in the accounts of respondents:

CP: Okay. (...) So apart from having known them a long time, what is it that you *like* about them? What makes your friendship with them (...)

Sarah: *Nice people*! Is (… ) erm, erm, erm, nice people.

Yeah. Yeah. Yeah.

(Sarah, line 615)

CP: *(summarising*] So with this one here, this stone here [*points to stone representing closest friend/aunt*]

so she just like treats you normal, doesn't patronise you?

Donna: Yeah.

CP: Yeah. Mmm. Anything else you like about her?

> Donna: (12) She's moice
>
> CP: Nice?
>
> Donna: Yeah.
>
> (Donna, line 1063)

Shared histories, constancy and effort rather than ability to adapt their communication skills was more regularly reported as the salient issue in maintaining communication with friends. For example, Jack describes here how his friend Paddy and he have been through parenting together:

> CP: Yeah. [*both laugh*] Why, why do you say he's good? What is it about Paddy that's good?
>
> Jack: [*turns to clean sheet paper begins to write*] (14),
>
> [*writes dad, father*]
>
> CP: The dad
>
> Jack: Yes.
>
> CP: And the father
>
> Jack: Yes. Good. … …
>
> Yes, yes, okay.[*hand gesture child height*]
>
> CP: So you've been through the children thing together, is that right?
>
> Jack: Yeah, yeah. Shww [*indicates children of different heights*] Yes, good.

**(b) Other dimensions of friendship: beyond verbal communication**

Moving beyond communication or an exaggerated and unrelenting attention to it was described as an important way to develop or regrow friendships.

> 'it doesn't take much just to have a coffee and a drink or a meal to (…) because that gives time to grow the friendship'
>
> (Katie, line 1129)

Participants described doing things together as a significant part of recovery and an important means of maintaining affirming social communion. Post aphasia this sometimes took a different form. Priya describes walking with

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friends, not something she had previously done, as a different, and thankfully cheap, way of 'hanging out' with friends:

> 'We have so many other ways to enhance our friendship. Like walking and like stuff like that. So it [aphasia] doesn't really matter, erm, with that friend'
>
> (Priya, line 1909)

Sarah developed an impressive and systematic programme of social and cultural activities with close friends. Whereas previously social activities had been based around meals out and conversation, this shifted to less verbally dependent activities such as going to the ballet, opera and concerts. She also began to play email scrabble three times daily via an IPhone app with a close friend. She described this as a bridge to being in regular, sociable contact with a busy friend.

Katie described joining the gym and starting regular Pilates and swimming classes as a turning point in her rehabilitation after two and a half years at home. Getting out of the house was imperative to recovery and a flourishing of new friendships. With a partner in full time work and struggling to cope, she was furious that she hadn't received more help sooner to get her out of the house.

> 'The problem as far as I see it is not the speaking, it's the moving'
>
> (Katie, line 1487)

Beyond verbal communication Katie valued getting out of the house, joining new activity classes, spending time together over a coffee as important ways to grow new friendships or be with old friends in different ways.

### 3. Friendship is 'really, really hard work'

> Hhh. [*sits back*] Hard work. *Really, really* hard work. Yeah.
>
> (Sarah, line 1809)

This theme, prevalent across interview data in Phase 1, is concerned with the hard work that respondents described as a constant backdrop to keeping communication and friendship going.  Hard work was often perceived to be a

two-way requirement. Respondents with aphasia talked of the efforts required to manage their own altered lifestyles, relationships, communication, emotions and physical abilities. They were frequently aware also of the struggles and hard work of friends. They too were required to cope with altered communication, changed relationships and, on occasions, their own distress and anxiety faced with the life-changing consequences of stroke and aphasia on their friends. Often this was in the context of busy lives.

Re-reading my fieldnotes and journal entries, my own endeavour of supporting conversations and probing respondents' thoughts, particularly those with more marked language impairment, provided constant reminders of the hard work required for any conversation that aspired to breach surface reactions or probe more nuanced thinking. Both conducting and listening back to recordings of interviews could feel exhausting. Another visible symbol of hard work was the presence of partners and friends in the background of interviews, contributing additional information and insights before or after the research interview and participating in the logistics of determining times and dates to meet. Where a partner or relative sat in on interviews, as with Sam, Emily and Jack they sometimes contributed powerful vignettes of the efforts and energy they themselves invested in managing the business of life and relationships.

Different dimensions of hard work which emerged as sub themes included managing other stroke impairments, managing communication changes, managing the emotional hard work of aphasia, and managing the reactions of others. A final sub-theme described the hard work required to carry on communicating if relationships were to endure.

**(a) Managing other impairments**

As noted in Chapter 6, respondents were frequently dealing with communication difficulties alongside changes to mobility, balance, dexterity and vision.  Melanie, Sarah, Katie, Sam, and David had marked right-sided paralysis affecting upper and lower limbs. Donna had significant balance difficulties and problems using her right arm. Priya and Binda were unable to

use their right arm and hand. Emily, Jeff, Jack and Grant were less noticeably impaired physically though all experienced some degree of difficulty with sensation, or balance. Some participants experienced fatigue and depression post-stroke, while others had developed epilepsy or disorders of circulation and were required to take medication. Some respondents described how the effects of medication exacerbated feeling tired or having the energy required to socialise with friends.

**(b) Managing communication changes**

Clearly an initial, and, for most, an ongoing area of hard work was dealing with the impact of impaired verbal communication. All respondents initially had little or no spoken output and some remembered expressing a torrent of unintelligible speech in early interactions with friends and family.

For others, their recollection was of being silent for several years, taking in what was said but being unable to participate in one-sided conversations.

> 'I couldn't (…) a lot of my old friends came to the house but I couldn't talk to them. It was ho- horrendous'.
>
> (Katie, line 111)

Difficult communication did not just concern the mechanics of communicating. Not being able to talk about difficult subjects such as relationship troubles, feelings of inadequacy and loss of work prospects were all cited as topics that friends avoided. Emily and Priya highlighted a perception that some friends who were getting along with their own lives found it uncomfortable to talk about the impact of stroke and aphasia on life chances and expectations such as finding a partner or getting a job. Priya, for example, described her sensitivity to friends' avoidance of conversations relating to life aspirations:

> 'Erm, before my stroke, erm, I was top of my class and I was, erm, I was a, a, I was going to uni and I was a graduate optometrist and I had so much in my life ahead of me still and [*clears throat*] erm, I feel that they feel that, erm, they can't talk about how I've changed.'
>
> (Priya, line 1653).

**(c) Managing emotions: doing the inside work**

Many respondents conveyed the mental and emotional drain of interminable moments of exclusion, the hard work of getting a turn or having a presence in friend-based interactions. Katie described how communication changes meshed with frustration, fatigue and questions of self worth as she tried to join in social conversation with her friends:

> Katie:    Six, eight of us were sitting, I, I just didn't say a word. And (...) Because I was angry. (...) Angry because I was *tired*. But you are (…) Why is it that I am not enough, I am not *important enough* that you will listen to what I have got to say? [*laughs*] so because I was so angry I just (2)
>
> CP:      Zipped up?
>
> Katie:    Yeah. And that is quite common
>
> (Katie, line 1292)

Many interviewees talked of similar wearing struggles to manage frustration, anxiety, depression and loss of confidence. Melanie's account was one that cyclically revisited a profound sense of anger, loss and grief:

> 'I get so *tired* and so *angry* and ooh!'
>
> (Melanie, line 705)
>
> 'Because if you're aphasia it just tears you apart you know. I used to communicate so *well* and I (...) and the _sorrow_ you know'
>
> (Melanie, line 2149).

Sarah became tearful as she recalled her 'shattered' confidence and the impact that this had on both her communication and friendships:

> CP:      And some people also say that things like confidence and that get in the way?
>
> Sarah:    Oh yeah ooh yes. [*nods strongly and frowns*] Ne- got (...) _Aw-ful_.
>
> (Sarah, line 1161)

Asked to expand on the issue of confidence she described a decade of working hard:

> 'Erm, [*voice trembles*] (5) [*looks at hand in counting gesture*] Keeps on going. Yeah. Be erm (5) [*raises and looks at hand*] Two, three, four, five, six, seven, eight, nine, ten years ago I can't (...) erm, (3) Talk. (...) [*voice trembles*] I can't (...) erm, (...) Comm-un-i-cation (..) [*back and forth gesture*] is *easy* for me. (2) Speaking *out i*s erm [*voice breaking throughout this sequence*] (...) *difficult.* Yeah. [*Wipes tear from face*]'
> (Sarah, line 1186)

Although in many ways she described herself as coping well with life and friendships, the impact of losing her expressive language, as she illustrated, continued to be an effortful and emotional experience.

Melanie, whose impairments included emotional lability making her prone to outbursts of uncontrollable laughter mid-conversation, described her thoughts and exasperation when considering whether or not to contact a friend:

> 'But I'm thinking oh, she's busy or I might laugh. Oh God! And it's just so boring. I'm just so fucking bored with it all, you know. And it's just give me a break I want some (…), you know'.
> (Melanie, line 2473)

**(d) Managing the reactions of others**

Respondents recognised that friends too could be confronted with feelings of despair, awkwardness and loss of confidence. Shock, distress, fear, frustration, embarrassment, and uncertainty were all reactions that participants described as reading on the faces of their friends.

> 'I can sort of sense when people are thinking oh my God what's she like or not, you know and I think that's through years of experience.'
> (Melanie, line 1486)

Asked why he felt the early rush of hospital visits from friends subsided, Jack agreed with his partner Dawn that visitors could feel uncomfortable and awkward:

CP:      And again, why do you think that is [friends stopped visiting]?

Jack:    I dunno. [*shakes head*] . Hhhh.

Dawn:   I think because people feel a bit *awkward*, don't they?

Jack:    Yes. Erm, erm, erm. [*mimes puzzled face*]

CP:      They're not quite sure what to say?

Jack:    Yes, yes. Yeah, yeah.

(Jack, line 560)

Binda, who was British Asian, equated his own sixth sense of other people's discomfort with his sensitivity to racism and the fear it can engender in others. He described how, early on when his speech was more impaired, he could sense the distress or embarrassment of friends but not have the language facility to offer words of reassurance:

'I couldn't talk. I couldn't (...) reassure them, erm. (3)

Yeah, I *could* talk but very, very halting. (2)

So erm (...) later on I became (...) very, very (...) I became upset about that.'

(Binda, line 444)

The hard work of mending troubled friendships could require resilience and fortitude on both sides. Determined not to allow precious friendships to buckle, Priya described plucking up the courage to talk about how she felt left out with two of her close friends. She described her understanding of how she and her best friend also needed to put in a concerted effort for their friendship to endure:

'I know it's hard for *her* but I can't help it but, erm, it's also hard for *me* to realise that, erm, some things are different and I just have to, erm, *we* just have to get along with it and, erm, yeah. She's my best friend.'

(Priya, line 839)

For others, summoning the courage to challenge friends' reactions and unhelpful behaviours brought risks of potentially upsetting fragile friendships. Emily for example described an ambivalent relationship with her former best friend. Geraldine, naturally talkative, was described as filling the silence with

gossip. With aphasia, Emily found her friend's conversation both hard to participate in and difficult to follow as names became meaningless. However she was reluctant to feed this back to her:

Emily:    Yeah. And (4) yeah. And I should actually just say
           I don't understand that (..) Or, yeah.

CP:    So (…) What stops you saying that to her when she's
           babbling on about the gossip and that?

Emily:    It's easier to just say (..) it's fine and just carry on with it.

CP:    Easier to keep nodding along like.

Emily:    Yeah.
           (Emily, line 1784)

However, Emily, Priya, Binda, and Katie all described choosing to end certain disappointing friendships and acting with clear personal agency. Most often stepping away from relationships was in the context of choosing not to put up with friends who were perceived to patronise, avoid, pity or fail to put in the effort to understand. Both Priya and Binda identified a category of 'fuck off' friends. Priya 'excommunicated' a former boyfriend who failed to stay in touch:

Priya:    And erm, yeah, but I said yeah but, erm, I still have, erm,
           very, some speech and language difficulties. Erm, yeah. I
           (…) So I said that. And he just didn't text back at all.

CP:    Oh no.

Priya:    So erm, I so, I just said 'fuck him' [*laughs*] like you do.
           [*laughs*]

CP:    Yeah.

Priya:    So yeah. He's over there. [*moves stone away from others
           and laughs*]

CP:    Off the page.

Priya:    Yeah. So I've lost friends like that.
           (Priya, line 1438)

Binda wondered whether his vulnerability and honesty attracted rescuers and particularly women keen to care for him. Where he perceived individuals were shaping a relationship based on pity and control, they too were rejected:

> 'Erm, but I, I ..try not to be with a rescuer. Erm (…) *pity*, erm, erm,
> *pity* is shown by erm, a person who's a rescuer. Fuck off!'
> (Binda, line 1639)

**(e) Carry on communicating**

A final aspect of this theme was the need to carry on communicating. Texting, emailing, and phoning were identified as challenging for every one of the respondents. Although communicating was hard work a number of people reflected on the importance of actively maintaining a presence on the 'radar' of busy friends:

> ' You have to be on the computer a lot and on the phone a lot (…) so
> that they realise you're still around. Yeah '
> (Katie, line 1403)

> 'Communicating is very important to me. And I feel I've just got to try
> and reach out'
> (Melanie, line 777)

**4. 'More than me': friendship is two-way**

> 'On a conversation it's not about erm, it's not always about me
> [*laughs*]. And it's not like an interview, erm, it's a conversation. So I
> want to hear things about you too. And erm [*clears throat*] that's what I
> feel makes a good friendship as well, erm, [*laughs*] reciprocity'.
> (Priya, line 1797)

> 'Well, a person is only a friend if they can open up everything to you.
> When I first had the stroke nobody was allowed to tell me anything'
> (Katie, line 360)

Like Priya and Katie, over half of the Phase 1 respondents described the importance of two-way exchange in their friendships. Equal participation in

friendship, they suggested, could be severely compromised as communication, mobility, energy and confidence changes challenged the natural distribution of personal resources in a relationship. Loss of work roles, changes in financial and social status and heightened sensitivity to pity and the charitable caring of others confronted perceptions of relationship founded on mutual participation. Managing these imbalances as well as finding new ways to make a contribution to relationships in reciprocal or altruistic ways were prominent features of this theme. These experiences shaped the three sub-themes: a) Power, balance and equality, b) Reciprocity and c) Altruism.

**(a) Power, balance and equality**

> 'Equally. E-qual (...) e-qual (...) e-qual (...) my friends and me.'
>
> (Sarah, line 1891)

Sarah repeatedly referred to a perception of retained equality and shared, bi-directional effort in her account of close personal friendships that had withstood the onslaught of stroke and aphasia. Sources of imbalance described as threatening to the equal relations between friends included:

- Communication and attitude
- Power and family dynamics
- Roles and responsibilities
- Money and work

Respondents suggested these different elements often meshed together in a dynamic interplay.

*Communication and attitude*

Priya, whose language was perhaps the best preserved of all respondents in the study, remarked, about conversations with her friends:

> 'In my speech, erm, it has felt a bit like, erm, they talk seventy per cent or something and I talk thirty per cent or something.'
>
> (Priya, line 1816)

Friends she reported feeling closest to somehow maintained a healthy balance in friendship in spite of the communication skew. The ease with which participants could be linguistically over-powered by fast-talking, articulate

friends, family and healthcare professionals was self-evident in some of the dialogues between respondents and their partners/families that I witnessed. I too, became a player in one-sided dialogues as I conducted some interviews. (Appendix S).

Respondents were often very clear which friends managed the skillful act of making allowances for communication changes without treating a person as pathetic or a 'special case'. Committing time to listen and an effort to understand about communication issues were considered important factors in balancing the percentages. Donna identified her aunt as her closest friend. A skilled listening ear accompanied by a non-patronising attitude appeared to maintain a stabilising normality in the quality of their interaction:

| | |
|---|---|
| Donna: | Erm (3) she make me (…) |
| CP: | She makes you feel (…) |
| Donna: | Nothing going on. |
| CP: | Oh, nothing, like nothing is going on. |
| Donna: | Yeah. |
| CP: | So it's like with her, it doesn't matter that your speech is different, or that you've got kind of disabilities. It's just like it was before? |
| Donna: | Yeah. |
| CP: | Right. So she sort of treats you just the same as before. |
| Donna: | Yeah. |
| | (Donna, line 665) |

Offering advice to others, Jack drew on experiences where friends had either ignored him or treated him as incompetent. In this sequence Jack's vivid miming as he stuck out his tongue and flopped to one side seemed to parody someone severely physically and intellectually disabled.

| | |
|---|---|
| Dawn: | To treat him the same, I think. |
| Jack: | *Yes*. Yeah. [*nods*] |
| Dawn: | Obviously things do change, don't they. |
| Jack: | Yeah. Okay |

| | |
|---|---|
| Dawn: | And the conversation *has* to change. |
| Jack: | Yes. |
| Dawn: | But he's still the same person |
| CP: | So if they just remembered that you're the same person, just carry on. |
| Jack: | Yeah. |
| Dawn: | Yeah. Yeah, things will be differ- , difficult to talk to him and that but he's still there, he's still *there*, he's still the same person. |
| Jack: | [*falls to one side and sticks tongue out as if very impaired*] [*Laughs*] |
| CP: | You're not suddenly a completely different person. |
| Jack: | Yes, yes. |
| Dawn: | No. Yeah. |
| CP: | Do you think sometimes they look at you as a different person? |
| Dawn: | Yeah. |
| Jack: | Yes. Wer [*pulls strange face*] |
| | (Jack, line 3074) |

***Power and family dynamics***

Sensitivity to issues of power and (lack of) control was raised by a number of participants in relation to complex family dynamics. Some members of the Research Group noted how family could be an active barrier to friendship, neglecting the importance of friendship while they themselves occupied centre-stage with kindness and caring.

Issues of control and dependency were particularly apparent in relation to respondents who had more severe aphasia and who were living with a partner (also identified as a best friend). The potential for the person with aphasia being linguistically overpowered by their partner / friend was self-evident. But partners were also the people who managed communication with the outside world, including friends.

When the non-disabled partner took on additional roles and responsibilities at home some respondents described tensions created through guilt and the frustration at being unable to contribute financially or practically to everyday chores. Jack worried about additional pressures on Dawn, particularly relating to loss of income. David expressed concern that he was dependent on his wife as his driver as well as carer.

### *Roles and responsibilities*

Katie, described how the protective role her partner Rachel and her children took on contrasted with the behavior of friends, one of who had recently asked her to help out on training course:

> CP: So there was something important about putting you in a helper role?
>
> Katie: Yeah.
>
> CP: (…) rather than someone to be protected.
>
> Katie: Oh yeah, yeah. The only people who did protect me were the kids and Rachel.
> (Katie, line 502)
>
> CP: … Okay. So in your sort of close friendships we've got Dawn and we've got (…)
>
> Katie: Rachel.
>
> CP: (…) Rachel. And it sounds like, (…) the Rachel relationship has really changed quite a lot.
>
> Katie: Yeah. Oh! Yeah. *Immensely*.
>
> CP: Would she have been your friend, before your stroke would you have said she was your friend?
>
> Katie: Yeah. Because we had very, (...) *shared* responsibilities. Yeah. So just from the stroke that, that became very difficult.
>
> CP: The change in responsibilities?
>
> Katie: Yeah. Yeah. Was her. All over to Rachel. Hmm.
> (Katie, line 670)

Later in the interview she attributed, in part, an improvement in her friendship with Rachel, to a resumption of shared responsibilities.

Not everyone shared Binda and Katie's desire to escape the protective care offered by family. Donna, a single parent, was living with her school-age son and new kitten. She identified family members as key people in her friendship circle. She seemed comfortable with the uni-directional care, support and co-ordination offered by relatives-as-friends as long as it came with a non-patronising tone. Donna's small circle of close friends included her mum 'because she does everything for me' (Donna, line 860) and an older woman from the stroke club whom she reported played a mothering role to her, regularly braiding her hair.

### *Money and work*

Another aspect of power described as impacting on social participation and social relationships was loss of employment, loss of the status associated with work roles and the financial implications of long-term unemployment. Grant had set up and run an international engineering company prior to his stroke. A well-educated man, widely travelled, he reported feeling passionate about his work and business, which previously occupied him full time. Onset of severe aphasia led both to loss of his career and, in time, necessitated moving to a large housing estate. Both Grant and his wife associated this with downward social mobility. In addition to losing contact with all former work colleagues bar one (the co-director of his business who lived abroad) he described this changed social status as being an additional barrier to forming and maintaining friendship. Visiting his flat, I noted the sentiment of apology and embarrassment (explicitly articulated by his wife) for asking me to visit an area they perceived as 'rough'. Using a combination of writing, diagrams and responses to issues raised by other study participants, Grant indicated that issues of status and employment amplified the more obvious problem of 'talking':

> CP: [What gets in the way of friendships?]
>
> … … or some people say because they don't have much money (…)
>
> Grant: Yes
>
> CP or their (..) sort of *status* [*writes status*] changes

Grant:     *Yes*, yes

CP         Because they're not I think *some* people say because they don't feel quite so important or quite so interesting for example

[*writes important, interesting, work*]

Grant:     Yes. yes [*points to 'work'*]

CP:        Because they don't have a job?

Grant:     *Yes, yes, yes*!

(Grant, line 2903)

Jack highlighted throughout his narrative, his perception that loss of the ability to drive and therefore his living as a delivery driver, operated as a barrier to maintained friendship. Without money and without work he described his sensitivity to losing his place amongst his circle of football friends. No longer able to afford season tickets to watch the football with them he and his son were dependent on the generosity of friends who shared their ticket allocation. Money also constrained choices about which leisure activities he could afford. In addition to weekly support group fees, he and his partner needed to cover the cost of both their train fares as he was reluctant to travel alone on the underground.

CP:        So have you got any thoughts on things that can (..) really help friends?

Jack:      Yes. Shh [*writes 'money'*] (2) Money.

CP:        Money. That is a big one for you.

Jack:      4) [*writes 'little'*] Little. [*points to money and little*] Little. Little.

CP:        Is (…) So the money thing, is it that you, you haven't got the money to (…)

Jack:      Yes, yes. No, no, not like to (…) Look, okay, [*underlines money, underlines little*]. Go on, go on.

CP:        Yeah. So that kind of gets in the way of the

Jack:           [*Yes!*

CP:        doing things with them maybe. Yeah, okay.

Jack:      Yes. [*laughs*]

(Jack, line 2428)


Dawn:    Because everything, if he goes to an exercise class or he goes to the gym or he goes swimming, everything it's *money*.

Jack:    Yes, *yes*!

(Jack, line 3638)


**(b) Reciprocity**

Reciprocity describes a mutual exchange of practical, emotional or social goods for the benefit of both parties.  Over half of the respondents talked of reciprocity in friendship as important to them. For some respondents this contrasted perceptions of passively receiving instrumental and emotional support or the protective care giving of family members.


Respondents in the study described and demonstrated a range of resources available for social exchange. Binda, Jeff, Sarah and Katie all talked explicitly about the role of humour in contributing to relationship maintenance. Other skills and resources cited as important offerings within reciprocal friendships included: child-minding, driving, walking the dog, listening to friends troubles, and offering quiet unrushed space to talk about and unpick complex topics. Within her circle of friends in her social housing community Melanie described how she had established strong routines of practical, mutual exchange where friends helped her with paperwork, phone calls, computer support and changing light bulbs while she would reciprocate using her cooking and baking skills. For example, her friend Jenny made phone calls to workmen in return for a fresh cooked meal:

'So Jenny erm, (..) rings and then I (…) she doesn't like cooking and everything so I make something, you know.'

(Melanie, line 617)


She described the same strategy for 'paying back' emotional support for neighbours Helen and Eva:

'But I'm cooking for her and Eva because they have been, they have been so lovely. And when I was really down and everything'(Melanie, line 1271)

She described in a follow-up interview how making a contribution through her retained and lauded cooking skills challenged perceptions of incompetence as well as balancing the trade of instrumental and emotional support.

Melanie:   I, I, I think erm, because I, you know, I like cooking and so we have drinks or a coffee or something and I, I, I make something and then they all say that's (…) And it's just nice to be part of that community. And to (2)

CP:   So you cook for them and they enjoy that and they compliment you.

Melanie:   Yes, that's right. And that helps me, you know, I think oh, gosh. And it's, erm, (3) it is very important to me because I just feel erm, that that re-, repris- I can never say that bloody word! [*laughs*]

(Melanie, meeting Feb, 2011)

Shared experiences of disability operated at an individual level and within a broader network of community peer support. Priya and Emily gave examples of enhanced relationships with ex-school friends once the experience of living with a hidden disability became shared. Both had key friends from school days who had experienced dyslexia at school. Priya described re-establishing contact with her old friend via Facebook and at her sister's wedding after several years break. Mutual understanding appeared to have had spin-off benefits to family members too:

'And we will see each other more regularly and I told her all about my stroke and she, she's dys-, dyslexic as well and she has diabetes as well like, erm, and she told me all about that. And she was dyslexic when she was growing up but I didn't see it and she didn't see it. She could see that there was something wrong but she couldn't get to grips with it or something. And erm, yeah. Anyway. And erm, [*clears throat*] erm, yeah, but erm, but erm, she told her mum about me and erm, her

mum will call my mum [*laughs*] for a heart-to-heart and, erm, yeah, it's just like we had never lost contact at all.'  (Priya, line 1556)

## ( c ) **Altruism**

Altruism took two other forms within the data:

- acts of emotional generosity to spare friends from hurt
- altruism in the context of volunteering and peer support

Some participants identified a drive to protect and reassure friends and family faced with the trauma of stroke impacts. In one case a respondent described being unable to bear the pale, stressed face of his wife when she came to visit him in hospital.  Unable also, on account of his aphasia, to veil secrets with language and lies, he confessed to a previously secret affair, partly he reported as an act of self-preservation but partly as a strategy to enable her to leave him. Others expressed a need to protect close friends from their inside story by maintaining a 'positive spin'.

Priya, for example, expressed how a 'positive spin' on her conversation covered times when she experienced depression and envy for falling behind expectations she had for herself:

> 'I erm, I put a positive spin in it but, erm, (2) I feel that [*clears throat*] so far, erm, I don't have the things that, erm, they have. I don't want … [*clears throat*] Erm, that's not the right way to say it but, erm, I don't have the things that I expect of myself'.
>
> (Priya, line 1712)

Artful management of clumsy but patronising attempts of friends to comment on communication skills was another form of altruism. Katie described how she responded to friends who say 'well done' or 'clever girl':

> 'I don't, I don't reply. Just 'Oh, thank you' or something, and move on to the next thing. But it makes them feel better.'
>
> (Katie, line 1058)

All six of the interviewees from the Research Group took part in some form of volunteering activity – contributing time and skills to befriending, support

groups, training, coaching, community projects, fundraising and campaigning. Some respondents reported that adopting roles as helper, formally or informally, were pivotal to confidence-building and self-management.

Volunteering environments were also noted as a context for growing new friendships, typically with peers who also had aphasia, but also with project leaders and co-ordinators without aphasia. Grant noted that new friend Paul, the leader of a community gardening project, was not the best communicator, but seven years of weekly volunteering later counted him amongst his small inner circle of friends. These also included, several peers with aphasia from the same group. Jeff described how for him, volunteer work opened the door to rebuilding a network of 'half and half' friends (Jeff, line,1324) who replaced former work colleagues. These were his new community of half colleagues, half friends to replace the many work acquaintances of his pre-stroke life.

## 5. Constantly changing: the friendship kaleidoscope

Participants described their experiences of a dynamic ebb and flow in their friendships. Although some respondents such as Donna and Grant, embedded in their close family network of support, perceived few ongoing changes in their relationships, most Phase 1 participants presented a strong impression that friendship was not static. David used the term 'kaleidoscope' to describe the visual patterns that signaled for him the onset of stroke. A cyclical moving in and out was how Jeff mimed the impact for him of having many friends, a diminishing funnel of friends and a reopening of the funnel as new and old friends reappeared on his 'radar'. Jack frequently illustrated his sparse expressive language with strong, rapid arm movements into and away from his body. These spatial metaphors and the frequent descriptions of shifting configurations of self, others and external factors suggested the constantly changing patterns of the kaleidoscope was an apt image. Pieces of the kaleidoscope could diminish or multiply as people faded in and out and qualitatively as friends became closer or more distant.

**(a) People fading in and out**

Jeff described the gradual decline in contact with work colleagues, particularly his email chums outside his home town as they either didn't email or emailed and got the shortest of replies given Jeff's inability to write post-onset of aphasia. Here however he describes how, over a period of two to three years new friendships multiplied and flourished through his work for a range of stroke charities:

> Jeff:    And little bit friends cut out stroke [*indicates horizontal line in air*] (…) and later on, later on, later on (…) slowly, slowly, slowly (…) [*gestures moving along the line*] faintly, faintly, faintly. University [*drops hand to lap indicating down*] work and more and more and more and more and more charities [*begins slow circular gesture*]
>
> CP:    So as one fades out the other comes more into focus?
>
> Jeff:    Yes. Maybe two or three years
>
> (Jeff, line 1616)

A strong sense of movement was also echoed in accounts of early days in hospital. Melanie, Jeff, Katie and Priya talked of the rush of friends to visit in hospital.

> 'I had absolutely hundreds of people erm when I was in hospital and everything' (Melanie, line 67)

In his video story Jeff talks of piles of 'fruit and cards and flowers'.  This rush of people and activity could be in contrast to voids of boredom as time went on.

This was not the case for everyone however. David recalled his time in hospital as 'really boring all the time' (David, line 153). Spending empty time trying to communicate with visitors seemed a good way to pass the time and build awareness together:

> David:    Yeah. And friends, friends from work came I got quite a lot.
>
> CP:    So in those hospital days you had quite a lot of visitors coming along (..) to try and beat the boredom?

David:     Yes, yeah. But I didn't know what to say because I couldn't *speak* much. But it seemed to work somehow.
           (David, line 452)

Jack also indicated the spatial movements of friendship as he described changes in his relationship both with his best friends prior to his stroke and with his family. Drawing on recurrent, expansive arm gestures away from his body combined with a frequent 'Pscht, bye bye' utterance he described how former work and football friends were less present now since he had lost his job, money and speech. While they were less prominent he perceived that his family relationships had grown closer.

Jack:     [*writes 'Family' beneath CP heading of 'Friends'*]
CP:       Family?
Jack:     Yes.
CP:       You …
Jack:     Yes. (3) [*draws line from his writing 'family' to where CP had previously written 'Stroke', then draws 2 way arrows between 'friend' and 'family'*]
          *Friend*! [*back and forth hand gesture*]
CP:       Oh, so you're, are you saying (..) that your family sort of becomes your friends?
Jack:     *Yes, yes*. Good. [*back and forth hand gesture, points to 'stroke' and 'family' on page*]
CP:       Yeah. So your family are really
Jack:        [Yes, good.
CP:       important
Jack:     Yes, yeah
          (Jack, line 2973)

These comments were reinforced throughout the interview as he picked up stones representing friends of family and regularly moved them closer or more distant to the stone he had selected to represent himself.  On a follow-up member-checking visit he reinforced this more strongly by repeatedly drawing

a circle around the inner sanctum of stones representing his partner, two children, and dog.

Katie also talked of her awareness that friends and friendships were changing in depth and intensity. She describes this as being a situation always open to flux. Probed on how her friendships shift from outer to inner circles she described how this was often a feature of time. Here she asserts it could also be a consequence of her daily changing internal state:.

| CP: | So it sounds like you've got a lot of people who would be in this outer circle? |
|---|---|
| Katie: | Yeah. Yeah. Yeah. I don't know if we did it tomorrow they would be in inner circle. |
| CP: | So things might change? |
| Katie: | Yeah. Things change all the time, yeah. |
| CP: | What do you think would shift people from the outer circle to the inner? |
| Katie: | Erm, perhaps the way I was feeling. Erm. Might bring them into the inner circle. |
| | (Katie, line 900) |

**(b) Getting closer and falling behind**

The fading in and out of friends in friendship circles was not always perceived as loss but as a struggle to keep pace. Many participants suggested both friends and organisations lacked awareness of temporal barriers and the exclusionary impact of fast-paced conversation.

Constantly being one step behind and enduring repeated compromises of expression was described as part and parcel of Priya's every day conversational frustration:

| Priya: | Erm, the things that are different is like erm when I talk to her on the phone, erm, I, [*clears throat*] I *can't* say everything that just pops into my mind. Because [*clears throat*] it's like erm, (…) erm, (5) it's like all straddled, erm |
|---|---|

> (…) And like I want to say something about, erm, (..) a, (..) a dress but I *also* want to say something about how she looks in a dress or how she, erm, erm, how it makes her feel.
> And it's all scrambled up and I can't come up with the erm words fast enough to, erm, talk to her about it.

CP: Mmm, (..) mmm

Priya: And erm, so [*clears throat*] then the, erm, then the story moves onwards and, erm, that just gets left. And erm, like I have to deal with that *every single day,*

(Priya, line 880)

Not being able to 'keep up' in friendship conversation appeared, for some respondents, to mirror the experience of falling behind in relationships and life, particularly as compared with friends and peer groups. This seemed especially relevant for people who experienced a stroke as a young adult. Priya, for example, talked about the painful experience of falling behind her two closest college friends. Previously they had been known as 'the three amigos'. Priya described her upset and envy as the other two kept texting, Facebooking, communicating and living life at high speed, whilst she was now operating in a different slipstream of time.

> 'And we were the three best friends and everything like that. And I feel that, erm, they've grown closer and (..) I've not been able to grow closer to them because of my disability.'
> (Priya, line 675)

Priya, Melanie and Emily, who experienced onset of aphasia at 23, 28 and 18 respectively, expressed emotions of disappointment, yearning, and envy when they compared themselves to friends whose lives remained on track with ambitions. Priya described the experience of recalibrating expectations and time scales:

> 'I erm, I put a positive spin in it but, erm, (2)
> I feel that [*clears throat*] so far, erm, I don't have the things that, erm, they have. I don't want (…) [*clears throat*] Erm, that's not the right way to say it but, erm, I don't have the things that I expect of myself.

> … …to get a job, to erm, get a boyfriend, erm, like [*clears throat*]
> to go travelling, and erm, to eventually get married and have kids
> and do all of the normal things like everybody else. And but it will take
> me a little bit of time to get there but I hope I get there. [*laughs*]'
> (Priya, line 1745)

Emily's account described her ambivalence at seeing friends away at University enjoying a different life, while she focused on rehabilitation activities. Viewing Facebook pages of her peer group newly immersed in university life raised brutal comparisons with her life of rehabilitation at home.

> Emily:     Erm. Because I, I don't (...)
>
>             Because I think (...) writing and that (...) it's hard.
>
>             And also the erm, (6) [*writes 'photo'*]
>
> CP:        Yeah, photo.
>
> Emily:     Photo like, like happy things and now I'm *here* like.
>
>             And also (...) erm,  [*writes 'uni'*]
>
> CP:        Uni?
>
> Emily:     Uni and lots of pictures and things that I don't, I (2)
>
> CP:        So is it, (..) do you go on your friends' Facebook pages?
>
> Emily:     Yeah. Yeah. Now it's fine. But erm, but (2)
>
> CP:        But they're mainly at uni and their photos are all of things
>             that they're doing and (..)?
>
> Emily:     Yeah. Yeah. And it's hard.
>
>             (Emily, line 1539)

Although several participants reported maintaining strong and close friendships with former colleagues, a natural fading of friendships formed at work prior to the stroke was also a common experience. Others regretted the evaporation of work-based friendships but accepted it as part of the natural attrition that occurs with losing a shared focus. For example, Katie was philosophical in describing a loss of contact with former teaching colleagues:

> 'But they are not there now. Yeah. Yeah. Shame. But it is (…) That is
> how it goes. You were friends with someone then you move away'.
> (Katie, line 822)

The way a sense of proximity to people and friends could change over time was further highlighted during member checking interviews. These typically took place several months after the initial interview. Showing Emily a digital photo of the friendship stones she had selected at our first meeting she commented that she would now change it slightly. For example, she moved one friend a little further away as that relationship continued to deteriorate. She also now wanted to add her sister as a friend. This was based on a recent frank conversation about the nature of her disabilities and Emily's perception that at last her sister had a better insight into the impact of aphasia on her life. Communication between them had altered, she reported, on account of this conversation.

> Emily:    I think like now, I think my, erm, Kathy is better like, erm, like erm, talking about, about things and lots of like, erm, sister and friend as well. I think it's better now.
>
> CP:    So better, the relationship with Kathy feels better because she (…)
>
> Emily:    Realises and, and talks erm (…)
>
> (Emily, member check, line 159)

**(c) Recovery and turning points**

> Sarah:    Still growing (...) still (...) growing erm, 10 years (...) ago
>
> CP:    Yeah so things are still improving?
>
> Sarah:    Exactly, yeah, yeah.
>
> (Sarah, line 119)

Ten of the twelve Phase 1 participants remarked on changes in abilities, relationships and wellbeing over time. Most commented on the ongoing nature of recovery, in some cases, as with Sarah, more than a decade after the onset of aphasia. Feeling better, doing more, recovering language and changes in confidence and self-esteem were factors noted by many as contributing to improvements in relationships.

Respondents identified a range of pivotal moments and turning points in enhancing friendships. These included being able to drive again or use public

transport independently, getting out more, or developing confidence generally. Moving to an accessible housing community, a converted convent, that had an unusual atmosphere of neighbourly care and attention had worked well for Melanie and it was where she now located a significant group of friends.

> 'Because it's such a different, a different, erm, (...) I think, I don't know what it is about the convent but it seems to be a special place and I think perhaps because of the gardens and everything but I don't know. I've known, I know the people in flats and it doesn't seem to but it just seems to be. And I have wanted to communicate with people, you know.' (Melanie, line 860)

Priya recalled the first time she was able to send her friends a text as an important breakthrough. Getting out and about, after more than two years imprisoned at home was perceived as a breakthrough moment for Katie. She described this as prompted both by the confidence boost of a shift from 'patient' to 'helper' at her local stroke group and in response to tensions at home:

| Katie: | Then about a year and a half later she said, 'would you like to be a helper now?' So I said 'yes, please'. So that was good. And then I joined the local gym that was at the time when things were really bad in the house. So I thought to myself I have to do something just for me. |
| --- | --- |
| | I went to Pilates and I went to swimming. And this has given me a *whole new life*. Charlie is also into swimming. And going in the gym. So it has given a *ne:w* life, all the going out for meals, and very good. It is great. |
| CP: | So that was a bit of a turning point? |
| Katie: | Yeah. I think I went after two and a half years ago. |
| CP: | What made you go along to |
| Katie: | [What made me go along was my partner has gone. There were me and two boys. And I thought well, I have to do something. So I went to that. |
| | (Katie, line 207) |

A striking feature of the data was how many participants attributed increased self-knowledge, and qualitatively different, evolved friendship experiences to the discovery of peer support. This theme is developed further under theme 6 in relation to identity.

Sometimes however, recovery was on the part of the friend as they too progressed in coping with the trauma of the stroke experience. For Katie, one previously very close friend, Rachel, was only now, 6 years later, making it back as a friend as she, Rachel, recovered her own self esteem and took a more relaxed approach to friendship and sharing responsibility:

> 'Rachel is obviously a friend. But (...) getting more so now that I (...) because she is a bit better now.'  (Katie, line 342)

## 6. Friendship and identity: going missing and finding yourself

Referring to the unfinished business of reconstruing identity after aphasia, Binda remarked that 'Friendship and aphasia is a painting that's never finished' (email, October, 2010). The theme of identity interacted with many of the other themes and sub-themes described above. Key aspects of this theme related to losing (and retaining) a core self, a sense of rebirth, resisting the imposition of identities (particularly by family members) and establishing a collective identity with peers with aphasia.

### (a) Losing the self's core

As illustrated in the contextual background to the findings (Chapter 6), many respondents articulated an experience of exile or existential absence early post-onset of aphasia. Melanie, who in her narrative made repeated reference to a loss, or 'ripping out' of her core perceived that her 'disappearing act' did not go unnoticed by friends, particularly during the initial flurry of hospital visits:

> 'lots and lots of people were erm, erm came to the hospital and everything and they said 'oh my God she's just gone' you know and so slowly or pretty fast actually people were very they didn't know what to do and everything like that (...) and I was just in another world'
> (Melanie, line 301)

Although not everyone shared Melanie's perception that they had 'gone missing', for those who did, maintaining a presence within equitable relationships with friends could prove elusive. How, Katie asked, could she be a friend to others when she perceived herself to be diminished as a person and a stranger to herself?

> Katie:    Because in the first three years I wasn't anybody to be with. Whereas now I feel I do have a friendship to believe in. It is erm (..) I believe that I can be a friend to Dawn [partner], can be a friend to Penny, to Daphne
>
> CP:    You had three years where you feel (...) three years where you feel that you couldn't be a friend?  Why is that?
>
> Katie:    Because I didn't know myself. Erm I wasn't friends to anybody.
>
> (Katie, line 388)

Katie, Melanie, Sarah, Donna, Priya, Binda and Emily reported experiencing prolonged and ongoing periods of low confidence and fragile sense of self. For some, confidence was almost synonymous with identity. Melanie believed her lack of confidence and self-conscious concern about how others saw her now presented significant hurdles to maintaining former friendships and developing new ones. Asked about factors which got in the way of forming friendships she replied:

> 'Erm, I think *I* get in the way of *me* in a sense, you know.
>
> And I, I, I am very critical of myself and erm, and I'm always, when I had counselling and everything and they said you're always thinking about your past life and now and it's so different and everything like that. But I sort of want to say well, it was so different, you know'.
>
> (Melanie, line 2232)

For others, confidence was not such an issue but loss of the ability to earn a livelihood seemed the most dominant factor. This appeared to be the case for both Grant and Jack who repeatedly raised the issue of money and work.

Whereas some participants' narratives were consistent and definitive in articulating perceived impacts of aphasia on identity, others were more ambiguous, one moment highlighting continuity between present and past selves and at another emphasising discontinuity. Emily for example, talked about changes in confidence and personal expectations. Her entire account, littered with 'I don't know' speech markers, expressed uncertainty and ambivalence. At times her narrative dwelt on her changed communication abilities and altered self-assurance, at others the locus of change was clearly with her friends. Again, in this extract I check my understanding of Emily's perception of changes to identity:

| | |
|---|---|
| CP: | And you're the same, you're just you? |
| Emily: | Yeah. |
| CP: | Or are you a bit different, do you think? |
| Emily: | Erm, no. |
| CP: | You feel you're the same you. |
| Emily: | The same. Yeah. |
| CP: | Apart from the speech, speech is obviously a bit different, but *you're* the same you. |
| Emily: | Yeah. |
| CP: | But *they've* started acting a bit weird. |
| Emily: | Yeah. I think it's the stroke what (…) Because it, it's hard like. |
| | (Emily, line 1751) |

Sarah who previously worked as a lawyer made repeated references to a robust and stable personal identity. Asked to choose from a selection of stones to represent her and her friendship circle she was particular about selecting a solid large solid white pebble to represent herself. Her two closest friends (of over 15 and 20 years standing) were also represented by large grey stones (see Fig 7.1). Her narrative conveyed something steady and immutable both about herself, her continued status as a lawyer, despite being unable to practice for over a decade, and these strong persisting friendships. She seemed able to distinguish her array of stroke impairments, including profound

changes of communication and confidence, from a core sense of self that remained firm and in many respects continuous.

**Figure 7.1**          **Sarah's friends**
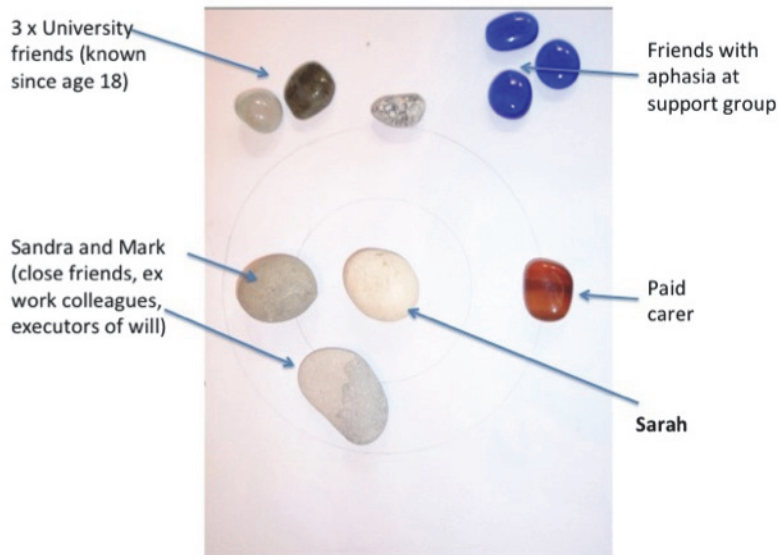


'Before the stroke erm (...) erm (...) lawyers erm and (...) erm (...) get along. And after (...) wards (...) it's different and the same. '
(Sarah, line 776)

Indeed struck by a juxtaposition of robustness and fragility, I asked whether she thought her selection of stones might look any different had we completed a similar exercise ten years earlier, prior to her stroke:

CP:          [*looking at choice of stones*] That's a really kind of big solid stone there. Would you have chosen the same stone ten years ago for you?

Sarah:     Yes, [*nods stro*ngly], yeah, yeah.

CP:          So it's sort of (…) something really kind of solid inside you?

Sarah:     Yes

CP:          (2) But your confidence perhaps maybe

Sarah:              [Shattered. Hhhh [*smiles, leans forward*]

| | |
|---|---|
| CP: | Yeah, yeah. And that's still changing? |
| Sarah: | Yeah. [*looks down, face drops slightly*] |
| CP: | Yeah. |
| Sarah: | [*sits back*] [*raises eyebrows, looks down at stones*] |
| CP: | (3) Any other big things that are sort of different, Sarah? |
| Sarah: | No, no, no. |
| CP: | No. No. So you're, you've got a very, (…) *strong* sense of who you are? |
| Sarah: | Yes, yeah, yeah. |
| | (Sarah, line 1246) |

A conversation with Sarah over coffee some months after this interview prompted some further reflections on the impressive way she managed her friendships.

---

**Box 7.1 Reflection**

Fascinating conversation with Sarah this morning when we bumped into each other in the coffee bar (before our member check session). She talked of how she is comfortable and sort of at home with her routine of practical and cultural activities. Nothing will shift her weekly routine with her home carer/friend on Wednesdays. And the weekly / monthly routine of suppers, music outings with chums and the week in week out visits by her old work colleague, for conversation and admin sort outs seem equally solid and reliable. I wonder if her apparent robustness and clarity has helped these friends accommodate to the massive changes?  But a glimmer of contrasts in perspective too when she said *she* had accommodated to her changed language but felt *they* still lagged behind. They wanted her language to be better, she inhabited it as part of who she is now but seemed to suggest that they still struggled to let the old Sarah go.

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**(b) A sense of rebirth**

Talking of the impact of stroke and aphasia on self, language and relationships Binda expressed his perception that the sudden loss of the ability to talk rendered him naked and vulnerable to friends and family:

'I was there stripped naked'

(Binda, line 1505).

Descriptions of return to the nakedness and dependency of infanthood as people struggled with the loss of language, physical independence and control were common in participants' stories of the first period following their stroke. Emily, Priya, Melanie, Jeff, Katie, Binda and David made reference to their stroke as signaling the beginning either of a new life, or a starting point to embark on reacquisition of pre-stroke lives and identities. Stories of the early months and year post-stroke contained multiple references to developmental processes of learning to walk and talk again:

'For two years you know it was like a baby again '

(Melanie, line 953)

'My first word was 'mum'. And my second word was 'dad''

(Priya, line 187)

Donna, whose friendship circle consisted almost entirely of family members described why her mother was close:

CP:      And what about, and then you've got your *mum*,

         Who is this nice stone here. It's funny, she looks a bit like you, [*compares two stones*] you can tell you're your mother's daughter.

Donna:  [*laughs*] Hmm.

CP:      [*laughs*]

Donna:  Yeah.

CP:      Why would you call your *mum* a friend?

Donna:  (4) She does everything for me.

         (Donna, line 830)

Reflecting on their work with others with aphasia some Research Group members with longstanding aphasia referred to those newer to stroke (less than 2-3 years since time of onset) as 'the young ones' regardless of their chronological age.

Several participants experienced rudimentary language skills as imposing a child-like character on the way they presented themselves to friends and family. Absence of language could remove options for self-presentation and leave people feeling vulnerable and exposed as well as questioning what might lie beneath the language facade:

> 'Erm, couldn't bullshit. I couldn't bullshit. I had to (…) face myself. I under- I had to understand myself… … Yes, yes, um (…) I've got nothing to hide. [*laughs*] You know I'm naked.'
> (Binda, line 240)

Binda, reflected for himself on certain advantages to the more open communication of what he termed 'a simpler life' (line 1482). Exposing his vulnerability, he believed, in many instances had surprisingly deepened relationships with friends:

> Binda:    You know, erm, (…) time and time again when I am vulnerable, when I am, (…) let my whatever, 'dark side' out, hundred times people are closer, erm, be- become closer to you. Weird. Weird.
> CP**:**    When you show your vulnerability?
> Binda:    Yeah, yeah.
> (Binda, line 1599)

## (c) Resisting imposed identities

Part of the difficulty expressed by participants in finding an equilibrium of self after stroke was a perception that others could impose unwanted and inaccurate identities.  Most often these characterisations reflected dominant grand narratives of disability such as assumptions of victimhood, incompetence and loneliness. These responses were reported as being manifested through patronising 'does he take sugar' behaviours, infantilising

or excluding conversation, evident fear on the faces of conversation partners, or a perceived lack of confidence (on the part of friends or family) that the individual with aphasia was competent to join in.

The most noticeable examples of imposed identities were cited in reference to family members. Melanie, for example, explained the complex relationship with her mother as they both grappled with a perceived second childhood:

> 'I was like a child again. And erm, and I think for a couple of years, she had that child back and then I began to, a little bit of me began to appear which isn't like my mum, you know. And erm, (2) and she, she's very proud of me but I know she, she's frightened of me and I just, I, I can't (…) In the end I think I have to (…) And this sounds very selfish, I think, you know, I'm an only child but I have to live with *me*.'
> (Melanie, line 965)

Priya and Emily, both still living at home at the time of their stroke made strong reference to the formidable, anchoring presence and support of their family. Jack, Grant and Jeff symbolised this by locating their spouse as best and closest friend when selecting the stones. Where participants selected family members as friends, finding a balance between anchoring presences and a space to reconsider identity could be challenging on both sides. Jack, described himself as more family than friend orientated, a trait exacerbated, he considered by the onset of aphasia. Whilst he located his partner, Dawn, as his closest friend and ally, he gently teased her for a new tendency to care and protect:

> CP:     Some people say, erm, which is understandable (…) that family get a bit sort of, erm, (...) protective?
> Dawn:   Hmm.
> Jack:   Yes, yeah. [*points to Dawn*]
> Dawn:   Me.
> Jack:   Yes, you. [*laughter*]
> (Jack, line 682)

Recovery and a sense of affirmation, for some people could only be achieved away from the protective family net as Binda describes it. For him it was the creative space of friendship rather than family that supported reflection and personal growth:

> 'And slowly I had an identity by erm, an open space by choosing, choosing erm, erm, a friend and choosing an activity outside, well outside my family, my protective net. So the, the, erm, I feel [*clears throat*] erm, that's why friendship is so crucial. Erm, erm, it's so crucial in order to get, you know, what am I about?'
>
> (Binda, member check interview, line 972)

Where participants had very little expressive language, the power of relatives' unchallenged portrayal of them to outsiders was striking. Sam lived in a council flat with his mother. She asked to be present during the interview, predominantly adopting a respectful and silent listener role. However while I was attempting, with limited success, to identify Sam's network of friends she interjected:

> Mum:     Well, can I interrupt? He really hasn't got any friends, he's a loner.
>
> Sam:     [*stares at page*] (? No)
>
> Mum:     He had friends years ago when he went to India, he had lots of friends then. He is really a loner.
>
> Sam:     [*no reaction*]
>
> CP:     [*to Sam*] And would that be the same (..) before
>
> Sam:     (? Unclear)
>
> CP:     Before your stroke as well?
>
> Mum:     Mmm. [*agrees*]
>
> CP:     So you'd be a bit of a loner? [*writes 'loner'*]
>
> Sam:     [*no reaction*]
>
> (Sam, line 1006)

Sam had the most severe aphasia of all interviewees and his lack of verbal expression was matched by very limited facial expression throughout his interview. Even with non-stop recourse to drawing, writing, diagrams and pre-

prepared artefacts I was frequently uncertain whether Sam had followed my line of questioning or whether I had accurately interpreted his response. Against this backdrop of silence and uncertainty I wondered how often the loud and unchallenged voice of his mother (or others) dominated. Although unsure in this excerpt whether he had understood his mother's portrayal of him she repeated her evaluation of his character as 'a loner' a little later in the interview. On this second occasion it raised a clear scowl of irritation from Sam. This example was extreme but carried echoes of other participants' accounts of being vulnerable to the way family members chose to define them to others.

**(d) Establishing a collective identity with peers with aphasia**

Given this sometimes-oppressive home environment, many respondents perceived stroke and aphasia support groups to represent a more freeing context – a place to breathe, to 'be' and to begin a long, cyclical process of figuring out what was happening. In contrast to the isolation of home, peer support could represent 'the first step on the ladder of friendship' (Research Group 15).

With many pre-stroke friends 'gone' Melanie described setting up a local support group as a way to explore unknown territory:

> 'I was just in another world. And so all those people were, most of them were gone you know. And I thought, I thought (..) I didn't know what was happening. So I thought what I would like to do is find people in the same situation and that's why I, erm, set up the group'
> (Melanie, line 312)

Priya coined the phrase 'Fast friends' to describe new friends with aphasia. Here she describes how aphasia (amongst other shared interests) fast-tracked bonds of friendship with another young woman with aphasia who she met at an aphasia support group:

> 'In that one coffee trip we erm, we *bonded.* Erm, (3) like erm (3), yeah, erm (…) And we have been friends ever since. … …

I've felt and been through and erm, and going through as well and she's also shared what she has felt and been through and goes, is going through as well. And erm, we bonded but, erm, it's not just about our aphasia. It's the, erm, hhh (…) erm, (4) it's what *brought* us together but it's, it's not about that anymore. And erm, we like erm, we both like (...) shopping and like erm, (…) like erm, like travelling and everything else. It's about so much more than that. … …

It's about so much more. Erm. Yeah. So that's what I feel is fast friends.'

(Priya, line 1106)

Peers and volunteers at support groups were described as companions to do things with, to laugh with, to learn with. Grant, for example proudly showed a photo of himself with friends with aphasia at the official opening of a regenerated local garden they had worked on. As time went on, people with aphasia at these groups could become 'colleagues' and friends. This is how Sarah described her new 'colleagues' with aphasia at Connect, as companions engaged in a meaningful, collaborative task of work, getting to grips with aphasia and getting on with life. Jeff, in common with many respondents, experienced loss of his work and loss of many work-related colleagues. Reflecting at the end of his interview on losses and gains he identified his roles in peer support initiatives as an important source of replenishing friends as well as finding meaningful new work opportunities:

Jeff:    Erm, (5) well, (...) it's always sad and erm, (...) work and colleagues. Erm, (6) but it, it, sort of new job. Erm. New sort of, new life. [*both hands gestures not quite, pulls face*]

CP:    So for you having a stroke and having aphasia it's almost like you've started a new job and a new life?

Jeff:    Yeah. Yes, yes.

(Jeff, line 1840)

Melanie, Jeff, Katie and Sarah all expressed a strong sense of mission in terms of offering support to peers and liberating themselves and others from the solitude of aphasia. Binda, who in later Research Group meetings

expressed a growth in his sense of aphasia activism through participating in the project, reflected in his interview on a perceived sense of citizenship and solidarity with his peers with aphasia. Viewing the different shapes and colours of the stones chosen to represent his friends, he reflected on the both the individuality and the community solidarity of his peers with aphasia:

> 'You know that, erm, [*pauses*] (7) we are (…) part of bloody the community. Don't, erm (...) you know, we are individual coloured and you know, bright and dull and (…) So don't forget us.'
>
> (Binda, line 1677)

Not all respondents however, had easy access to peer support or welcomed all aspects of being with peers with aphasia. One participant described his enjoyment of football conversations with some support group members but his perceived lack of social and cultural fit with a local group prone to garden parties and National Trust outings. Several participants in their twenties, thirties and forties were particularly sensitive to the age and tone of support groups.

Sharing stories of aphasia and illness created powerful bonds of community and identification for some participants. However, relentless proximity to the consequences of stroke could also remind participants of the uncertainty of recovery and futures. Melanie, who was active in leading a support group for many years, described how engagement with the peer support group had initially given her confidence from the shared experience of disability and exclusion. Her commitment to peer support was total. However, she also noted the emotional cost of repeated exposure to others' grief whilst she grappled with her own sense of multiple losses:

> 'I think, erm, I overdosed if you like on, erm, people with aphasia. And so for more than ten years, you know, that was, you know, generally people with aphasia. And I think erm, (..) people with aphasia, you know, it's very *sad* and grief and everything like that. You know, I went to a lot of funerals and everything like that, you know. And you think, oh God! You know.'
>
> (Melanie, line 327)

The death of friends with aphasia and the spectre of death from a second stroke for one or both parties in a friendship occurred in three accounts. Grant described losing one of very few post stroke friends, a much-loved friend with aphasia who attended his gardening group. Death surfaced most profoundly for the Research Group when Katie, our own colleague and friend, died suddenly from a second stroke ten months into the project. Her funeral, with standing room only for the hundreds of pre- and post-stroke friends seemed to juxtapose the serious business of stroke with the extraordinary potential for developing and strengthening friendships old and new.

Katie was one of the strongest advocates for the affirming, transformative power of peer support among a welcoming community of equals. Here she describes the energising, affirming experience of entering Connect:

> Katie:     Well, when the light indoors opens and you go in and straightaway I am *happy* to be there. There is (…) I mean, *every single time* I have gone in there I am happy and I have more energy. Because of the (…) The minute they open the door [*animated*] 'Oh, hello, Katie. Oh, hi Charlie. Hello, whoever'. It is wonderful.
> (Katie, line 1596)

Identity also surfaced continually in Research Group meetings and was a prominent theme in the Phase 2 interviews.

## 7.2     Summary

This chapter has described the themes and sub-themes that emerged from the 12 in-depth interviews conducted as the exploratory phase of the project. These six themes derived from analysis of Phase 1 interviews and Research Group discussions constituted the six branches of the visual model of friendship and aphasia, the Forest of Friendship diagram (Fig. 7.2). This is also reproduced in Appendix W. The diagram acquired its name, the 'Forest of Friendship', as the Research Group compared the visual layout of the mind map to branches and trees. The group discussed metaphorical allusions to places in which walkers might wander happily or suddenly become quite lost.

Like friendship, the notion of a forest conjured images of a place that could have natural appeal, or a more sinister edge.

Although data illustrating each theme has been presented individually in this chapter, the naming and visual layout of the diagram were employed to reinforce a sense of intersecting branches of a complex, dynamic phenomenon. This diagram became the working model of friendship that we used to frame the actions of Phase 2 of the project, developing and running the Friendship Events. Methods for developing Phase 2 of the project will be described in the next chapter.

**Figure 7.2     The Forest of Friendship diagram (Phase 1)**
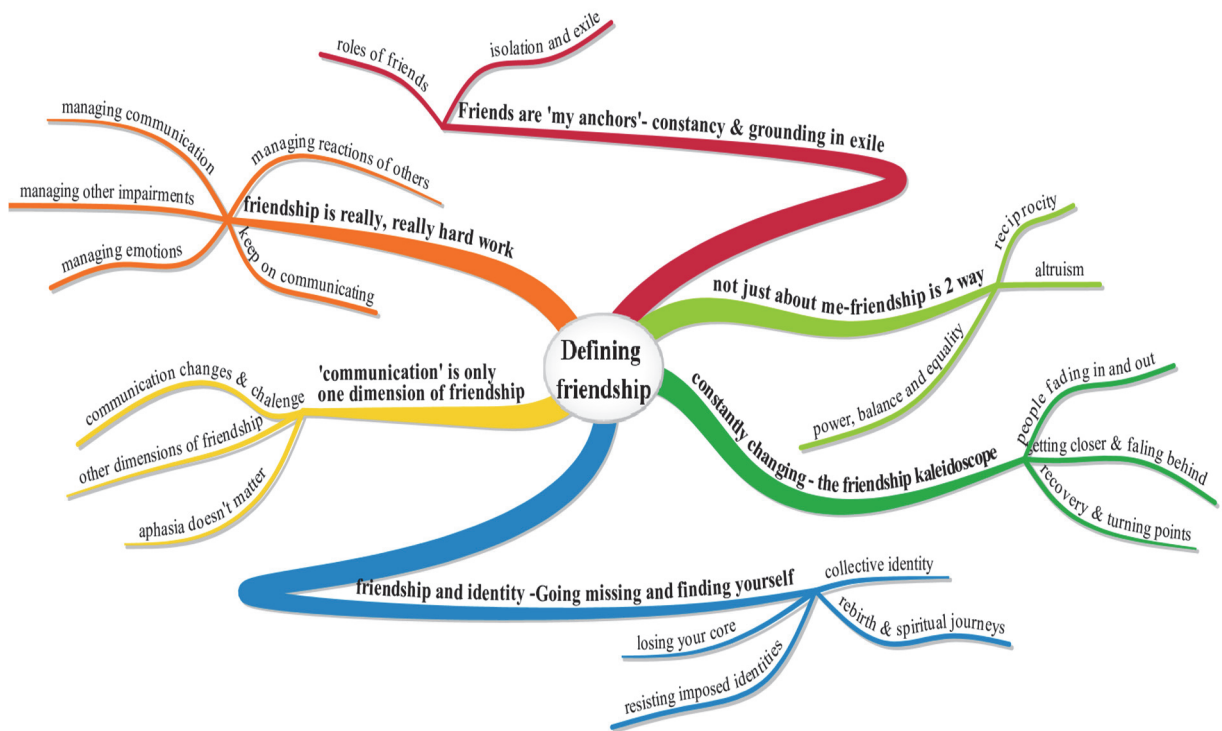
# Chapter 8
# Methods for Phase 2

## 8.0    Introduction

This chapter describes the research methods and processes associated with Phase 2 of the project. This phase comprised an innovation component, with two Friendship and Aphasia Events, and a cycle of evaluation and elaboration. In this evaluative phase I conducted follow-up semi-structured interviews with 16 of the Friendship Event participants and the Research Group reviewed findings in relation to our explanatory framework of friendship and aphasia and overarching research question:

> How do working-age adults with aphasia define, experience and make sense of friendship after stroke?

Phase 2 additionally addresses the questions:

- How do working-age adults with aphasia respond to peer-led Friendship and Aphasia Events?

- How do working-age adults with aphasia sustain and develop friendships in the context of living with stroke and aphasia?

This chapter begins by describing the process of developing the Friendship and Aphasia Events and the component products. It then describes the methods of recruitment for Phase 2 participants. Finally, it describes data collection and data analysis used for the Events and interviews.

## 8.1    The Friendship and Aphasia Events

The Events were envisioned as a creative, two-way learning opportunity, focused on collaborative sharing of stories and experiences.  Stories and personal narratives are a central feature of qualitative research inquiry, whether belonging to the interview respondent or researcher (Riessman, 2008). The power of stories to give voice to the experiences of disenfranchised groups and to produce change in both the teller and listener locates storytelling as a fitting tool for participatory inquiry and constructivist epistemologies (Labonte, 2011). Storytelling as method has been used formally and informally within healthcare research and health education to

facilitate participation and generate new insights (Koch and Kralik, 2006). Storytelling within this context was not planned to conform to the more structured story dialogue method described by Labonte (2011) or the storyline construction used by Koch and Kralik (2006). However, in common with these approaches and Freirean principles of knowledge production through critical awareness, the Events drew on stories illustrative of themes from Phase 1 as a springboard for small and large group discussion.

Two Friendship and Aphasia Events were run, one at the Connect premises in London and one in a community hall in Northampton. A full programme for the days is presented in Appendix I (page 439). In summary, the days consisted of an introduction to the research project, and a series of small group activities to promote discussion of who participants identified as friends and how they considered their friendships to have changed post-onset of aphasia. These storytelling activities included group discussions stimulated by using the coloured stones and short video stories developed and presented by Research Group members. These materials are described more fully below (pages 211-212) and illustrated in Appendix I.

The aims of the Friendship and Aphasia Events as determined within Research Group meetings were for people with aphasia:

- To share experiences and stories of friendship
- To explore and discover issues relating to the changing dynamics of friendship
- To raise awareness about the importance of friendship
  (Research Group 11)

In developing the Friendship Events, we wanted to produce a 'product' which would be creative, lasting and relevant to people living with aphasia. The branches of the Forest of Friendship diagram generated in Phase 1 served as a useful starting point for developing a structure and materials, though this did not constrain the content of the Events. All materials and activities were designed to promote discussion based on responses to the Phase 1 themes, as a way to elicit new stories rather than as a method of imposing predetermined narratives.

### 8.1.1 Materials

Over a period of approximately 12 months the Research Group discussed and developed various activities and materials that we then shaped into a day-long programme. Decisions about who, what and how much to include were driven by the Event aims, the desire to keep the day inclusive and fun, and our previous experiences of facilitating and participating in peer-led events for people with aphasia in a variety of statutory and voluntary sector organisations. For example, we were conscious that the hard work involved in communicating suggested participants would want time to sit back and listen as well as time to engage interactively with peers. Unrushed time for supported storytelling and discussion placed limits on the number of video stories and activities. After a trial run, we abandoned earlier thoughts about running a poetry activity or creating a group story about friendship. In selecting stories to present on video, individuals with aphasia from the Research Group honed personal stories to present one or two salient points about what had changed or what was important to them rather than attempting to explain all aspects of their friendship experiences post-onset of aphasia. Editing decisions or selecting 'best fit' materials from several trial recordings were based on group feedback and collaborative discussion between myself and the person with aphasia who was creating and filming their story. Typically these decisions related to practical considerations about audio-visual quality of the material, filmed in one to one sessions after meetings or at a Research Group member's home, as well as perceived clarity of key messages.

A full set of materials created for the Friendship and Aphasia Event are illustrated in Appendix I. These included:

- A practical activity focused on selecting friendship networks using coloured stones and pebbles. This was introduced through a DVD recording of Melanie selecting and explaining her own circle of friends.
- Jeff's story – a DVD in which Jeff talks of experiences of losing former work-related friends and gaining new friends through his volunteer work and peer support activities.
- Sarah and Sandra's story – a DVD showing two long-standing friends, one with and one without aphasia, in conversation about their

friendship. They converse about the impact of Sarah's stroke on their relationship.

- Priya's story – a DVD in which Priya, talks about the impact of aphasia on her life, her ambitions and her relationships with friends.
- Sacred Monsters – a short extract of a professional dance sequence (Khan and Guillem, 2008), introduced by Binda, who draws analogies between dance and his own relationships with friends
- A takeaway pack including a booklet summarising the day's stories and activities, postcards with examples of poetry and artwork relating to friendship and aphasia, contact details for Research Group members and a link to the prototype project website.

During the development phase we invited and commissioned two individuals with aphasia, an artist (Sharon) and a poet (Chris) to develop materials representing experiences of friendship and aphasia. Both have previously worked with others with aphasia to explore experiences of life with aphasia through creative means. For example, Chris employs aphasia poetry to reframe thoughts and 'aphasia language errors'. She positions this as non-traditional and creative rather than deficit aligned (Chapter 1). These individuals came to two Research Group meetings where we discussed the major emergent themes from Phase 1, the Forest of Friendship diagram and our summary discussions and ambitions for the Friendship and Aphasia Events. Both artists subsequently produced and presented back to us a series of paintings and poems that illustrated their own impression of the different themes from our model of friendship (Appendix J). We displayed Sharon's original paintings and Chris's poems on both days and selected examples of the poetry and artwork to include in the takeaway pack and postcards.

### 8.1.2 Process: Communication access and the Friendship Events

The Event was planned in such a way as to promote a relaxed, social setting in which participants with aphasia could reflect on experiences creatively and collaboratively. The aim was to imbue the events with a similar ethos to our Research Group meetings, ensuring that they promoted PAR principles of:

- Equal and democratic participation

- Collaborative reflection
- Acknowledgment and valuing of difference
  (Koch and Kralik, 2006)

In line with principles of good communication access (Parr et al, 2008; Swinburn et al, 2007), the Research Group addressed how communication might be supported before, during and after the day by attending to:

- Environment
- Documents and materials
- Interactions

A full summary of how the group ensured all aspects of the day were communicatively accessible is provided in Table 8.1.

**Table 8.1. Features of communication access employed at the Friendship Events**

| Environment | 'Documents'/materials | Interactions |
|---|---|---|
| • Relaxed, friendly environment – all facilitators briefed to welcome participants<br>• Spacious environment with forethought to room layout and who sits where, e.g. sufficient space to include but separate relatives from people with aphasia<br>• Accessible and fully visible slides to introduce activities/sessions<br>• Flipcharts well positioned to support key word writing and | • Accessible invitation and confirmation letter<br>• Accessible agenda<br>• Accessible evaluation form<br>• Accessible power point presentation<br>• Short, edited DVD stories narrated by people with aphasia<br>• Pre prepared communication props at each table including:<br>➢ Summary of video stories in photos and key words to support memory and language<br>➢ Visual analogue scales<br>➢ Visual Yes/ No props | • Ground rules relating to listening and turn taking<br>• Additional time to think and respond<br>• Trained communication supporters (without aphasia) at each table, e.g. writing key words and drawing to facilitate comprehension & expression<br>• Story teller with aphasia (from Research Group) at each table<br>• Modelling of |

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| summaries | ➤ Workshop questions | questioning and |
|---|---|---|
| • Pen and paper at all tables | ➤ Bag of stones per table | communication by Research Group members |
| • Ample breaks and refreshments – spreading the event over a whole day | | • Use of gesture, drawing, personal communication props |

In preparation for the day, we discussed a range of 'What If' scenarios and problem-solved how to deal with these, for example, how to respond to participants who became distressed or were struggling, for any reason, to participate. We also developed a full set of briefing notes for the supporters without aphasia who were recruited to support each of the days. These briefing notes are included in Appendix I and cover how to support a welcoming, friendly atmosphere, communication support strategies and how to handle data collection and feedback on the days.

### 8.1.3   Recruitment

Ethical approval was granted from Brunel Research Ethics Committee in November 2011 for Phase 2 recruitment and data collection. Similar ethical issues to those arising in Phase 1 data collection such as safeguarding of vulnerable adults and consent to use visual and audio material were addressed.

Inclusion criteria for Phase 2 participants were similar to Phase 1 namely:
- ❑ Self reported evidence of aphasia
- ❑ Under 65 years of age
- ❑ Ability to participate in a whole day event
- ❑ Ability to travel to and from the event venue

Exclusion criteria were:
- ❑ People with severe receptive and/or cognitive difficulties who were unable to participate in group activity and evaluation interviews.
- ❑ People unable to travel to the venue or manage personal care activities (independently or with their own carer) during the full day events

As in Phase 1 of the project the Research Group reviewed inclusion criteria and those Research Group members active in support groups developed a list of potential individuals to invite to the days. As in Phase 1, we used a purposive sampling framework to cover inclusion of a mix of participants of different age, gender, severity of aphasia and time post stroke.

One Research Group member from London and one from Northampton volunteered to approach individuals from the groups with a flyer, giving brief information about the Events and their timing / location. If interested, individuals were given an information sheet explaining more about the project and the Friendship and Aphasia Events (Appendix F). I then met or telephoned interested individuals to discuss the written information and provide further detail about the Events and follow up interviews. People who wished to participate in Phase 2 of the project were given an accessible consent form to complete and return in a stamped addressed envelope.

We explained to those who consented to participate in the Events that they could decide whether they wished to attend the follow up one-to-one interview after participation in the Events. People who were interested but not able to participate in the Events were given general information about the project and directed to the project website.

We anticipated recruiting 12-15 people per site to allow for last minute cancellations and illness. The days were not marketed at relatives and friends without aphasia as we decided that the days should give full scope and 'airtime' to people with aphasia to voice their own experiences of friendship. We were concerned that the presence of current friends and relatives might inhibit full and open discussion of any difficult changes and negative experiences. We feared that these dialogues might surface discomforting opinions and behaviours, e.g. expressions of pity or examples of maintaining friendships through guilt, which the day would not have time to address. However, given our previous experience that some relatives/ partners are reluctant to leave their partner/friend with aphasia, we developed a version of

the information and consent sheets for relatives and friends who might remain through the Event. On each day we briefed a helper, who, if required, could facilitate a group of relatives/friends positioned apart from individuals with aphasia.

### 8.1.4   Participants

Fourteen individuals with aphasia were recruited for the London event. Nine of these 14 attended the event. Reasons for non-attendance were:

- urgent hospital appointment
- seizure two days earlier
- benefits assessment
- forgot  (two people)

All nine people who attended the event agreed to participate in a follow-up semi-structured interview.

Eleven individuals with aphasia were recruited for the Northampton event, with ten attending on the day. One person was unable to attend due to illness. Two participants declined to take part in follow-up interviews. One participant attended who had been interviewed in the first wave of interviews so was not re-interviewed. Seven people agreed to take part in follow up interviews.

One person attended the event in Northampton with his wife. The wife and son of a Research Group member also attended the day in Northampton to provide support with catering and refreshments. One helper at the day did not have aphasia but had personal experience of stroke. These four individuals without aphasia but with personal experience of the impacts of stroke sat together on a small table, set slightly back from the other participants during activities in Northampton.

A full list of participants attending the Friendship and Aphasia Events are given in tables 8.2 and 8.3 (page 218). Biographies of all individuals interviewed in Phase 2 are included in Appendix D.

### 8.1.5   Roles of Research Group members

In preparation for running the Friendship Events we identified a list of roles and functions that individual Research Group members volunteered to fulfil. For example, Barbara volunteered to introduce both days and set up the warm-up activity. Melanie, having prepared a demonstration video, used this to introduce the stones activity and lead feedback from the large group as to whom participants in the Events chose as friends. Jeff, Sarah and Priya (or fellow Research Group members with aphasia if they were not present) introduced their DVD story segments and the ensuing workshop questions relating to important issues in friendship and perceived changes post stroke. Research Group members with aphasia also acted as welcomers at the beginning of the day and positioned themselves at tables to participate as storytellers and questioners in small group discussions.

My designated role during the Events was to operate as a member of the support team and co-ordinate data collection. For example, I helped with room set up, positioning and checking audio-visual equipment, attending to aspects of health and safety and ensuring the general comfort of participants. I also took a lead role in briefing helpers without aphasia while other Research Group members welcomed event participants. During large group sessions I acted as flipchart scribe while Research Group members with aphasia led and facilitated feedback. During small group sessions I acted largely as an observer, staying removed from discussions at the small group tables but on occasion offering additional information or communication support as requested at individual tables.

**Table 8.2          Participants at the Northampton Event**

| Participant | M/F | Work pre stroke | Age | Time post onset of aphasia (years) | Living arrangements | Level of aphasia Boston severity scale/ Self-rating |
|---|---|---|---|---|---|---|
| Karen | F | Admin clerk | 28 | 1.5 | Lives alone. Newly converted flat | Severe/mild |
| Chris | M | Postman | 45 | 1.8 | Lives with wife | Severe/severe |
| Derek | M | Soldier | 52 | 2.11 | Lives alone Separated from wife | Mild/mild |
| Ron | M | Service fitter | 65 | 2.9 | Lives alone | Mild/moderate |
| John | M | IT manager | 61 | 1.4 | Lives with wife and adult daughter | Severe/severe |
| Terry | M | Salesman | 49 | 13 | Lives alone Divorced after stroke | Moderate/ moderate |
| Gary | M | Delivery Driver | 35 | 1.8 | Lives alone | Moderate/mild |
| David | M | IT project manager | 56 | 4 | Lives with wife (married since stroke) | Moderate/mild |
| P9 | M | Attended Event, declined interview | | | | |
| P10 | M | Attended Event, declined interview. Not aphasic | | | | |
| Also attended: 3 x relatives; 4 x helpers; 5 x Research Group members: Melanie, Barbara, Jeff, Binda, Carole | | | | | | |

**Table 8.3          Participants at the London Event**

| Participant | M/F | Work pre stroke | Age | Time post onset of aphasia (years) | Living arrangements | Level of aphasia Boston severity scale/ Self-rating |
|---|---|---|---|---|---|---|
| Joan | F | Car manager | 52 | 3.6 | Lives with husband | Mild/mild |
| Anthea | F | Nurse | 56 | 11 | Lives in residential care home | Mild/mild |
| Frank | M | Hospital porter/ roadie | 57 | 3.11 | Lives alone | Mild/mild |
| Shana | F | Secretary | 40 | 9.8 | Lives alone | Severe/severe |

| Richard | M | Musician | 68 | 6 | Lives with wife | Severe/ moderate |
|---|---|---|---|---|---|---|
| Sonya | F | Hair-dresser | 47 | 10 | Lives with daughter & grandson | Severe/mild |
| Trisha | F | Mechanic | 39 | 2.7 | Lives with boyfriend | Mild/moderate |
| Cherry | F | Charity worker | 41 | 1.10 | Lives with husband and 2 young children | Severe/mild |
| Martin | M | Travel agent | 48 | 1.5 | Lives with wife and family | Moderate/ moderate |
| Also attended: 3 x helpers; 6 x Research Group members: Priya, Binda, Tom, Barbara, Melanie, Carole ||||||||

### 8.1.6   Data collection

Consent forms covered data collection from both the Events and the follow-up semi-structured interviews (Appendix F). Participants were asked for permission to use audio and video recordings as well as photographs to support post-Event discussions and interviews. Consent to collect and use visual material was revisited at the Event and in interviews as part of a process of on-going consent (Dewing, 2007).

At the Friendship Events, following a further check for consent, a digital recorder was located on each of the small group tables and the Research Group member or communication supporter present on the table switched this on or off to record conversations at each table. I set up a fixed freestanding camcorder on each day to record from the front of the room an overview of the Event. Communication supporters took photos of room layout, small group combinations and individual participants' selections of friendship stones.

I collected, wrote up and stored all artefacts created during the days, e.g. flipchart notes, drawings and diagrams co-created at individual tables, words, quotations and stories noted down by helpers at individual tables or on a 'Thought Board' located on a flipchart positioned to the side of each room.

Other data captured as part of the informal evaluation of the events included:

- Accessible feedback forms completed by participants at the end of the day
- Feedback notes and emails from helpers without aphasia describing their perceptions of facilitating and participating in the day and the process of facilitating the day
- Audio-recorded debriefing sessions at the end of each day with Research Group members and non-aphasic helpers.

Rationale for collecting this pool of data was to:
- Generate examples and memories which might prove useful in facilitating discussion in one to one interviews
- Capture immediate responses and reactions to the process of running events which might be useful for future events
- Record visually and verbally examples of people, stories, responses to activities which might prove helpful in Research Group reflection sessions.

Data relating to the Friendship Events was also captured in fieldnotes made during the day and in my journal entries. Collection and recording of a wide range of data employing flexible methods is consistent with methods employed in PAR inquiries (Koch and Kralik, 2006; McIntyre, 2008).

### 8.1.7   Data analysis

Analysis of data from the Events was iterative, cyclical and pragmatic. It enabled us to ask questions about what experiences were shared and different, discuss how materials and resources may have contributed to building awareness and actions, and deliberate on possibilities for dissemination (McIntyre, 2008; Stringer, 2007).

The main research purpose of the data generated at the Friendship Events was to inform the next wave of interviews and inform and support Research Group conversations as we continued to discuss our evolving model of friendship. A second purpose of analysis was to begin evaluation of the Events from the perspective of participants, helpers and Research Group

members. The aim of the full evaluation (incorporating data from the semi-structured interviews and Research Group reflection) was to inform actions relating to future Friendship and Aphasia Events and potentially to inform dissemination plans.

I listened to audio-recordings from each of the days repeatedly to produce an overall record of the day and a summary of issues covered at each table. This was supplemented with information collected in the debriefing sessions at the end of each day and artefacts such as photos, drawings and key words co-constructed between participants and their communication supporters.  I then produced a list of general issues, which had been shared in the large group and a list of individually salient issues, which specific people had raised as important to them. Examples are given in Appendix H. For example, lists generated on flipcharts in full group discussion related to identities of friends, examples of friendship changes post-aphasia and opinions on what participants felt was important about friendship.  The use of these materials is described in more detail below under methods employed within semi-structured interviews.

Following reflection in the Research Group on material generated in group discussions and flip charts we decided to add anonymised summaries of issues raised and discussed to the project website. This was to enable participants and relevant others to have ready access to ideas generated at the Events  (Friendship and Aphasia, 2013).

Evaluation material relating to the content and process of the days was reviewed systematically. Six participants in Northampton and eight participants in London completed feedback forms. All written comments were documented though these were minimal given the writing difficulties experienced by most participants. Evaluation of different activities was generally via a simple tick or cross against a visual reminder of the content of the session. Some participants completed forms independently, however helpers without aphasia supported some participants to complete feedback forms. It was decided beforehand that these forms would not form part of the analysis for this project

owing to the range of methodological questions about how the presence of the communication supporter may or may not have influenced views expressed, and the thinness of the written data. Examples are provided in Appendix K.

Analysis of debriefing sessions and materials with Research Group members and helpers focused on three broad questions:

- How well did the Event achieve its stated aims?
- What aspects of the process worked well or not so well?
- What was the learning for you from the day?

This body of descriptive material was reviewed, summarised and brought to the Research Group for further discussion (Research Group 18).

## 8.2     The Phase 2 interviews

### 8.2.1   Participants

Participants who took part in Phase 2 interviews attended the whole day Friendship Events in either London or Northampton (tables 8.2 and 8.3, page 218). As in Phase 1, we were reluctant to subject participants to language testing.  However we again asked participants to self-rate their perceived level of aphasia on a visual analogue scale (Swinburn and Byng, 2006) and, after each interview, I rated participants on the severity scale of the Boston Diagnostic Aphasia Examination (Goodglass et al, 2001). The 1-5 score on the visual analogue scale and the 0 (no usable speech)-5 (minimal discernible difficulties) scale on the aphasia severity scale gave an indication of whether individuals were rated or self-rated as having mild, moderate or severe aphasia.

### 8.2.2   Data collection

In total 16 people participated in semi-structured interviews. Semi-structured interviews were chosen as they allow for maximum flexibility whilst also gathering data on similar issues across a range of respondents (Holloway and Wheeler, 2010).

Aims of the Phase 2 interviews were:

- To probe individual perceptions of the Friendship Events and any actions or reflections resulting from participation in the events
- To elicit and elaborate in a confidential, communicative space individual experiences of friendship, which were convergent with or divergent from the stories of friendship show-cased on the days.
- To document advice or insights regarding personal approaches and strategies perceived as useful in maintaining and/or developing friendships in the context of aphasia.

Prior to conducting interviews, I assembled relevant artefacts from the Friendship Events to act both as props to support participants' memory and communication, and tools to help me explore their perceptions. These props and tools included:

- photographs of participants at the small tables with their selection of stones taken on the day
- typed flipchart summaries of issues raised on the day
- the takeaway booklet and postcards
- accessible summaries of video stories
- accessible feedback forms used on the day
- quotes and stories from the small group discussion generated through repeatedly listening to audio recordings created at each of the workshop tables and revisiting fieldnotes and reflections on the days.

A topic guide acted as an aide-memoire during interviews (Appendix G). This covered four broad topic areas:

- General responses to the Friendship Events including any memorable people, stories or activities
- Personal experiences of friendship and friendship changes post-onset of aphasia
- New thoughts or insights about friendship since participating in the day
- Any advice to others about friendship in the context of aphasia.

After reiterating the purpose of the research interview and easing into the interview by checking basic demographic details, I asked respondents to reflect on the Friendship and Aphasia day and highlight any issues or stories

which struck them as memorable, interesting or relevant. As in Phase 1 interviews, exploratory questions covered experiences, feelings and knowledge (Patton, 2002; Holloway and Wheeler, 2010). For example, I asked questions and used probes such as:

- What were your experiences of friendships after stroke and aphasia?
- How did you feel when your friend did that?
- What do you think others (friends, family, health care providers) could do to help?

There was no pre-determined order to questions. Because most participants had limited unprompted recall of the detail of the Friendship Events or had marked expressive language difficulties, many of the interviews took a chronological approach to reviewing the day. For example, after some open-ended general questions I would probe participants' perceptions of the day section by section. This process was facilitated by working through the takeaway booklet (which summarised the different sections of the day) and some of the key themes presented in the video stories. For example, as interviewer, I would summarise one of the video stories (using photos, key words and diagrams where appropriate), ask for participants' reactions to the story/discussion and probe if the person's own friendship experiences had any particular resonances with or differences from the video presenter's story. If the interviewee had difficulty expressing concepts or recalling discussion points from the day I would present stories and issues raised by the other participants at the day using probes such as 'Some people on the day said...is that similar/different for you?' (See Phase 2 transcript, Appendix P). Therefore this set of interviews, whilst semi-structured, was more structured than the in-depth interviews of Phase 1.

Interviews took place within two weeks of attending the Friendship and Aphasia Event. They were conducted at a location of participants' choice, either at home (eight interviews) or in a quiet room at a convenient venue such as Connect or Different Strokes (eight interviews). One interview was conducted in the presence of the participant's personal assistant and best friend. The participant had requested this as his friend routinely acted as an

interpreter/communication supporter in a range of interactions. One interviewee with very severe aphasia requested that his wife join us at the end of his interview to help fill in certain information gaps. In both cases these contributions were also transcribed. In each case I was careful to distinguish the views of the person with aphasia from those of their relative/friend. In summary, fifteen individuals were interviewed alone and one in the presence of his friend / personal assistant.

All one-to-one interviews were audio recorded and transcribed verbatim, employing the same transcription conventions employed in Phase 1 (Appendix O). Interviews lasted approximately one hour (range 47-73 minutes).

### 8.2.3   Data analysis

As noted, analysis of Phase 2 interviews aimed to address the research questions:

- How do working-age adults with aphasia experience and make sense of friendship after stroke?

- How do working-age adults with aphasia sustain and develop friendships after stroke and aphasia?

- How do working-age adults with aphasia respond to peer-led Friendship and Aphasia Events?

As in Phase 1, data were analysed drawing on principles of thematic analysis (Braun and Clarke, 2006; Boyatzis, 1998).  However, this time the analysis and discussion of units of data took place in a back and forth process with the Research Group. This resembled more closely the process of collaborative interpreting and analysing described by exponents of participatory research (Stringer, 2007; McIntyre, 2008; Koch and Kralik, 2006).

Analysis of the Phase 2 interviews began with familiarisation with the data through repeated listening to the audio recordings and multiple readings of transcripts. I reviewed the transcripts one-by-one, creating notes and analytic memos in the margins. I then reviewed the transcripts one-by-one for preliminary categories in relation to the three key research questions.

Driven both by limitations of time and a desire to bring data back to the whole Research Group as quickly as possible I took the decision not to code these transcripts line by line. Research Group members with aphasia had suggested that we review together whether the experiences of this second wave of participants confirmed or disconfirmed themes and patterns represented by version one of the Forest of Friendship diagram. I therefore reviewed the interviews specifically looking for responses that were new, or surprising, or which raised questions about our previous descriptions of themes and subthemes. I brought these patterns and illustrative stories to Research Group meetings where we debated meanings, and their fit or discrepancy with the Forest of Friendship thematic map developed in Phase 1.

Miles and Huberman (1994) suggest that where researchers have established a clear conceptual framework, where research questions are clearer and where research is interested in cross case comparisons, that it may be possible to carry out analysis which is both 'quick and clean' and trustworthy (Miles and Huberman, 1994:84**).** Shortcomings of this method of analysis include drawing conclusions too early or limiting data to pre-determined themes potentially leading to tunnel vision. Miles and Huberman (1984) advise that these potential pitfalls can be limited by sampling data from a wide range of informants, using data from different settings and by sceptically reviewing the data with colleagues. Our own process of sceptical review and triangulation drew predominantly on an iterative series of Research Group discussions (documented in Research Group meeting notes 18-20) where we interrogated and discussed new insights from interviews, and where group members with aphasia sought to clarify or counter respondent data (from Phase 2) with their own personal experiences and insights. Review of interview material against other sources of data such as fieldnotes, transcripts and recollections from the Friendship Events and reflective journaling also gave rigour to the analysis.

This process led to our exploration of several new patterns of data that had not been strongly apparent in the Phase 1 interviews. We also reflected critically on the role of the Forest of Friendship diagram in supporting data

analysis, and the diagram evolved further in the light of this second wave of interview findings. The synthesising of new data with these Research Group discussions and the (re)naming and (re)positioning of themes and concepts within the Forest of Friendship mindmap created the rich 'braided process of exploration, reflection, and action' (McIntyre, 2008:5) which is a recognised hallmark of PAR projects.

Data analysis of the Phase 2 interviews also facilitated further evaluation of Event participants' responses to the materials and activities employed in the Friendship Events. Analysis of this information was considered important to amplify findings from the evaluation sheets and inform our understandings of how different activities and materials had supported the aims and outcomes of the storytelling days. We considered that this evaluation data might be particularly relevant to revising the programme and materials for future learning events. I reviewed individual transcripts one by one for responses relating to evaluations of the event and its processes and initially grouped responses under the different sections of the day. Subsequent scrutiny of the data highlighted participants' reflections on what aspects of the days had prompted new thoughts or actions relating to friendship and, where applicable, their perceptions of how any transformations had come about.

## 8.3    Summary

Phase 2 methods generated data in two full-day Friendship Events and a series of 16 semi-structured interviews with participants at the days. Artefacts developed as part of the Events and in the process of running them provided additional data alongside fieldnotes and reflective journaling. Data were analysed and synthesised through a combination of broad thematic analysis in relation to the research questions and reflective, iterative exploration of stories generated in the Events and interviews with the Research Group.

# Chapter 9

# Phase 2 Findings: Exploring and Sustaining Friendship

## 9.0    Introduction

This chapter reports on findings from the two Friendship and Aphasia Events and the 16 semi-structured interviews conducted in Phase 2. These aimed to elaborate meanings from Phase 1 and addressed the overarching research question:

> How do working-age adults with aphasia define, experience and understand friendship and aphasia?

Phase 2 findings explored convergence and divergence from the experiences and understandings developed in Phase 1 and that were summarised in the original 'Forest of Friendship' diagram (Figure 7.2, page 208).  This chapter describes the elaborations and additions that culminated in the revised diagram, presented at the end of this chapter. Because the Research Group discussions were so instrumental in shaping this final model, this chapter also includes data from Research Group meetings.

Phase 2 also had a set of research objectives with an orientation towards action and practice as well as participative theorising about friendship and aphasia. For example, the Research Group wanted to probe:

> How working-age adults with aphasia responded to the peer-led Friendship and Aphasia Events?

> How working-age adults with aphasia sustained and developed friendships post-aphasia?

These issues are woven through this set of findings. An evaluation of the Events from the perspective of the full range of participants who attended the day (participants with aphasia, Research Group members, helpers without aphasia) is provided in Appendix K to allow more space for presentation of different participants' views. Some aspects of the Event evaluation, which are particularly relevant to the discussion of participatory processes involved in doing PAR with people with aphasia, are also developed in Chapter 10.

**Table 9.1** **Summary of key differences between themes reported in Phase 1 and Phase 2**

| Theme heading | Summary of themes from Phase 1 | Phase 2 Changes |
|---|---|---|
| 1. My friends are 'my anchors' | Perceptions of friends who perform a grounding, anchoring role in this period of exile, by exhibiting loyalty, constancy and a firm belief in their friends. | **Elaboration**: More detail on friends having faith and belief in you when you have aphasia<br>Cross-over between friendship and family, ex-partners, friends |
| 2. Communication is only one dimension of friendship | Impacts of language loss and changes in communication as they impact on friendships.<br>Aspects of friendship that are less related to communication or transcend it. | **Elaboration**: More evidence of limited use of communication access by friends and absence of support for friends on adapting communication |
| 3. Friendship is 'really, really hard work' | Struggles and effort required to maintain and develop friendships in the context of physical and communication disabilities, emotional responses to aphasia, and unpredictable reactions of others | Reiterates all major points from Phase 1 |
| 4. 'More than me': friendship is two-way | Experiences of imbalances in power and the social exchanges of friendship. Importance of acts of reciprocity and altruism. | **Elaboration**: Reviews reciprocity alongside an important early focus on the 'me, me, me' of early rehabilitation. Contains elaborated discussion of making a contribution. |
| 5. Constantly changing (Time, time, time) | Friends fading in and out as some friends are lost and some are gained. Perceptions of falling behind and also constant changes due to recovery over time | **New:** Reshaped with a more explicit focus on time. Situates friendship within passage of time and the life-course. |
| 6. Friendship and identity | Impact of aphasia on perceptions of self and identity.<br>Impact of identities imposed by families and the creative space of peer support to help affirm and reconfigure identity | **Elaboration:** Theme expanded to include more discussion of peer support and reconfiguring of identity |
| 7. Humour and hanging out | Ways participants used humour<br>Descriptions of enjoying companionable 'being' with friends and pets | New theme |
| 8. Doing friendship differently | Ways friends with and without aphasia adapted creatively to the challenges of maintaining friendships in the context of aphasia | New theme |

**9.1     Experiencing and sustaining friendship: themes from Phase 2**

Table 9.1 summarises the key similarities and differences between the dominant themes from Phase 1 and Phase 2. This section describes these new elaborations and additions to the set of themes arising from the Phase 2 findings.

**1. My friends are 'my anchors'**

Phase 2 findings strongly corroborated earlier findings relating to participants' ease of identifying important friends and friendships characterised by loyalty, constancy, commitment and dependability. Sometimes these were friends of longstanding, who had been there 'through thick and thin' (Priya, line 820). Sometimes they were friendships developed more recently.

The theme of anchors and anchoring arose initially in the interview with Binda. During Phase 2 he elaborated on his understanding of the anchoring of friendship as a mutual, two-way process of listening:

> 'My friends are my anchors and I'm an anchor to my friends …a circuit …A large part of me is aphasia …I kind of don't budge …so my friends come to me if they want to, you know … kind of listening more '
> (Binda, Research Group 20)

In necessitating a slower rate of interaction, he perceived that aphasia conversations gave his friends the space to probe issues more deeply, revisiting, clarifying, progressing thinking on a topic that served mutual benefit.

As a way of introducing this dynamic, bi-directional process of friends anchoring and grounding each other he chose to represent what it meant to him in visual form in the Friendship Event. The clip of Akram Khan dancing with Sylvie Guillem (Khan and Gullem, 2008) begins with an awkward staccato dance as the two dancers clash and bump awkwardly into each other emotionally and physically. The final sequence however shows the two dancers moving harmoniously in a flowing synchronicity, each mirroring the others movements as they operate apparently from a single, rooted pair of legs.  Summarising the way, for him, relationships with good friends can also

withstand the bumpy, staccato dance of aphasia and move to a deeper level of connection Binda explained:

> 'Your relationship is ... friendships ... person er, people want a very great deal of patience … because erm ... erm the reality of ... of erm you know ... … in life is ... very erm … like er  … like er my language ... is very kind of …  sta- catto. And erm as long as you know it requires people … either both aphasia and not aphasia ... it requires you know ... steady looking and ... patience and trust ... in order to … he would get there, she would get there because you know they're ... worth listening to … absolutely. But staccato, staccato'
> (Preparation for Friendship Event, Oct 2011)

Although the dance sequence was the aspect of the Friendship Events that met with most mixed response, the presence of strong, anchoring friendships was powerfully demonstrated in Phase 2 interviews. This second set of interviews also highlighted a new layer of complexity where anchoring friends shared roles as family members, partners, and ex partners.

Three people who attended the Friendship Events identified an ex-partner as the central anchoring friend in their life. In Derek and Shana's case this was the only person they identified as a real friend.  Derek had his stroke the day after his ex-wife announced she was leaving him. Since his stroke he reported adopting a strategy of self-exclusion, choosing not to contact former friends in case they now treated him differently. Asked about important friends now he replied:

> Derek:  The only, the only, unfortunately for me, is the only one that *that* erm, applied to is my estranged wife who erm, who is actually quite erm marvellous in as much as she knows that I'm *different*, she has the *patience* to erm, yeah, erm, (..) but she's not afraid to kick my arse if I need it, you know.
>
> CP:  Yes, yes. So she's not treating you with kid gloves.
>
> Derek:  That's right, yeah. Yeah, yeah, yeah. So but you know, she's, she speaks on the phone every day to make sure everything

is okay. But erm, erm

CP:            [Would you class her as a friend?

Derek:    Hhhh I, that, that, I, [*sighs*], she [*laughs*], she's probably the

best (…) Yeah, definitely, yeah.

(Derek, line 949)

Shana was the only person who became visibly upset during the Friendship Events. Selecting stones to represent her friends, she chose not to represent peers with aphasia or holiday friends in her circle. She selected a solitary stone to represent Danny, her partner at the time of the stroke.

Shana:    And then Danny and I, erm, (…) you know,

boyfriend and girlfriend, you know,

CP:            [mmm

Shana:    and then *no speech* at all. But he can, you know,

Danny knows inside out what I'm saying.

CP        Almost like (…)

Shana:            [*imitates soundtrack of X Files/paranormal*] The *vi:be*!

[*both laugh*]

CP:        So he's like telepathic.

Shana:    Yeah.

(Shana, line 297)

Danny now lived in the flat above her and continued to help out, for example booking holidays, or attending Accident and Emergency on occasions where she fell.

CP:        Right. So he sounds like he's kind of worried (…)

Shana:    Worried about me.

CP:        Yeah, worried about you, yeah, yeah.

And has that made your friendship different with him?

Shana:    Erm, yeah, because there's stroke, you know.

Erm, (…) *protects* me.

CP:        Right.

Shana:    But (…)

> CP:       Is that okay, or not okay?
>
> Shana:   Not really! I'm, (…) [*sits up, raises fist, looks determined*]
>
> CP:       You're sitting up like (…) Erm, you're a tough, feisty (…)
>
> Shana:   Yeah.
>
> CP:       Do you think he over, *over* protects you?
>
> Shana:   *Mothers* me.
>
> CP:       Mothers you.
>
> Shana:   Sometimes but so Danny is (..) fine really, you know.
>
> (Shana, line 359)

In this complex, ambivalent relationship Danny appeared to show the enduring commitment and protective behaviour more usually associated with family members. Shana described Danny as offering practical and emotional support and on-going affirmation of the person she was before the onset of aphasia as well as after. As well as 'mothering' however he was a loyal friend and ex-lover.  In many ways this enduring and ambivalent relationship echoed the complex suffusion of family, partner and friend roles described by others in both Phase 1 and 2 interviews. This was most notable where those that participants identified as their closest friends were also their partners and ex-partners.

**Friends and having faith**

A second aspect of the friends as 'anchors' theme that was significantly more prominent in Phase 2 interviews was the issue of good friends having faith in their friends who developed aphasia. Having faith in friends was associated with friends who believed in and reinforced a sense of competence for individuals with aphasia. Gary had introduced this storyline at the first Friendship Event.  He voiced his frustration that former friends made assumptions that he couldn't join in with certain activities with 'mates' because he wasn't up to it.

Friends who believed in the continued competence of the person with aphasia were contrasted by some to the perception of being 'written off' by "fair-

weather" friends. Anthea, for example, described the disappointing reaction of former nursing colleagues:

> 'But some people, erm, you know, the, they see that the, the, the stroke as erm, we are, (..) … … Let me see if I can find the word, the right word (3) isn't really em*barrassed* but because you have the stroke they think well, you're finished. Yeah'.
>
> (Anthea, line 373)

Here and elsewhere Anthea made reference to her perception that some friends considered her no longer capable of participating in shared pre-stroke activities such as partying, dancing and shopping.

Participants identified faith and belief in the possibility of recovery as an important feature of relationships with close friends. Ron, who lived alone, was another respondent whose closest friend was an ex-partner, now living with her husband. Ron described Julie as '110 per cent a good friend and all the rest.' (Ron, line 1488). He regarded her as a constant source of energy, confidence and forward momentum, her belief almost propelling him forward, both in the early days and now, almost three years later. He described her motivating talk and his perception of her as a constant 'force' behind his forward progress:

> Ron:     But it was 'you've got to get up' and 'it's up to you now' and (...) 'I will, erm, be, be with you as much as I can and you're going to get *over* this, you know'. That was the *force* to say that that word, you're just before. The force.
>
> CP:      The motivating.
>
> Ron:     Yeah, the motivating *force.* And certainly Julie was the main stay of what's, what it was all about.
>
> (Ron, line 1534)

The accounts of John, Richard and Chris, provided similar illustrations of a driving faith from partners as friends. All three had severe aphasia and all three had selected their spouse as their best and closest friend. A quiet respect for partners was reminiscent of the tone of Jack's interview in Phase

1, another participant with severe aphasia. Respondents described wives who, in contrast to therapy services, persisted in tireless pursuit of improvements in physical, communication and social wellbeing. Debating this issue in the Research Group, we discussed the danger that this powerful, unquestioning faith might mutate into unquestioning pursuit for restitution at all costs. In several of the interviews I probed whether there was a perception that the role of wife as pseudo-therapist might change relationships or create new tensions between partners as friends.

There was ample evidence in my interview with Chris that Tina, his wife, was a dynamic, motivating force. In the research interview between Chris and me, he had suggested Tina's new role as physical and social rehabilitation manager was not something he worried about. I asked Tina's view at the end of our interview:

| | |
|---|---|
| Tina: | But he again he's very motivated. And while he's motivated I'm going to push him. Because what (..) You get to the stage where if you don't put the effort in you won't get anything back. And we will never give up, will we. Never. |
| Chris: | No. Come on. |
| CP: | And is that, I mean, that must have had a kind of quite an impact on your relationship and your sort of friendship. Is (..) |
| Tina: | Erm, it's made our marriage stronger |
| Chris: | Yeah. |
| Tina: | I feel we're stronger together, aren't we? |
| Chris: | Yeah. |
| | (Chris and Tina, line 2447) |

I witnessed other relationships between individuals with severe aphasia and their partners where it would be easy to make assumptions about a (female) partner's rescuing concern and protectiveness. Richard had severe aphasia and significant mobility difficulties. He was also a tall man whilst his wife was petite. According to Richard and his wife Shirley, they had lost few friends since his stroke six years earlier. Although the effort of getting out was considerable, they continued to attend music events with friends. Not always

certain about access and, for example, how Richard might manage downstairs toilets, Shirley reported that she just trusted that if other friends were with them, they would be able to handle access situations or falls together. Richard described how his relationship with Shirley was not one of over-protection even though she was a formidable force. My tentative suggestions about her attributes are based on a brief meeting earlier.

CP: Yeah, yeah. So your relationship (…).

Richard: *Yeah.*

CP: (…) Is still good, is still (…)

Richard: *Yeah.* Yeah.

CP: It looks like it. She looks like she's very (…)

Richard: *Yes.* [*laughs*]

Hoo, hoo, hoo. Hoo, hoo, hoo.

[*mimes protective arm in front of face*]

CP: Scary? [*laughs*]

Richard: Yes.

CP: She looks very, she's very *practical* as well. [*writes 'practical'*]

Richard: *Yes, yes. Yes. Yes.*

CP: And sort of no-nonsense, (…) is that a fair (…)

Richard: Yeah.

CP: So she's, she, some people are erm, very (...) What's the word? Can be very worried and very emotional.

Richard: No. No. No. [*laughs*]

CP: Not Shirley, not Shirley.

Richard: Oh no. Oh. Pooh!

These new findings highlighted in more depth the way that good friends could be tough as well as kind. It also reiterated the complex blurring of boundaries between friends and family, particularly in relation to men and their partners.

## 2. Communication is only one dimension of friendship

Many of the challenges of managing friendships in the context of altered communication were reiterated in the Friendship Events and Phase 2

interviews. Shana, for example, perceived that difficulty moving beyond superficial social chit-chat had been a major barrier to developing conversations and developing relationships:

> CP     I was interested because you have quite a lot of other groups of friends or people (…)
>
> Shana:  Yes but ac*quaint*ances. I mean, because 'Hello', 'Hello'. 'Oh, how are you?', duhdeduh, 'I'm fine'. 'Okay, bye'. And that's it!  Not a phone call like 'Oh, did you know that' and *oooh*.
>
> CP:     Right. So you would call a friend is someone you'd have a phone call with?
>
> Shana:  Yeah
>
> CP:     A bit more in-depth kind of gossip and chat.
>
> Shana:  Yeah, yeah.
>
> (Shana line 172)

Other examples reinforced the importance of communication changes and challenges as one important dimension of friendship. Phase 2 findings also sharpened understandings of communication access and friendship.

**Communication access and friendship**

The data corroborated findings from Phase 1 suggesting that friends employed communication access techniques rather infrequently or not at all. For example, Sonya made frequent reference to her diary and a communication book full of dog-eared lists, personal artefacts and information. Asked whether her friends made use of the book or tried to support conversation with artefacts of their own, she indicated that few friends used her materials, or thought about bringing along their own:

> CP:     Erm, your friends then, Sonya, when you're with them, do they do these kind of things? [*points to communication book and diary*]
>
> Sonya:  No. (…) Just me.
>
> CP:     You're doing it?

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Sonya:  Yeah. Yeah. Because I'm saying it a little bit and then like it's not. Yeah. So.

CP:  Yeah. And they don't always think to bring things along or (…) Do they?

Sonya:  No.

CP:  Do they ever bring photos along?

Sonya:  No.

CP:  It's you who does it?

Sonya:  Yeah, a little bit, yeah.

(Sonya, line 1847)

Asked whether friends had received professional training or support in adapting their conversations all but two participants recalled no input at all for friends:

CP:  When you were having erm therapy and rehabilitation, did your friends and family get any help from the rehabilitation staff on what to do or how to communicate differently,  or how to keep your relationship going, strong?

Anthea:  [*laughs*] Not really. No, no, no, no.

(Anthea, line 700)

CP:  Out of interest when you were having erm, your hospital treatment or whatever, did anyone give you or your friends any support around relationships and maintaining relationships?

Derek:  *No.* No. No, nothing, nothing at all, no.

(Derek, Line 1540)

The perception of people with aphasia was that friends who had accommodated well to communication changes had done so naturally. Most often this entailed a simple technique of learning to 'shut up'. Gary recalled that this came naturally to his best friend Jack whom he had invited along to the interview.  Clicking his fingers he illustrated that Jack just knew what to do straight away.

Gary:    For time he come of, I, straightaway he [*points to Jack*] learned how to shut up.

CP:      Yeah, right, okay. So with Jack, straightaway yeah.

Gary:    He do, do the

CP:      Why do you (...) How do you think *he* does it, and maybe other people don't?

Gary:    Don't know.

CP:      So he wasn't taught how to do that, he just kind of got it?

Gary:    Yeah

CP:      Yeah.

Gary:    Good. Like. He knew. [*clicks fingers*] Erm.

         (Gary line 641)

Others like Ron took matters into their own hands. Here Ron describes how he coached his long-term friend Adam from the tennis club not to talk to him as if he was deaf:

Ron:     Yes, yes. That's right, that's the same, with *Adam* is the same, you know quite honestly (..) Just slow down a little bit and also erm, get the *volume* down for erm, you know. One of those things, as I say, my hearing is really very, very good.

CP:      What did he say? Did he start talking a bit [*imitates someone speaking loudly to deaf person*]

Ron:      [*laughs*] Yes, yes. It's getting the c- the cotton wools in the ears.

CP:      Right. So did you, did you tell him what to do?

Ron:     Yes. In the end I (...)

CP:      Turn it down a bit?

Ron:     Yes. The volume, yes.

         (Ron, line 656)

Friends and partners who contributed their perspectives at the Friendship Events, or on several occasions in informal interactions after the interviews, corroborated a lack of formal training. Instead they reported learning from stories and information from peers with aphasia, heeding family members who

offered reassuring insights into people's preserved competence, or from previous personal experiences of working alongside disabled people.

Within the Research Group we visited this issue several times as we reviewed findings and revised the model of friendship. Group members with aphasia endorsed the view that the use of supported conversation between service providers and people with aphasia using their services is crucial. The transaction of information, such as times of appointments, accessible letters from benefits offices, and accessible information about stroke were all deemed very important. But the issue of whether or not friends should be expected or encouraged to attend training courses was more contentious. A passing conversation with Richard's wife Shirley confirmed her view on the issue. She described quitting a research project aimed at training partners of people with aphasia to communicate. She disagreed with certain instructions from the research Speech and Language Therapist to alter her style of speech, perceiving that the techniques promoted an infantilising and unfamiliar pattern of interaction.  Individuals with experience of providing peer support pointed out that people with aphasia as friends cannot write key words, summarise conversations, recall names or generally employ supported conversation techniques. Yet in many cases strong friendships had sustained or developed between people without these techniques. So it appeared that communication access, as professionally defined, was not necessarily a pre-requisite for friendship.

Discussions in the Research Group on this topic also suggested that supported conversation techniques were not always a panacea for improving conversations between friends. The conclusion of these discussions centred on two inter-related issues:

- The importance of keeping conversation natural. Preservation of equality in interactions with friends was perceived by the Research Group as critical

- The need to be aware of issues of power and patronage implicit in the act of 'supporting' conversation. Within the Research Group we were unconvinced by evangelical calls (by therapists) for training programmes

for everyone including friends. Debra went a step further linking this to a way of keeping therapists in business.

> 'I don't erm like that word supporting conversation with friends … I like the word empathy, positive … Supported conversation it doesn't link up I feel … friendship is not like a medical terminology at all'
>
> 'Friends know all about you … so they do it in a better way'
>
> 'teaching people to do techniques … it smacks to me of jobs for the boys and girls'
>
> (Research Group 22)

In summary, Phase 2 findings reinforced the important role of communication in managing and maintaining friendships. However, the many examples of enduring connection and communion in the absence of formal communication partner training suggested that some friendships transcended strong reliance on verbal communication. This underlined the importance of considering communication access and communication support as just one dimension of friendship and just one branch of the model of friendship.

### 3. Friendship is really, really hard work

Phase 2 data confirmed the hard work of keeping friendships going in the context of aphasia and multiple stroke impairments and consequences. The many intersecting strands of hard work were also strongly present in Phase 2 data. Individuals described or illustrated, through their actions and interactions, the relentless, hard work of communicating (Shana, Richard, Sonya, Chris, John, Terry). Respondents also described the hard work of managing other conditions such as depression, fatigue and epilepsy (Karen, Derek, Martin, Chris), the stresses of low confidence (Derek, Ron, Frank), the unremitting challenge posed by infrastructural barriers such as transport, access to work and finances (Cherry, Gary, Ron, Karen, Frank) and the work of confronting perceptions of incompetence from family and friends (Shana, Gary, Anthea, Joan, Cherry).

Derek described the multiple dimensions of effort he experienced when considering whether or not to get in touch with old friends:

'Erm, because it's a *big effort* for somebody who's, who's, who's had a stroke or who has aphasia to, (…) .hhh to, sometimes can't (…)
Like Jeff struggles with his writing and that sort of desperately. I don't really, it's obviously been repaired. My numbers don't work. But, but it's a real *big effort* to, to be able to *contact* friends.'
(Derek, line 615)

Choice and effort on the part of others were also salient in these interviews. Joan reported that she was quick to dump friends and former work colleagues who made no effort to call. Chris and Tina, by contrast, reported losing none of their close friends. Tina articulated the added value she now attributed to these friendships. She recalled the willing, helpful input of their friends, firstly the practical support of lifts and fact finding in the dark days of Chris's surgery, then the efforts of friends to continue including them in social activities such as holidays and meals out. These were examples of much-valued friendships that lasted through long-term, two-way effort both on the part of friends and the person with aphasia.

**4. 'More than me': friendship is two-way**
In Phase 1, this theme explored perceptions of balance in friendships, the role of reciprocity and the importance, for some individuals, of making altruistic contribution to friendships. These issues surfaced in Phase 2 interviews also.

A balance of give and take in friendship within the context of clear support needs post-onset of aphasia, featured in the accounts of Richard, Chris and John, all of whom had severe aphasia. All expressed a worry about wives (regarded as best friends) not receiving adequate support. In this extract Richard demonstrates his concern, at feeling powerless to support his wife, Shirley, either practically or verbally:

CP:      So it's two-way?
Richard:  Erm. No, no. No. Erm, is nononono (…) [*mimes sitting back*]
CP**:**      Right, so you sit back a bit?
Richard:  **Yeah**. Sort of (…)

| CP: | Yeah. So is that [*points to 'two-way'*] something that's a bit hard for you? |
|---|---|
| Richard: | *Yeah*. So. |
| CP: | Some people said that they want to be able to *help* more. They want to *support* their partner. |
| Richard: | **Yeah**. Erm, [*imitates someone without speech*] |
| CP: | It's hard because of the speech? |
| Richard: | Yeah. Kuh ah - dah, Gee: ta, erm, gee:-, Sh: (...) She: d (…) Erm. Shi:d. Shuh: erm. Wa - Wa: der (…) Water. Yeah. |
| CP: | So it takes a long while? |
| Richard: | Yeah. Yeah. |
| CP**:** | A long while to find the words? |
| Richard: | *Yes. Oh. Yeah.* |
| CP**:** | Yeah, yeah. Okay.  Do you worry about Shirley? |
| Richard: | Oh *yeah.* |
| CP: | Hmm. |
| Richard: | Yes. Yes*.* |
| | (Richard, line 1268) |

Follow-up conversations with two of these partners/friends suggested that they assumed new roles readily and without self-pity. However, Richards's wife (discussed above) commented on the huge impact of being made a cup of tea by her husband, the first in six years since his stroke, suggesting that small acts of reciprocal kindness were not to be taken for granted.

Several respondents talked about strong two-way expectations of support within their close friendships. Gary and Jack demonstrated this in the interview with Gary. Friends since college, both spoke of a friendship deepened by Gary's stroke. Gary described feeling more secure now about expectations of reciprocal support:

| Gary: | Gary: For example, Jack, if anything happened to me, I know he'll be there for me. Same me back. Hmm. |
|---|---|

> CP:     Right, right. So he'd be there for you and you'd be there for
>         him.
>
> Gary:   Yeah. Same. Helping.
>
>         (Gary, line 1374)

Anthea, however provided a warning that expectations of reciprocal support don't always translate when put to the test. She expressed disappointment in her former partner / best friend who, unable to cope with her disabilities, left her shortly after the onset of her aphasia:

> 'But what I can't understand with him is that if I, if it was the other way
> round I would be there for him *anyway.'*
>
> (Anthea, line 874)

A different reflection on the salience of thinking about others was raised by Cherry, who had worked for a charity prior to her stroke. Discussing her response to the video presentation where Priya shared her revelation that 'the world doesn't revolve around me', Cherry responded with a complex mime. Almost two years into her rehabilitation, Cherry indicated that a day-to-day concentration on the basics of walking, talking and maintaining her role as mother to her two young boys meant that a focus on herself was currently a more pressing priority than thinking about other people:

> CP:     And the other thing she talked about, remember she said,
>
>         'and suddenly I realised that the world doesn't revolve
>         around *me*'.
>
> Cherry: (2) Yeah. Erm. (4) Yeah. [*looks unsure*]
>
> CP:     Not quite sure what she meant by that, were you. You're
>         looking a bit puzzled.
>
> Cherry: Erm. [*clears throat*]. Me, yeah, but erm.
>
> CP:     For you (…)
>
> Cherry: Erm. (5) Me [*laughs*] walking up the street [*mimes walking
>         with difficulty*] Me [*laughs*] (…)
>
> CP:     Yeah, so walking slowly with your stick.
>
> Cherry: Yeah. And erm (…) all around pff, yeah. [*laughs*] [*Mimes*

> *sequence of walking, working, thinking, frequent pointing to self*]

Cherry: Very slowly. [*laughs*]

CP: Yeah. So are you saying that you don't kind of identify so much with that? Or are you saying that, from your, your lovely mime that you just did, you're having to think a lot about walking and you kind of have to, there's a lot that you have to concentrate on. [*Cherry says 'yeah' throughout*] So it's quite *hard* to think of other people almost.

Cherry: Yeah, yeah.

> (Cherry, line 1458)

Reflecting on this issue in the Research Group, Jeff referred to the natural and essential focus on self in the early months and years. He also asserted that for those who remain trapped at home, it can be difficult to escape from the 'me, me, me' focus. Opportunities to grow new friendships, for example at support groups, might provide a context and an impetus to move beyond the 'me, me, me'.

> 'Some people … me, me, me … very early the stroke maybe it's no problem … I don't know how many weeks or years but ... … well example, the meeting. It's obviously the friendship. At home it's the me, me, me.' (Jeff, Research Group 20)

Phase 2 data therefore affirmed the importance of timing and creating opportunities outside the family home as contexts to break out of the natural but heavily individualised focus of rehabilitation.

**Making a contribution**

The 'buzz of wellbeing' (Friendship Event 1) that making a contribution could provide was, in the opinion of Derek, underestimated by those concerned with rehabilitation. For him, making a contribution through chauffeuring friends with aphasia to and from support group meetings, or tending his chickens, gave him a powerful sense of competence and affirmation:

> 'It's a reason for me to carry on, to, to live, to, to give back or to give.

> Erm, yeah, rather than to receive. I, I get *so* much out of being able to help people. Erm. Erm. Lots of things I can't do anymore.
>
> So when I find something I *can* do and it makes, it makes somebody else happy or something else happy, you know, be it an animal, you know, it's, it's very important. It gives me a real buzz.'
>
> (Derek, line 1012)

Gary was another strong advocate of the healing powers of making a contribution. He talked of doing DIY jobs for friends both as a way to demonstrate his competence and as a way to build self-esteem.

> Gary: Helping, like helping people. I do it to help me, I let them know that, a bit work.
>
> CP**:** So helping other people can make you feel like you're helping yourself.
>
> Gary: True.
>
> (Gary, line 973)

Discussions at the Friendship Events and in the Research Group affirmed the important payback to confidence and self-belief through offering support to friends. This exchange between friends and fellow citizens for mutual benefit stood out in contrast to perceptions (both external and internalised) of the 'needy' disabled person or helpless stroke victim.

### 5. 'Time, time, time': temporal aspects of friendship

This reshaped and renamed theme reflected the importance that most Phase 2 interviewees gave to the issue of the time. This theme concerned the different dimensions of time which participants described as being important to the changing dynamics of their friendships.

When respondents were asked for suggestions that might support people with aphasia and/or their friends with friendship maintenance, the most commonly mentioned resource was time.

> Anthea: *time* yeah (…) But the, the thing with some people is that

> they're, they don't have the time to (…) Yeah. Yeah.
> (Anthea, line 928)

Cherry: Time. Yeah

CP**:** Time is very important for both of them.

Cherry: Yeah. Well, I - have - aphasia. Very slow, you know. Slowly, slowly (...)
(Cherry, line 1040)

CP:: any suggestions to help others
[*shows list of suggestions from Event and Shana points to 'time, time, time'*]

CP: So time, time, time.

Shana: *Yes, yes, yes, yes*!
(Shana, line 1744)

In the preliminary version of the diagram, this theme existed in a related but subtly different incarnation. Previously entitled 'Constantly changing: the friendship kaleidoscope', this earlier version focused on the fading in and out of friendships over time. In his video story, Jeff illustrated his experience of losing lots of work friends, then gaining many new friends through his volunteering roles. Although his vignettes prompted tales of changes in friendship over time, less than half of the participants at the Events identified strongly with the shrinking and growing numbers of friendships. Some members of the Research Group singled this out as the 'weakest theme' from the first version of the diagram (Research Group 18). As we reviewed the Phase 2 data, we refashioned the over-arching conceptualisation to have a sharper focus on time and different aspects of time. The revised theme concerns the interplay of time and friendship in the micro-moments of every day interactions, the unfolding course of recovery over time and the developmental course of friendships as life moves on.

**(a) The tempo of conversation: time and interaction:**

As noted previously, many participants suggested both friends and organisations lacked awareness of temporal barriers and the exclusionary impact of fast-paced conversation. Some respondents described tolerating these imbalances whilst others described adopting a strategy of taking an observer rather than participant role in conversations amongst friends.

Terry's narrative portrayed a constant undertone of frustration. Although friends were happy to make allowances for his effortful word searches, he experienced friends telling him to take his time, repeatedly, multiple times each day as both wearing and frustrating:

CP:     You said that that really 'gets your goat'.

Terry:  Yeah.

CP:     When people say (…)

Terry:  Take your time.

CP:     Yeah. So why, why does that 'get your goat'?

Terry:  Because I'm absolutely fed up with it.

Terry:  Fourteen years (…) 'take your time', 'take your time.' And I reckon it's twice per day, yeah.

CP:     Really. That people say it to you?

Terry:  Yeah. 'Take your time.' 'Slowly.'

        (Terry, line 850)

Temporal adjustments in interviews where participants sifted slowly through communication books, various personal artefacts and IPad applications demonstrated in situ the strain that altered communication could place on traditional temporal etiquette. My fieldnotes and reflective journal entries after interviews consistently returned to the issue of time and managing to stay patient and focused in the great lapses of silence as respondents opened, dropped, misplaced, became side-tracked by pieces of paper or went to fetch personal artefacts needed to piece together stories one slow step at a time.

Friends who learnt how to manage the altered tempo of interaction and 'hang in there' comfortably with the silence were much valued. Derek, for example,

contrasted the interruptions of well meaning 'helpers' with the qualitatively distinct communication space provided by knowing peers:

> 'I was trying to remember a name of something and he kept on second guessing me or trying to put words into my mouth
>
> and it just, it just frustrated me *so much* because it just so much
>
> cos I was almost there and I just, Ashok [volunteer], I want to say something! I got so *cross!* [*laughs*] So yes, so and I, I think I made a comment about him saying that she has to shut up and give people time. Erm, which I love about the group. Because I think that everybody who goes there they know it's a foregone con- (…) Yeah, some people struggle but nobody is in any rush, you know.'
>
> (Derek, line 747)

**(b) Time and recovery**

As in Phase 1, almost all participants remarked on changes in abilities, relationships and wellbeing over time. Most commented on the on-going nature of recovery, in some cases more than a decade after the onset of aphasia. Many participants recalled feeling better, doing more, recovering language and changes in confidence and self-esteem as factors that helped improve relationships.

Many individuals identified specific times and pivotal experiences, which they believed had served to re-kindle or even deepen friendships. Some respondents referred to fleeting moments of realisation, sometimes prompted by changing circumstances at home, sometimes by an observation, sometimes by a reflection on how life was or was not shaping up to expectations. For example, Joan reported the spur to reconnecting with the social world was escape from the boredom of her life alone at home:

> Joan:   After a bit about six to eight months I was terrible and that's when I thought to myself, get off your arse and get out back there.
>
> CP:   So for you that moment was after about six to eight months?
>
> Joan:   Yes. You've got to do something. Yeah.

> CP**:** Do you know what it was that made you, you know, after six to eight months suddenly think I've got to put a smile on my face and
>
> Joan: [I don't know why. Maybe I got fed up. (Joan, line 1425)

Richard perceived his recovery and social re-launch gained momentum when he regained his driving license, nine months after his stroke. Like Richard, many respondents made reference to critical moments in their recovery. Some used expressions such as 'suddenly I realised' or 'and then one day I thought…' to illustrate shifts in thinking or activity. Often, however, participants struggled to articulate clear rationales for why and how these shifts came about. In the Research Group, Priya represented her view that these pivotal experiences were not so much one-off moments but the beginning of a process of realisation:

> 'For me (…) the penny dropping was a trigger for me to slowly, slowly get back my friendships but it wasn't like a moment and the penny dropped (…) it's like a continuum, it's the start of hard work.'
>
> (Research Group 18).

**(c) 'It's only natural': Friendships and the life course**

The life-changing and life-long impact of stroke prompted many participants to reflect on friendship patterns at the onset of their aphasia and now, years later. Those who were in their twenties and thirties at the time of the stroke particularly reflected on comparisons to age peers and the challenge of recalibrating expectations and time scales.

Shana suggested that the distance between herself and her peer group from Australia was not just geographical but to do with different lives. Talking about why her many 'friends' did not make it into her friendship circle of stones she explained:

> Shana: Yeah, but *time difference*! And there's a life, you've got family and friends and (…)
>
> CP: So things that get in the way are partly that you can't get in touch with them during the day cos they're asleep.

Shana:   Yeah. [*both laugh*]

CP:       And also you said they've got a *life*?

Shana:   Yes

CP:       Say a bit more what you mean?

Shana:   Well, Jean and Shane are married with two children.
           It's, erm, you know, young ones.  So, the  (…)

CP:       So they're full on.

Shana:   Yeah.
           (Shana, line, 104)

Although several interviewees reported maintaining strong and close friendships with former colleagues, a natural fading of friendships formed at work prior to the stroke was also a common experience. Some participants reported regretting the evaporation of work-based friendships but accepted it as part of the natural attrition that occurs with losing a shared focus. Others, like Chris, reported that he was never particularly close to colleagues at work, so this was not experienced as a loss.

Many respondents similarly reflected on friendship changes within a broader context, not necessarily related to aphasia but as part of the natural ebb and flow of friends over the life course.

'Friends come and go, don't they, over that time.'
(Frank, line 355)

'No, having said that I'm only human. Yeah. Old friends erm, erm, we lose contact with and new friends because I'm human, yeah.'
(Terry, line 733)

Having children, divorce, family illness, redundancy and moving house on the part of friends or ripple effects on friendship, for example the illness and death of a friend's wife, were all described as having natural impacts on the availability and presence of old friends.

Others perceived newfound time as a resource to be cherished, as if enjoying retirement. Joan highlighted time as a new commodity that she perceived had enhanced her close friendships. She described how she was able to enjoy more regular, less stressed meeting time with her close circle of friends after she was medically retired:

> CP: And you had more *time*.
>
> Joan: Yeah.
>
> CP: So that kind of, I think you were saying before that that kind of helped you develop almost *nicer*, better relationships with these guys here like Teresa and (…)
>
> Joan: *Oh yes,* oh yes. Because b- before I from, (..) got stressed and narky, I used to see them (..) not very (..) Or maybe about a month. Tss. Because I'm, I was too naughty and all that. But now pfff, I'm three, four times a month. [l*aughs*]
>
> (Joan, line 894)

Time therefore could be both a barrier and a resource in friendship.


## 6. Friendship and identity

As in Phase 1, identity featured strongly in the narrative accounts of Phase 2 respondents. This second set of findings enriched understandings of identity in several ways. Firstly, the findings from the Events and semi-structured interviews suggested that aphasia raised awareness of identity. Secondly, this set of findings intensified the focus on family members and family-as-friends as facilitating or constraining identity re-construal. Thirdly, they re-emphasised in stronger terms the functions and mechanisms of peer support.


### Awareness

> 'Aphasia is a catalyst – it brings things to a head and forces you to think about identity' (Research Group 18)

For project participants and Research Group members with aphasia, thinking about aphasia and how others, including friends, perceived them, appeared to magnify issues of identity and friendship:

> 'So I have a problem with having, knowing, yeah, you, that erm, they erm h- how, how do *normal* people (…) I can't, I'm the *odd* one, how

do *normal* people view friendship sort of thing. I'm trying to work it all out.'

(Derek, line 330)

In a long exchange with Cherry where she revealed that she recognised a before-stroke and after-stroke identity, she indicated that reflecting on the Friendship and Aphasia Event, prompted her not so much to think about friends but to think about her own identity. In this extract, she describes that because her young children have carried on just the same since her stroke this has emphasised a sense of before-stroke and after-stroke identities for her:

| | |
|---|---|
| Cherry: | Yeah, yeah. But erm, Louie and Dom [her children] talking duhdeduh and (…) |
| CP: | So their life has just gone on sort of normally (...) |
| Cherry: | Yeah. |
| CP: | And you're thinking with you, there's two people. |
| Cherry: | Two people. |
| CP: | Yes, yeah. Yes. So it made you, the day, and coming on the day made you think about those (...) |
| Cherry: | Yeah. |
| CP: | Yourself as these two people. |
| Cherry: | Yeah, yeah. |
| CP: | Hmm. |
| Cherry: | [*laughs*] |

(Cherry, line 1974)

Identity for many respondents was not something that was fixed or clearly resolved. Accounts suggested it was fluid and constantly unfolding in response to internal shifts of self-realisation and external interactions with people and events. As Binda reflected, reconfiguring identity could feel like being inside a pinball machine:

'For me its kind of … like a kind of pinball machine cos you know like dodging and diving … work, … disability … you are in constant

dialogue with world, friends … I reconfigured my identity and I'm reconfiguring my identity all the time.'

(Research Group 20)

**Family members and identity**

As noted in the task of identifying friends, it was apparent in the selection of friends that some family relationships and partnerships fused into friendships. Chris, Richard, John and Martin selected their spouse while Karen chose her sister as her closest friend. All had significant aphasia and all reported that their friends/ family members supported them practically in terms of the logistics of communication, getting out, and by taking on new roles as therapists, breadwinners and organisers. Karen, for example drew on her sister's support to organise three daily visits from carers.

The multiple texts daily from her sister revealed the other side of friendship also. Frequent questions or comments about the dogs and affectionate 'love you' or 'see you soon' messages suggested this sisterly friendship was far more than the administration of life.  In contrast Trisha, who described herself as very close to her twin sister, was clear that for her, family did not blur into friends

> CP:      Would you count your twin sister as a friend then?
>
> Trisha:   No! No. Mind you I think she was in my, erm (…)
>
> I don't know. Maybe I *should* do.
>
> Because we were, we were twins like we had the same friends, so I supp*ose* she should be. [*laughs*]
>
> (Trisha, line 280)

This affirmed the regular mantra of our Research Group that everyone was different and reinforced the fact that assumptions about friendship and family relationships always required checking out. It also raised questions about possible gender differences. None of the four men with severe aphasia expressed loss of confidence or identity change as a major issue. Perhaps this was because their wives played such a strong role in anchoring them and

reinforcing their competence and security and history. Perhaps it was because their focus was more on external issues such as work and financial security.

Members with aphasia in the Research Group were more sensitive to the potentially claustrophobic atmosphere of families. Other than Jeff, none chose family members as friends. Their predominant view was that time with friends enabled a 'recharging of batteries' and accessing 'fresh air' away from the fixing and fixating behaviours of families (Research Group 18). Barbara asserted that her friends knew her from the inside and therefore she could talk about anything with them. This was not the case with her family whom she described as 'less light-hearted and more intense'. Two participants from Asian families perceived that powerful cultural commitments to family could get in the way of even acknowledging the importance of friends. One of them commented:

> 'my family honestly does not understand the concept of friends…they
> don't see the importance of my friends.'
> (Research Group 18).

**'Fast friends' and the role of peers with aphasia**

Given this sometimes oppressive home environment, many respondents perceived stroke and aphasia support groups to represent a more freeing context – a place to breathe, to 'be' and to begin a long, cyclical process of figuring out what was happening. In contrast to the isolation of home, peer support could represent 'the first step on the ladder of friendship' (Research Group 15).

Listening to alternative stories of coping and recovery were reported as helpful to locating bearings and, for some, creating new maps of stroke recovery:

> Ron: So, as I say, the, the, the *new* friends, as I say, have been *very, very good* quite honestly
> CP: What is it that's kind of you like about it?
> Ron: Well, it's just different, *different stories*, *different problems* with, of having, having the stroke. Whether your disability is

> on the arm, the leg, was the speech part of it, pretty bad,
> and, you know, you know.
> It's just a different stories of what they're trying to say.
> (Ron, line 364)

Discovery with new friends with aphasia was most often associated with a process of collectively developing confidence and the mutual giving and receiving of support:

> Ron:   But after these, the last year, fifteen months it's, it's, it's a different *journey* now. You know, it's a journey that I'm really going to *have* and *hold* and I'm going to get more *confidence* of things like that quite honestly. And with the other friends that have got the sa- same, sa- there's different sort of problems and all these, it just keeps a (...) What's (...) I am just trying to get that *word*. Get (...) They all want obviously confidence and support and everything else and I, I,
> and myself I, I want to be support and things like that.
> (Ron, line 416)

Unsurprisingly, many of the study participants, who had been recruited via the Different Strokes or Connect support networks, could not stress highly enough the role that peers had played in supporting them to recover a sense of wholeness. Several people, like Derek, described a perception that statutory rehabilitation services and medical support underestimated the transformative power of peer support:

> 'It's erm, the, the erm, the importance of the *peer* support that I have,
> that I still have that originally from the Different Strokes group has been
> *enormous*! the benefit has been far greater than any drugs or (…)
> … … Erm, it's so important. It is, you go you can relax. You don't, you
> know, you can *be yourself* whatever you are now. You know, you can
> be that person. *So* important. It's made such a difference to my life. To
> get that across to people. You know, to really stress the importance of
> it, erm, it is, it's not enough, erm, *emphasis* put on it in my opinion
> because I think a lot of people you will never see, you very rarely see

them, just shut themselves away and they never come out again, that
will be it.'
(Derek, line 1570)


**Reconfiguring identity with friends**

In Phase 1, Katie, amongst others, had highlighted the importance of friends
to identity and the necessity of finding some sense of self to be able to be a
friend to others:

'Without friends I don't think I would have an identity!'
(Katie, Research Group 5)


Anthea, for example, echoed the reflections of Binda and Katie on the
steadying role of friends from important personal communities:

Anthea:  Ray, Jean, Edwina and erm, Hamish. They are not only my
         members of the church but also they're friends to me, you
         know, I can talk to them if there's anything worrying me.
         Yeah.

CP:      So that's what makes a good friend for you?

Anthea:  It does, yeah, yeah, yeah.
         (Anthea, line 207)


Many Phase 2 participants commented warmly on the video interaction
between Sarah and her old friend, Sandra, which was played during the
Friendship Event. This interaction seemed to embody for some the loyalty,
struggle, humour and affirmation of both individuals and friendship. Joan, for
example, compared herself to Sarah, and her best long-standing friend
Teresa, to Sandra:

Joan:    Lovely. *Beautiful.*

CP:      Yeah

Joan:    It was just like me and my friends.

CP:      You and your (…)

Joan:    My friends. And I thought that was *lovely*
         It was (...)  Yeah. [*laughs*]

> CP:      Yeah, yeah. Is that maybe a little like you when you're
>
> chatting with Teresa?
>
> Joan:    Yes, that's, that's, that is about me, yes, lovely.
>
> CP:      Hmm.
>
> Joan:    Her [*points to photo of Sarah*] it was very much like me.
>
> That's how I felt like her. Lovely.
>
> (Joan, line 1007)

During analysis of the Phase 2 interviews and, towards the end of the project, as we deliberated on the final version of the Forest of Friendship diagram Research Group members with aphasia perceived the need for a more dynamic, creative dimension to the identity branch of our diagram to reflect its overarching significance. In addition to repositioning Friendship and Identity from the bottom to the uppermost, aspiring high, branch of the diagram, the Research Group played with ideas of reshaping the image in different ways to represent its perceived importance and its powerful interaction with each of the other theme branches. Jeff, for example redrew the organic mind map as a tree with identity as the trunk.

> 'an oak and … intertwined (anchors and identity branches) … 3D!'
>
> (Research Group 19)

Others reiterated the way the grounding of good friends enabled the tree (identity) to grow and interact with the other themed branches of friendship experience:

> 'identity is really under threat especially early on when you're floundering… and you're friends having confidence in you and trusting you is so important - they're like an anchor you can hang onto.'
>
> (Priya, Research Group 19)

Deliberating how best to verbally frame a new sub-theme of identity change and affirmation we scrutinized and rejected concepts such as 'adaptation' and 'adjustment' to disability.  This was partly on account of the reductionist and medicalising connotations associated with these terms. We searched for a

vocabulary that embodied change but gave scope to imagination, flexibility and fluidity.

> 'it's not so much adaptation as reconfiguring and reinventing.'
>
> (Tom, Research Group 18)

'Reconfiguring' and 'reinventing' were also perceived to represent agency and dynamism, which rebuffed both the 'fixating' tendency of family dynamics and the 'tickbox' pigeon-holing of healthcare workers and processes:

> 'but the professionals … whatever she does she have to put a box … I think lots of therapy … they have a *goal* and they want to do *this*, and this test … if you'll … if you belong, you reached this stage. That's therapy!'
>
> (Barbara, Research Group 20)

Friends, in contrast, were perceived to represent a 'naturally holistic' approach to recovery and self-management, giving greater scope for choice and agency (Research Group 20). Barbara summarised the power and potential of friends in the introduction she prepared to the Friendship Events:

> 'Professional people and family they give you a lifebelt and cuddle. But friends give you a space and time to express yourself. They understand you, they know what you like and not like – what make you tick. They can transform your life and confirm your identity. '
>
> (Barbara, Research Group 13)

**7. Humour and hanging out**

This new theme reflected the powerful thread of humour that ran through Phase 2 interviews and the light-hearted ambiance of the Friendship Events, Humour had been present in Phase 1 data, for example the humorous dialogue and two-way teasing between Jack and his partner, however it had been less salient in the interviews. Throughout the study, humour was rarely far from the surface of Research Group meetings. It lubricated and lightened the hard intellectual and communicative work of our meetings. Planning for the Friendship Events, the Research Group members with aphasia were keen to ensure humour was well represented. One Research Group member

proposed a stand-up comedy routine on friendship as a potential contribution to the day. Reflecting on the frequent and funny misunderstandings with friends, Barbara mused on 'a confusion of people with aphasia' as an apposite collective noun. Laughter was a noisy backdrop to the support group meetings I attended during recruitment of participants to the project. Moments of humour punctuated interviews with participants, sometimes as fleeting episodes of light relief, sometimes, not as a tension relief strategy, but as intrinsic to funny stories and amusing storytellers with aphasia. The presence and diverse functions of humour within the project process seemed to reflect the experience of humour in participants' lives and relationships.

> 'I come out with words that are laughable …amusing …all my friends without aphasia …we **scream** with laughter at words that sound the same …that for me is an important aspect of relationship …humour.'
> (Research Group 19)

> 'People think people with aphasia have no sense of humour – we need to show we have humour.'
> (Research Group 19)

**(a) Humour: 'You can either laugh or cry'**

Humour was described as playing a range of different roles in interactions between participants and their friends. Humour was noted as a way of expressing important elements of identity, signalling social affiliation and group solidarity or as a pro-active strategy for defusing tension created by uncertain communication.

Both Gary and Frank resumed their pre-stroke role of making people laugh by harnessing technology. Frank used Facebook to share jokes and humorous photos or stories.

> Frank:    I just send stupid pictures and things like that, you know. Because it's like the things that you can (…)
> CP**:**    Yeah, so that's something you quite like doing.
> Frank:    Yeah, yeah. I've always been a joker. That's not changed,

that's not changed, so.                    (Frank, line 424)

Gary who was congenitally deaf experienced more problematic distortions in speech and intonation after acquiring aphasia. He had been creative in developing a method of joke telling that involved showing photos and incongruous signs on his phone. He reported that he engaged more with humour now and had extended his joke telling since acquiring aphasia:

Gary:    True. Afterwards, it was like stroke. After more.

CP:    So you tell more jokes now?

Gary:    Yeah.

CP:    But I mean, it's obviously not that easy with the *speech* telling jokes?

Gary:    No, but I could have it here [*shows phone*]

CP**:**    Yeah, yeah, on your phone.

Gary:    Phone.

(Gary, line 1578)

Trisha also enjoyed humour. As a result of an accident several years before her stroke, she experienced chronic back pain. She set her watch alarm to sound an imitation duck 'quack' at 30-minute intervals as a strategy to remind her to stretch. She clearly enjoyed the laughter we shared each time the alarm sounded. Sometimes this intruded as she was tearfully talking about her double disabilities. This was not the only time I noted in my research journal the powerful juxtaposition of humour and pain.

During the Friendship Events, participants identified that after stroke there was 'a lot of emotion flying about'. Humour, many reflected, could be a useful tool to defuse tension and counteract the high emotion and drama of stroke disability. Some friends had been with participants when they became ill. Many had attended hospital visits or supported stressed family members during the medical crisis and homecoming. Many respondents acknowledged that manifestations of frustration, anger or sadness could heighten the tension in friendship interactions.

Although the Research Group recognised that humour was not always as apparent in the intensity of the early drama of stroke, as time went on, the ability to engage in humour and an atmosphere of light-hearted being together recreated for many participants a balance and familiarity in relationships. Advice to friends generated in the Friendship Events and confirmed in many interviews was 'don't take it personally' and 'lighten up'. For some people humour, or the possibility of more light-hearted 'being' with friends and family marked a resumption of more ordinary life.

Recalling how she emerged from an eight-month period of social withdrawal, where help from rehabilitation staff and visits from former work colleagues had been disappointingly absent, Joan linked laughter and a 'smile on your face' philosophy as key to her own resilience and recovery:

> 'No. (..) So then I got on and I thought to myself right, well do it yourself then, love, do it yourself! And I did. And I've put a life-line in me laugh.'
> (Joan, line 685)

She described putting a smile on her face as a strategy to face the world and re-engage socially.

Experiences of humour and laughter described at support groups underlined this association of humour with getting out. Several participants cherished the light-hearted tone of support groups as a fundamental and colourful component of support group communities. In addition, sometimes a person's natural sense of humour appeared to be enhanced by the 'differentness' that changed language and communication created. A number of support group members singled out Jeff, as a friend. In his own interview he drew an analogy between his post-aphasia self and a 'Marcel Marceau' mime character. With few words and compromised spoken comprehension, telling jokes assumed a different tempo and style. However his humour and light touch was much appreciated by others at the group, as was the light-hearted camaraderie of others:

> Karen:  Erm. [*points to individuals in photos from Event* ]
>
>          Yeah. Funny.

CP:     He is funny, isn't he.

Karen:  Funny. [*laughs*] Funny.

CP:     So people like Derek and Jeff.

Karen:  Yeah.

CP:     And Gary, did you say?

Karen:  Yeah. Yeah. [*laughs*]

CP:     So you like them because they're funny?

Karen:  Yeah. [*laughs*] Yeah. Erm, (…) [*pointing at photo*]

CP:     Oh yeah, Ron, yeah.

Karen:  Yeah. (3) Funny. [*laughs*]

CP:     So all of those folks you rather, you'd count them as your friends.

Karen:  Yeah.

CP:     And there's something, you like them because they're a bit, you have a laugh with them?

Karen:  Yeah. Yeah.

        (Karen, line 688)


'I always take the Mickey out of Jeff, you know, saying, you know,

just a greeting from him can be like a two hour conversation

because by the time he's got it all out, you know.

And he takes it. (...) He understands it's messing, you know.

You know, but that's, that's, that's a standing joke anyway.'

(Derek line 755)


Discussion of humour and its function within friendship raised the issue of its perceived association with creativity and personal growth. Research Group members with aphasia suggested that the lightness of atmosphere at support groups or with friends opened a space not only for a more relaxed sense of 'just being' but for an openness and opportunity to see things differently:

'Humour helps you see things from a different angle.'

(Research Group 10)

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A rejigging of language, some members of the Research Group reflected, could mirror a disruption to and realignment of identity. In two separate discussions, group members with aphasia considered the onomatopoeic appropriateness of the word 'discombobulation' to articulate the funny disruption of speech and identity. No-one with aphasia in the group could accurately pronounce the word despite multiple attempts at co-ordinating and reproducing its unstable polysyllabic form, in a range of hilarious sequences. Barbara reflected that sometimes aphasia created an innately humorous process where the final attempt remained 'inaccurate' but was somehow the richer and the funnier for its new additions and confusions. Beyond finding humour in incongruity and non-conformity these new verbal forms could be associated with an enjoyable experience of co-creation, and another way of sustaining authentic relationships.

The creativity of using language differently was demonstrated throughout the interviews and events. Juxtaposing unusual word pairs or employing apparently incongruous lexical selection within aphasia language could be perceived by people with aphasia and their friends as hilarious, innovative, or unintentionally adding new layers of meaning. Joan, on several occasions used the word laugh and life interchangeably (lines 1025, 1140, 2064) in addition to her example of putting a life-line in her laugh cited above. Trisha, explaining how the dance sequence at the Friendship Event reminded her of sex with clothes on, amused us both with her description:

> 'I said it was like the, erm, the Kuma Satra
>
> with clothes on, that's what I said. [*laughs*]'
>
> (Trisha, line 1041)

Within friendships of trust and equality these non-traditional forms of expression could occasionally be enjoyed and appreciated rather than evaluated as errors. This sentiment had been the catalyst for the group's decision to ask a poet with aphasia to represent the early findings from Phase 1 interviews. Several of the poems make explicit reference to the fun and laughter of friendship experiences, and indeed the potential for humour to

explore the darker side of friendship as well as the lighter moments of togetherness (see Two Ways, Appendix J).

**(b) Hanging out with friends: Just being**

Respondents talked of a range of ways in which they spent time with friends. Sometimes these involved creative ways of doing things together where both friends made adaptations to accommodate stroke and aphasia (see Theme 8, Doing things together). Although there was no denying the importance of communication to relationship, ways of being with friends before and after the onset of aphasia were not always strongly activity or communication dependent. Sometimes they were described as 'just being together' in a quiet atmosphere of joy and warmth and love for their friends. Trisha aptly described her understanding of hanging out with friends for her:

> CP: Is that kind of similar to your mates? You sort of hang out together quite comfortably?
>
> Trisha: Yes, yeah, yeah. It's not erm (…) No one needs to do anything spe-ta-cular [*both laugh*]. The beer keeps flowing well, you know. Erm, no, we're alright.
>
> (Trisha, line 677)

In the Research Group Jeff, Priya and Binda, in particular, made frequent references to experiencing time with friends which was both the 'same and different' from doing similar things, with the same people before the onset of aphasia. Jeff, who had retained many pre-stroke friends and social activities, such as attending local rugby matches, described a heightened quality of being together with the same friends, in the same context after his stroke. He articulated a distinct but rather intangible quality of companionably enjoying the rugby with his friends.  He described being equally, actively, but differently engaged. He contrasted experiences of heightened connection during the game with conversations in the pub afterward:

> 'Watch the rugby … its more, more … more, more … the same friends but more, more … Hhhh … doesn't matter the … aphasia … doesn't matter its watch the rugby…its shouting … or worse [*laughs*] its doesn't matter… … Very good … in the er … midst of the rugby … very quick

> … me talking 'Forward pass' …same reaction [*clicks fingers*] *'forward pass'*… but after conversations in pub … me quiet, always quiet. But in the *game*!' (Research Group 20).

Listening to his description, several other members of the Research Group who have aphasia recognised similar subtle, transcending experiences of losing awareness of aphasia in the joy of shared engagement with friends.

Hanging out in a mutual satisfaction of company was also how people described the shared communicative space of support groups. Enjoyment here was based on an easy, welcoming atmosphere where there was no pressure to 'do anything spectacular' (Trisha, line 674). Anthea described how she relished forming new friends at her church group as well as at her local support group. Aware that others with aphasia had a less confident approach to forming new friendships, I asked her opinion of the vital ingredients:

> CP:      Hmm. So what is your, you know, what is it that *helps* make new friends in your opinion?
>
> Anthea:   Well, for me, for me it's the *warmth*. You know.
>
> CP:      The warmth?
>
> Anthea:   The warmth. When I come and when you, people are around and you know, as soon as you come they feel *warm* towards you.
>
> (Anthea, line 688)

A final strand of this sub theme was the importance of invitations and events. Two people involved with the project had recently got married (David, Tom), two people were in the throes of planning 25th wedding anniversary events (Chris, Jeff), one had recently attended a sister's wedding where she reconnected with some old school friends (Priya) and another had thrown a birthday party (Katie), reported as an important milestone in recovery, for 20 of her close friends. These events served as a focal point for gathering personal communities and being with old friends and new in an organized, planned way. Chris showed the date on the calendar and photos of eight couples that were accompanying him and his wife Tina on a weekend away to celebrate their silver wedding anniversary. Their conversation about it hinted at its

significance as a motivational rehabilitation milestone, a celebration of Chris and Tina's relationship, and an affirmation of the strong circle of friends who they both described as constant, much valued friends.

CP: Okay. And all of these guys [*points to sheet of friends photos*] are going with you. … …So these are really *good* friends?

Chris: Yes, good.

CP: These look like, they're all pretty old friends are they? You've known them a while?

Chris: Yes, yeah. Good.

CP: So they're sort of, so friends of both you and Tina.

Chris: Yes.

CP: Known them for quite a long time.

Chris: Lovely. Yeah, yeah, good.

(Chris, line 676)

Sharing space and time together were not always viewed through the frustration of communication and physical loss. They could be quiet, or light-hearted moments of shared presence where warmth or humour or an uncomplicated being together meant that aphasia didn't matter.

**(c) Family pets**

Pets could also play a quiet affirming role unaltered by aphasia. Pets featured strongly in relation to friendship in only one of the Phase 1 interviews. At the end of his interview, Jack shifted his selection of stones around to indicate jokingly that his dog was now a closer friend than his partner Dawn. Since becoming unemployed he spent more time at home and had embraced the routine of walking and playing with the dog. Dawn also recognised that Jack and the dog had become closer since Jack's stroke:

Jack: [*moves stone representing Dawn further away and puts stone representing dog adjacent to his stone*]

Dawn: Closer than me and the children, yeah. [*laughter*] He edges in.

CP:     He edges in, right, okay.

Dawn:   I don't think he was so close before you had the stroke, was you?

Jack:   Yeah. Oh.

Dawn:   Because I tended to do more the walking and things, didn't I? And the whatever

CP:     So you got a bit closer because you spend more time together?

Jack:   Time, time, [*moves arm back and forth*] yeah.

Dogs made an appearance in four Phase 2 interviews. Respondents recognized the power of pets not just to provide affection and companionship but routine and a sense of responsibility. Derek took delivery of a small dog the day after our interview. Reflecting on our conversation about friendship he wrote a follow up email:

> 'Animals are very important as friends, more so after a traumatic injury, they are non judgemental, unaware of physical or mental abnormalities and are totally reliant on you for their wellbeing, so the sense of achievement for providing for them is enormous.'
>
> (Derek, email 5.7.12)

Pets also created an atmosphere of light-heartedness. Derek's chickens provided several light entertainment stories at the Friendship Event. In one story, for example, Derek recalled passing out on his lawn and coming round to find a chicken sitting on his chest.

The background noises and humorous antics of dogs, cats and an unruly kitten punctuated several interview transcripts. Where dogs and cats were present in interview settings they often provided a welcome moment of light relief, shifting the focus from and taking the pressure off speech. I also noted in the social 'bookends' of research interviews the way the presence of pets naturally eased the process of introductions and farewells.

Karen lived alone with her two dogs. She referred to them as her babies and had photos of them on her phone and around her sitting room. In her newly

modified flat she had created a nursery room for the dogs. Barking interruptions throughout our interview were dealt with swiftly. In this extract, in mid-conversation about computer use, Karen got up, exited the room, walked toward the dog pen and squirted water at them as a speech-free technique to stop them barking.

> Karen:    Computer. [*dog barks*] [*Karen gets up and leaves room*]
>
>                   [*dog stops barking as Karen walks towards her*]
>
> Karen:    *Shut up. <u>No</u>!* [*Squirts dog with water*].
>
>                   [*Karen returns*]
>
> Karen:    Squirting Charlie. Ooh.
>
> CP:        If you squirt them they stop barking?
>
> Karen:    Charlie, yeah. [*laughs*]
>
> Karen:    Yeah. Speech not. [*both laugh*]
>
>                   (Karen, line 1316)

Between Karen and me the dogs were a topic of conversation, a rich source of humour and an illustration of the way she exercised control in the absence of speech.

## 8. Creativity: doing friendship differently

This second new theme summarises the many descriptions of resourcefulness and creativity of friends with and without aphasia who stayed connected and shaped different, in some cases, closer relationships. Also included here is a sub-branch of findings relating to the way respondents felt technology could support their friendships.

Personal accounts and responses to the video story of Sarah and her long-standing friend Sandra, led to an abundance of new stories and examples of enjoying old friends' company in new and alternative ways. For some, this was reported as an automatic response to changes in communication and physical abilities. For others it was a slower process of learning what worked and what felt comfortable.

**(a) Flexibility and resourcefulness**

Participants provided many examples of the ingenuity of themselves and their friends in adapting ways they passed time together. Continuing old friendship activities or commencing new ones often required creative problem solving. A barrier to David playing bridge was the difficulty holding up his 'hand' of cards given his right-sided paralysis. Friends at bridge produced a wooden card-holder. Richard and his wife, passionate musicians, were experimenting with playing the guitar together to accommodate Richard's paralysed right arm.

Chris and Tina's house was a testament to Tina's resourcefulness in setting up home-based rehab equipment. Tina had constructed a large wooden frame with lines of sponge-balls that Chris used for arm and hand exercises. She talked of the strong need for 'DIY rehab' after their perceived abandonment by statutory services and lack of information about on-going support options. Taking matters into their own hands, Tina and Chris illustrated some of their resourcefulness around friendship maintenance. These included: a laminated sheet of digital photos of friends to support conversation about different friends; harnessing Tina's friends to support her with time out at Pilates classes; asking friends to invite them for lunch rather than dinner to accommodate Chris's fatigue;

> 'And our friends are really good because they understand our limitations. We can't do late evenings. We don't go out late evenings.
> We don't eat out in evenings anymore.
> We'll, we do lunchtime things if we can do.'
> (Chris and Tina, line 2615)

Gary's combination of deafness and aphasia had dramatically altered the intelligibility of his speech to others. He took the initiative of inviting his best friend Jack to be present at our interview in case I needed help with translation. Jack had taken on the informal role of Gary's support person since Gary's stroke. As Gary learnt new ways to tell jokes, Jack enthusiastically set about learning more about life with aphasia and disability. Together they had taken up new activities such as going to the gym or watching subtitled movies, that Jack had previously researched for storyline, subtitles and accessibility.

CP:      So when you've done 800 press-ups he lets you stop.

Gary:    Yeah.

CP:      Okay. So that would be something different, he comes along to the gym to help you count.

Gary:    Yeah.

CP:      Any other things that you do differently now?

Gary:    Erm, erm, like film. Film.

CP:      Films, yeah, yeah, yeah.

Gary:    He come on for watch DVD.

CP:      Watching DVDs at your house.

Gary:    My place or his place. Good.

CP:      Yeah, yeah. And that's something you wouldn't have done before?

Gary:    No.

           (Gary, line 760)

Jack, a self-proclaimed 'IT geek', also acted as Gary's technology buddy, researching cheaper mobile phone contracts, fixing computer glitches or coaching him in the benefits of Twitter.

**(b) Technology and friendship**

Gary was not alone in exploring the use of technology in old ways and new to support connecting with friends. Invariably technology arose – either directly, in response to interview questions, or as part of supporting communication in the interview process. For example, interviewees elaborated points and places through use of an IPad and Google maps, mobile phone photos and contact lists, digital photos of friends embedded in laminated sheets. Respondents talked about the diverse ways in which they used technology to support both face-to-face and virtual contact with friends. Their illustrations highlighted both the possibilities and also the shortcomings and unfulfilled potential of digital technology in sustaining and developing friendships in the context of aphasia. Study participants did not perceive technology as a panacea for communicating with friends. Discussions in the Research Group highlighted the potential for it to create even more barriers to friendship - it could consume

even more time, highlight the challenge of new learning in addition to communication difficulties and emphasize exclusion from friends' very public displays of social networking.

'Technology absolutely can be a hindrance' (to friendship)

(Research Group 20)

'its not straightforward…its double whammy…it takes more time to learn'

(Jeff, referring to the dual challenge of technically learning and using new software which requires spoken and written language to set up)

(Research Group 19)

Appendix R summarises the various ways participants in both Phase 1 and 2 interviews used technology in relation to friendship.

Not surprisingly Facebook was a topic of technology talk around friendship. Participants reported mixed experiences. The online dot sometimes encouraged Shana to make contact with friends abroad with a quick hello, or a follow-up Skype call. She reported enjoying checking out what friends abroad were doing through photos they posted. Karen reported that she enjoyed using the likes / dislikes icons to let others know her opinions and maintain a virtual presence. David commented on Facebook photos as a tool that brought the 'more more human sort of thing about it' (David, line 1840) to the fore as he participated in the organization of a group holiday with strangers who shared his interest in archaeology via Facebook.

Other positive Facebook experiences related to those who chose to renew contact with old friends. For some, Facebook facilitated a re-establishing of contact, and a way to share present experience of stroke alongside a reconnection with past experiences and identities. For others, it was a lighter touch contact. Frank, for example, described re-establishing contact with a work colleague from 20 years ago. His decision not to disclose he had experienced a stroke demonstrated an example of the different disclosure choices that can operate within online identities.

CP:     What was that like then, reconnecting with someone

          you'd known a long time ago but obviously didn't know about

> your stroke and everything.
>
> Frank:   Yeah. It's weird really. He still doesn't know, you know. I haven't actually mentioned it. But he still thinks I'm the old Frank, going out for drinks and things like that. I don't drink and so (…)
>
> CP:      Why haven't you mentioned it?
>
> Frank:   I don't know really. I don't know. Because I mean like he's an old friend sort of thing. He's not a close friend now.
>
> (Frank, line 355)

Different forms of technology enabled agency and choice in relationship to friendship and being active or more passive members of online communities. Sometimes technology supported connection and expression of aspects of personalities, other times as with Emily and Priya, in Phase 1, it could reinforce a struggle to keep up with friends and their social networking.

**(c) Getting out and doing things**

Participants in both Phase 1 and Phase 2 described the importance of doing things with friends as a way to maintain friendships and familiarity. Participants talked about accompanying friends to the pub, to gigs and concerts, swimming, walking together, going to the gym, gardening and to Tai Chi classes. Time with friends at football, rugby, tennis and fishing remained important, though sometimes this entailed different approaches. For example, Frank had become more anxious in crowds so friends went along with him early and waited for most supporters to leave before they made their exit. Joan still loved to shop with her friends and revelled in the extra time she had to do this now she was medically retired. Holidays remained important for Ron and Shana. Priya commented in Phase 1 on the importance of spending intense, extended time with friends on holiday as a way of hot-housing understanding of aphasia. Socialising with family friends as couples could put a strain on communication but the familiarity of friendship activities and good friends who included the person with aphasia and treated them as competent was described as reassuring (David, Richard, Chris).

Many participants cited going to support groups as an example of activities that prompted getting out of the house. Some respondents (Joan, Trisha, Anthea, Gary, Ron) also reported meeting up with new 'fast friends' outside the support group for coffee, meals, shopping, concerts and in one case (Ron) a holiday abroad. These two new themes, 'Humour and hanging out' and 'Doing friendship differently', highlighted the creativity both of people with aphasia and their friends in responding to threats to friendship and threats to identity. They illustrated the possibilities and potential of friendship after aphasia where friendships were nurtured by love, flexibility, imagination and a two-way reconfiguring of ways to be together.
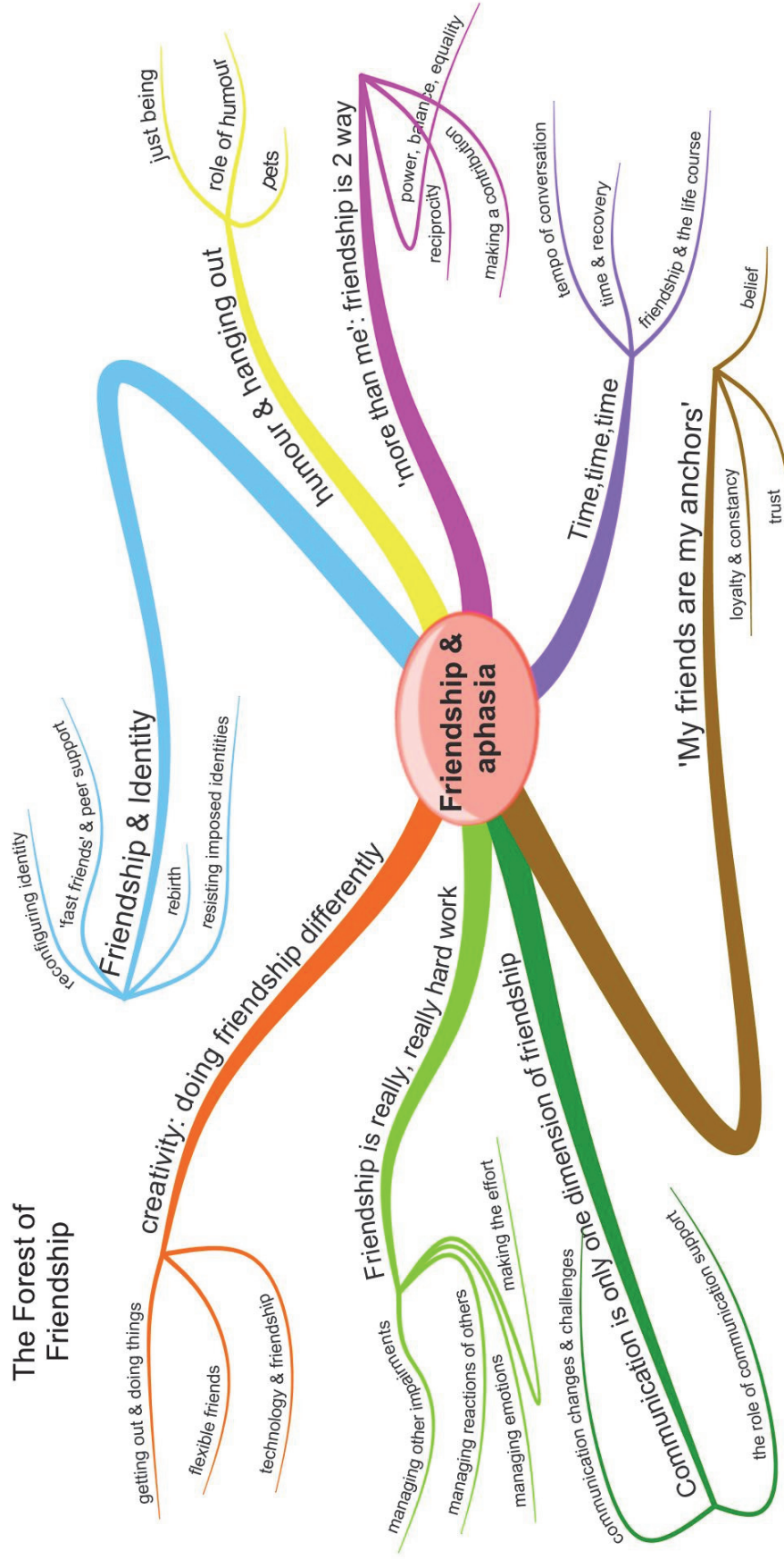
## 9.2    The Forest of Friendship diagram – version 2

As the Research Group discussed the emergent findings from Phase 2 data we repeatedly revisited the original Forest of Friendship diagram (Fig 7.2, page 208), checking which branches might be expanded, pruned, renamed or re-sited (Research Group 18-20).  The final version of the Forest of Friendship diagram, following incorporation of Phase 1 and Phase 2 data is presented on the following page in Figure 9.1.

## 9.3    Summary

This chapter has presented findings from Phase 2 of the study. The nature of the experiences described in the Events and interviews echoed many of the findings from Phase 1. Participants illustrated the creative strategies that both they and their friends employed in managing the changing dynamics of friendships.  Phase 2 data led to the creation of two new themes that explored new ways of managing and maintaining friendship post onset of aphasia. Phase 2 findings also enriched discussion of the blurring of boundaries between family and friends and the role of 'fast friends' with aphasia in supporting reconfiguration of identity. The next chapter focuses on the final set of findings, those relating to doing PAR with people with aphasia.

**Figure 9.1**     **Revised Forest of Friendship diagram**

The Forest of
Friendship

Friendship & Identity

reconfiguring identity

'fast friends' & peer support

rebirth

resisting imposed identities

just being

role of humour

pets

humour & hanging out

'more than me': friendship is 2 way

power, balance, equality

reciprocity

making a contribution

tempo of conversation

time & recovery

friendship & the life course

Time, time, time

belief

loyalty & constancy

trust

'My friends are my anchors'

**Friendship &
aphasia**

creativity: doing friendship differently

getting out & doing things

flexible friends

technology & friendship

Friendship is really, really hard work

managing other impairments

managing reactions of others

making the effort

managing emotions

communication changes & challenges

Communication is only one dimension of friendship

the role of communication support

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# Chapter 10

# Findings: Doing participatory action research with people who have aphasia

## 10.0    Introduction

Chapter 3 described the relevance of PAR grounded in values of trust and mutuality, and emphasising practical, relational knowing as a fitting methodology for the exploration of friendship. This chapter presents novel methodological findings, alongside discussion and reflection on the process of doing PAR with people who have aphasia. It tells the unfolding story of how we, as a Research Group, engaged collaboratively and companionably in our exploration of friendship and aphasia, addressing the research question:

What are the meanings of doing PAR with people with aphasia?

The chapter begins by evaluating some of the specific processes and practices that were employed as we experimented with methods to involve people with aphasia in PAR's cycles of reflection and action. Next, it reflects on our relational practices in the context of the theoretical influences described in Chapter 3. Finally, the chapter asks how relational and reflectional ways of knowing may have shaped the findings about aphasia and friendship.

There are multiple sets of participants in this chapter: the interview and Event participants; the participants who were members of the Research Group (some of whom also took part in the Events and interviews); and me, a member of the Research Group and participant in the Friendship Events. As writer of the thesis and co-ordinator of the research I also stand outside these groups in reflecting on processes and issues away from the Research Group. In this chapter the 'I' will refer to this personal reflection whereas I use 'we' to refer to shared reflection and insights debated within the Research.

## 10.1    Practicalities and processes of participating in PAR

As discussed in the methodology chapter, PAR aspires to be democratic, inclusive and empowering. When language is power and language both 'roots'

and 'routes' the expression of ideas when a person has aphasia (Black and Ireland, 2003:29), establishing a level playing field is challenging. This section reflects on specific techniques we used in an attempt to manage the 'uneven ground' (Maguire, 2006:67) between researchers with and without aphasia and participants with more or less access to language. Because standard techniques of supported conversation and adapting interviews have been well illustrated elsewhere (Kagan, 1998; Luck and Rose, 2007) these are not revisited in detail here. Instead I focus on strategies of data collection and analysis that are more unique to this study.

### 10.1.1 Democracy: inclusion and people with severe aphasia

The importance of including the voice of people with more severe aphasia in developing knowledge about friendship in the context of aphasia was a recurrent concern within Research Group discussions. This led to a decision to prioritise people with more severe aphasia for the second wave of Phase 1 interviews. This section describes some of the challenges and facilitative techniques in engaging people with severe aphasia in the co-construction of knowledge about friendship and aphasia.

I travelled to the Phase 1 interviews with individuals who had severely compromised language clutching a large kit-bag of pre-prepared communication ramps. These included pictures of activities which they may (or may not) take part in with friends, key word lists, types of activities and people which had arisen in the first set of interviews, and a bag of stones to facilitate selection and 'talking about' friends. I had spoken to participants prior to the interviews and sent an accessible letter recapping the types of question the interview might cover so that they could think about these in advance. I also forewarned individuals to bring to the interview any useful photos or artefacts which might support our conversation about friends. I noted in my journal an increased level of anxiety about 'getting good data' from these interviews. This was fuelled by a strong sense of responsibility to the Research Group and their mission to include the voice and experience of people with minimal language in the research. The possibility that I might

interview people with severe aphasia but then disregard their data as 'too thin' somehow seemed worse than not trying to include them in the first place.

Sam appeared earlier in the Findings (Chapter 7), where he was labelled a 'loner' by his mother. The following extract from my reflections on reviewing the videoed interview with Sam illustrate some of the challenges of silent interviews.

---

**Box 10.1      Reflection**

Re-watching this extract makes me cringe as I see and hear my physical and emotional discomfort.  The boom of my voice intruding into the silence held by Sam. I remember being struck by his inertness of expression and bodily movement and how this magnified my clumsiness in dealing with the file of communication props I had brought along. Trying to balance multiple communication props, the clip board, the stones between us and draw on these flexibly in response to the questions, Sam's blank responses, another try at a probe …these evoke the image of a circus clown juggling and dropping items and becoming faintly manic in trying to keep them together. This in contrast to Sam who sits next to me on the sofa, immobile and confidently balancing his coffee on the soft surface of the sofa arm. The more he sits motionless, silent, the more I seem to witter. The props introduced by me paradoxically seem to physically get in the way of establishing relationship. How different this interaction is from the smiling and relatively prop-free camaraderie I witnessed Sam enjoying last week at the peer support group.

Who is this guy? I have no idea who lies behind this wall of silence yet how easy it is to make assumptions. Assumptions that he has nothing to contribute or that any relationship with friends is as uncomfortable and gruelling as this interaction is for me. Yet whilst I so easily override him with my language he holds a strange control in his silence. When he does respond, such as the moment where he shows me a photo of himself, long haired, smiling with a group of fellow travellers in India, the impact is all the more profound.

(Research journal, January 2011)

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The many props and multiple techniques I used in this interview did serve to get me a little further in understanding some facts about Sam – the fact that he liked travelling, watching motor sport and listening to Led Zeppelin. What they did less well was move beyond itemising activities to reach his opinions about who his friends were and how he experienced friendship before and after his aphasia. In the absence of this information my voice and the voice of his mother had open access to defining and describing him. This experience prompted me to question an over–reliance on communication props that, in this instance, reinforced a disengagement and disconnection. It also made me value more deeply Research Group members with aphasia with whom I could extend discussions about communication support and identity.

Across all respondents, but particularly those with severe aphasia, two features of communication access stood out as particularly facilitative in 'getting below the surface,' or at least a little further below. These were: the use of coloured stones, and a 'Some people with aphasia say…' probe drawing on the experiences of other participants as a springboard to generating responses.

In the following extract I employed both techniques with Jack. This started a series of sequences where he indicated that friends who remained busy at work and, unlike him, with ready access to money, had created a distancing of former relationships:

CP**:**       Mmmm. And, and then some people say that (..) when they have a stroke friendships can get a bit out of balance [*gestures unbalanced scale*]

Jack:       [*makes swishing sound*] Yes, yes.
[*leans to one side* ] [*? Imitating lop sided*] (3)
[*writes +/- then at top of page 'friend' with 1 arrow pointing up and another out to side* ]
Oh. (4) [*writes*] Haha, (…) down (...) see. [*points to diagram*]

CP:       Now that's interesting. So can you explain this for me? [*points to his words and arrows*]

| Jack: | (4) [*writes and underlines 'friend'*] |
| | Friend. Psscht. [*hand gesture away from body*] |
| | Bye bye (…) bye. |
| CP**:** | They go off. |
| Jack: | ***Yes, yes***. [*gestures away*] Look |
| | [*moving friend stones away from self stone*] |
| | Yes, yes. Bye bye.[*moves stones back*]. Pscht. |
| | (Jack, line 2272) |

Leading questions are recognised as a technique for enhancing participation in qualitative research where people have mild to moderate language impairment (Luck and Rose, 2007; see also Chapter 5). The strength of this technique for the Friendship and Aphasia study, was that it grew out of continuous discussions with and scrutiny of the Research Group. As interviewer, I was equipped with an expanded, diverse, pool of 'Some people say…' probes, grounded in the experiences and suggestions of Research Group members with aphasia. These reduced dependence on pre-prepared pictographic and photographic material that, whilst helpful in supporting interactions, may constrain responses (Lewis and Porter, 2004), perpetuate the power of the researcher and be subject to interviewer bias in interpretation (Booth, 1996). As noted in the example of my interview interaction with Sam, over reliance on concrete, pre-prepared props can operate as a 'comfort blanket' for interviewers but may act as a barrier to connection at a more interpersonal level.

### 10.1.2 Creativity and flexibility: using the stones

Cornwall and Jewkes (1995) and McIntyre (2008) argue that an advantage of PAR is that it can encourage marginalised groups to participate in novel and creative ways. Jack's interview extract highlights the use of coloured stones to select and talk about people identified as friends. This technique was central to 11 of the 12 Phase 1 interviews and was performed in 14 of the 16 Phase 2 interviews in the course of the Friendship Events. My perception was that this particular technique, rather than my armful of pre-prepared, paper-based communication props provided an effective tool to 'kick start' conversations

about friends and friendships in a flexible, participant-centric way. As a member of the Research Group commented:

> 'It's absolutely physical…it does not require language. You can see the outcome. It's individual seeing. It's individual…and democratic' (Research Group 21)

Without explicit instruction as to how to define or position friends, most participants selected and arranged stones, thoughtfully and with minimal direction. Phase 2 interviews, which provided an opportunity to reflect on the process of the Friendship Event, identified the stones activity, for some respondents, as one of the more memorable highlights of the Friendship Event:

> CP: So you enjoyed it. Anything particularly memorable, anything that sort of stood out for you?
>
> Frank: That stones and friendship thing, yeah.
>
> (Frank, line 30)

Participants such as Tricia and Anthea highlighted the way that the concrete array of stones before them performed an affirming consciousness-raising about the number and range of their retained or new friendships.

My perception of the stones activity was that they enabled participants, without recourse to names or verbal labelling of qualities, to externalise rarely articulated matters of relationship. Respondents differentiated significant people in their lives and reflected on proximity and changing proximities of bonds, often by physically manipulating stones. The stones both supported and enriched verbal description of friendship particularly where participants had minimal access to expressive language. The spatial locating of friends around their self stone frequently led to explanations about why someone was perceived as a closer or more distant friend. Facial expressions, hesitancies or hand hovering gestures over particular people/stones offered ready openings for further probe questions.

The following sequence between Grant and me illustrates how the stones proved a useful placeholder and reference point for the slow to and fro checking of shared understandings. They externalised the co-constructing of meaning that is typical of more traditional interviews, focusing both Grant and me on establishing mutual understanding. Within this interaction, the list of names provided by Grant's wife became another resource rather than an imposed proxy voice.

CP:     OK. So if that's you there [*points to stone Grant has selected for himself*] so now pick some that represent your friends. So any (...) anyone who you'd say is your friend [*writes 'friend' in corner of page*]

Grant:   Erm OK [*decisively selects small grey stone and places it near to his*]

CP:     Yup, (...) that's a nice one. Who's this?

Grant:   (3) erm (2) erm (2) erm (5)

CP:     [*points to list of names provided by wife*] could it be any of these?

Grant:   No. Er, George, George

CP:     George. That's George

Grant:   Yes

CP:     OK [*writes 'George' next to stone*] That one's George fantastic. OK. we'll come back to him in a minute, how about any other friends that you want to (…)

Grant:   Well yeah yeah Peter! [*hand to chest then points to ground indicating*]
        Peter here

CP:     He's here in London?

Grant:   Yes, yes

CP:     Because (...) George [*points to stone*] lives in Nigeria?

Grant:   Yes

CP:     OK, do you want to pick one for Peter?

Grant:   Erm OK [*selects and places large oval stone almost similar distance from him as George*][*smiling throughout*]

CP:        OK [*touching stones*] so this is you, and this is George and this one's Peter

Grant:    Yes

CP:        good (2) erm [*labels Peter's stone*] Is George a closer friend than Peter? Or are they about the same?

Grant:    Who?

CP:        So George [*points to George's stone*] this is Grant [*labels Grant's stone*]

Grant:    this [*points to George's stone*] it's er (...) it's a real- (...) *more more*

CP:        He's *more* of a friend

Grant:    Yes, yes.

CP:        So he's a closer friend

Grant:    Yes

CP:        OK so he's a bit closer than Peter

Grant:    Yeah

CP:        So, erm that's interesting isn't it, so even though he lives in in Nigeria

Grant:    Yes

CP:        He's really (…) he feels like he's a good friend?

Grant:    Yes

            (Grant, line 809)

Physically locating and naming the stones representing George and Peter in relation to the stone he chose to represent himself, meant we had two firm reference points which we could mutually confirm.  Spatially the stones gave a little more information about Grant's perception of proximity or closeness to these friends. This transcended geographical proximity. Later in the interview, exploring why George was perceived as such a good friend it emerged that he co-founded the engineering business with Grant in Nigeria. Grant and his wife contacted George by Skype on a weekly basis. Temporally, the visual plotting of himself and his friends as stones meant that we had navigational points in our conversation which were often important markers as the elicitation and

verification of meanings between us could take quite some time, putting an additional memory load on both myself and Grant.

The physical properties of the stones seemed more salient for some respondents than others. Some participants chose handfuls of stones at random whilst others carefully searched for pebbles or coloured gems whose colour, size or shape represented an attribute of friends that could add nuance to the description of a particular friendship. Priya, for example, talked of her purposeful selection of boldly coloured and uneven, misshapen stones for three of her closest friends:

Priya:     I pick this girl as my friend because she is my clo-, erm, my best friend and, erm, she's been there through thick and thin and she's solid and, erm, she is not blue but erm, she is like, blue is like a solid colour and erm, yeah, like I want to (…)

CP:        (…) To represent something solid, she's been there?

Priya:     Yeah. And (3) my two other friends, erm, from uni, erm, they're here. And I've chosen the, erm, the like, a strange erm, formation erm, (2) for them both and, erm, because I've been [*clears throat*], it has been a rocky road to get their friendship back. Erm.

CP:        So both quite sort of knobbly

Priya:     Yeah

CP:        and interesting shapes,

Priya:     Yeah

CP:        sort of (..) not a smooth shape.

Priya:     Yeah. So that is the two that represent them.
           (Priya, line 1240)

Whilst the stones acted for some as a tool to enrich or differentiate descriptions, it was not a technique that worked for everybody. Two participants with very severe aphasia (Sam and Richard) did not take part in the stone selection and another with less severe aphasia (Derek) chose to observe rather than participate in the activity during the Friendship Event.

I asked myself whether Sam was unable to understand the concept of the stones or just unwilling to engage in discussion with me about his friends. Or perhaps non-participation was because he had no-one whom he now identified as a friend after two years living in virtual silence. Richard also had severe aphasia and seemed reluctant to participate in the activity during the Friendship Event. His reasons seemed more to suggest he just didn't see the point.

In summary, a consistent finding for individuals with and without severe aphasia was that a 'one-size approach' to communication access didn't fit everyone  (Palmer and Paterson, 2011). The coloured stones and 'some people say …' probes, fuelled by stories from the first wave of interviews (with Research Group members) and the on-going Research Group discussions, were powerful supplements to the traditional array of supported conversation techniques. Participation in this project inevitably drew heavily on my skills as an experienced communication supporter and exponent of the principles of communication access (Pound et al, 2007). It confirmed the call for researchers to develop skills as good supporters of communication as well as good interviewers  (Parr et al, 1997; Luck and Rose, 2007).  Techniques such as the use of key word writing, pictorial artefacts supporting spoken language, creative use of silences, frequent summary and spoken and written verification of information gleaned have all been facilitative in shaping mutual understandings.  However, as a Research Group we have reflected that creativity, time and a blurring of boundaries between effective and affective communication have characterised participation that is more than communication support.  In other words, establishing connection and trust and ways of exploring previously unexplored territory pertaining to relationships and self, may require more than a set of supported communication techniques.

### 10.1.3  Cycles of action and reflection

PAR is characterised by cycles of action and reflection. New thoughts fuel new activity cycles in a corkscrew fashion (Baum et al, 2006).  Data collection and

data analysis are nested within a creative, dynamic, collaborative process that should amplify the voice of those who own the 'problem' rather than those who are viewing it from the outside. Two processes that emerged from and corkscrewed through the action and reflection spirals in our project were the development of the Forest of Friendship diagram and the Friendship Events. These have been selected both because they worked well and because they are original in the context of participatory research with people with aphasia.

## 10.2    The Forest of Friendship diagram

Some Research Group members who participated in Phase 1 interviews had experienced difficulty in interacting with the raw, verbal data and detail of the interview transcripts. In these extracts, both Melanie and Katie reflect on the impact of being confronted with their altered language and a revisiting of traumatic times.

> CP:      So firstly just erm, what were your general reactions to the transcripts. Any (…) What did you think when you got them, took them away, read them?
>
> Melanie:  I felt very sorry. Sad. Yeah. I didn't find it (…) You know, when you came, Carole, that's fine. But I found it very upsetting actually to read them.
>
> CP:      Can you say why?
>
> Melanie:  Because I thought this isn't very, this isn't very good and I couldn't express myself and erm, (…)
>
> CP:      So it's more in relation to how you'd expressed yourself?
>
> Melanie:  No, no. It (3) It was just [*sighs*] the sorrow and just feeling [*sighs*] (…) And what I said, do you know what I mean. Yeah.
>
> CP:      It sounds like – tell me if I've got this right – a combination of what you were saying but also the manner in which you'd expressed it?
>
> Melanie:  Yes. Yeah.
>
> CP:      So two things going on.

Melanie:   Yeah, yeah, yeah.
           (Meeting to review transcripts, line 65)


Katie:     Erm, the first time I saw the front two pages I wanted to cry

CP:        Yeah.

Katie:     Because erm, I couldn't (…) I'm going to cry again. [*gets audibly upset*] Because all my life I have been, erm, careers, careers?

CP:        Yes.

Katie:     I have been open and honest and this stroke disallowed me to be the way I wanted to. So erm (4) And yeah.

CP:        In that it stopped you being gregarious are you saying or (…)

Katie:     And the (…) Yeah, yeah. The funny (…) Because none of the sentences make any sense. [*laughs*] I, I did erm, get used to answering the questions after the tape went on. Erm, but erm, I still think (…) I erm, if you had a camera and I still wanted to do, erm, this (…) Say four years ago I would have said no. Because I could not have, erm, put anything into words. I couldn't. So I said no, no, no, no, that's not for me. Now, erm, I can see how important it is and I want to do it. Erm, but it doesn't mean that the first three pages I still cry about. [*laughs*] Because it's terrible. It really is bad.

CP:        Can you say what you mean by bad?

Katie:     The language is bad (…)

CP:        Mmm

Katie:     Erm, hmm, yeah, about yes. It is all filled with gobble, gobbledegook, gobbledegook. It doesn't make any sense.
           (Meeting to review transcripts, line 128)


Subsequent to this experience, we adopted a different approach to co-analysing data. The Forest of Friendship diagram, first introduced in Research Group 7, was an attempt at employing a flexible, communicatively accessible tool that individuals with aphasia could engage with, interrogate and

manipulate. It was an experiment in co-analysis. Participation in data analysis as opposed to data collection challenges researchers who work with people with communication, cognitive and learning disabilities (Nind, 2011). Nind adds, however, that including the voice of marginalised populations in analysing and interpreting data is important because it is political. Participation in analysis is political not only because it reinforces the politics of inclusion but also because learning how to involve marginalised groups better may guard against the possibility of researchers using appropriated stories to illustrate the narratives and discourses of academics (Walmsley and Johnson, 2003).

As described in Chapter 7, the first iteration of the diagram acquired its name, the 'Forest of Friendship', as we discussed the resemblance of the mind map to a series of branches and twigs and the association of friendship and forests to states of enjoyment or becoming lost. Some group members talked of appreciating the visual layout, with clear branches and twigs as a way to acquire a tangible, more memorable hold on a slippery and wide-ranging topic. Some group members reported that the mind map allowed them to stay with the complexity and dynamism of friendship without over-simplifying rich, conceptual data (Research Groups 19, 20). The branches, which represented emerging themes and understandings of friendship and aphasia, seemed to affirm a sense of interweaving concepts whilst enabling discussion of friendship issues in 'bite sized chunks' and the active pruning or growing of new branches.

Several Research Group members commented on visual dimensions of colour, positioning of branches and overall shape of the image as they reflected on the function of the diagram in supporting their engagement with the research. Colour differentiated themes and acted as a helpful tool initially when locating the different branches we were discussing and exploring how branches differed and interlinked. A more symbolic contribution of colour emerged towards the end of our discussions about Phase 2 data (Research Group 19). One Research Group member suggested that the anchoring, rooting quality of 'My friends are my anchors' theme, might best be represented by a brown coloured branch. Another group member then

suggested that the Anchors theme might be better situated at the bottom of the diagram in a root-like position. This led to repositioning of 'Friendship and Identity' as the upper most theme of the diagram and a suggestion that this too might be re-coloured to represent a more skyward and hopeful orientation. So the final version of the diagram (Figure 9.1) retained the affirming Anchors and Identity themes as a holding framework for the other branches but reversed their positions from the original diagram (Figure 7.2). The group also debated how best to represent power visually within theme 4 and the diagram. Ultimately, one group member advocated for a twisting twig that hooked around and encompassed related sub-themes (Research Group 20).

With Research Group meetings typically held at one monthly intervals the diagram became a way of rapidly recalling and summarising past discussions and negotiating and agreeing new decisions about the data, particularly following Phase 2 interviews (Research Group Meetings 18-21). The diagram acted as a memory aid and placeholder for a large volume of data. The diagram was perceived as innately organic, rather than fixed. Research Group members with aphasia suggested that the branches and twigs enabled them to talk about, manipulate, question or reject different concepts in a more unconstrained manner than if faced with linear, verbal data. From my perspective, this collective grappling with the data and the organically evolving diagram was an important step in members of the Research Group taking ownership both of the preliminary model of friendship and the project itself.

Towards the end of the project the Research Group reflected with some pride on what had been created.

> 'Its not a plain, not 3 D, its more …multi-dimensional' (Jeff)
> 'the idea that we've created that is …quite good…obviously you've done lots of work but…we sort of invent, yes invent ' (Barbara)
> (Research Group 20)

> 'it's fantastic…it's there' (Binda)
> 'very good …we're …proud' (Barbara)

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'it's a little …a little masterpiece' (Tom)

(Research Group 21)

In summary, across the course of the project the evolving Forest of Friendship diagram created a platform for dialogue, supporting:

- Accessibility, from a language and memory point of view
- Repeated opportunities to visit and revisit voluminous data in a manageable way
- Co-analysis of emerging data from Phase 1, and particularly Phase 2, interviews
- A process of co-constructing and co-owning knowledge about friendship and aphasia

## 10.3   The Friendship Events

Within cycles of reflection and action the Forest of Friendship diagram also played a role in scaffolding the content of the Friendship Events (Research Group Meetings 8-17; Appendix L). Alongside the final version of the diagram, these Events represent a second important exportable product. The purpose of the Events was to find a more participative way for people with aphasia to think together about friendship. This section describes how the Events may have impacted on the project outcomes by reflecting on:

- How participants perceived that the Events changed their awareness of friendship
- How participation in the Events influenced the engagement of Research Group members in the research process.

### 10.3.1  Awareness of friendship

Many Friendship Event participants echoed Frank's views that friends and friendships were largely taken-for-granted and that it was unusual to have an opportunity to reflect openly on them. For example, asked for his general reaction to the Friendship Event, Frank responded:

Frank:     It made me think about friends actually.

CP:         Right. Was that something you had done before or not so

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much?

Frank:     No.

CP:         Thought about friends?

Frank:     Not really. I mean I just, you take them for granted really, don't you.

(Frank, line 64)

Cherry indicated that both the topic and the challenge of talking about it required warm up time:

Cherry:   And (…) Yeah. Erm, me erm, aphasia but (...) can't speak. And then slowly, slowly. [*gestures winding up mouth*] Erm, talk about it.

CP:         You're talking about for yourself?

Cherry:   Yeah

CP:         That looks like as you're indicating, you sort of almost *warmed up* as the day went on. Is that (...)?

Cherry:   Yeah, yeah.

(Cherry, line 66)

Although not all interviewees appreciated the stones activity during the Friendship Event, a majority of interviewees appraised it with interest, commenting specifically on the way it had raised their awareness of the affirming role and presence of friends. Trisha, for example, reported enjoying the realisation of how many different groups of friends she had:

Trisha:    Yeah. It was, it was funny because I thought oh, I need to put friends in, Tai Chi, drinking friends, friends I went to school with, and friends I drink in another place in erm town, and yeah, it's funny. (2)

CP:         Funny in (…)

Trisha:    Because you have to think about how many friends you've got then. I felt really *cool*. [*both laugh*]

(Trisha, line 38)

> Trisha: *Therapeutic* and *interesting*. Yeah, yeah.
>
> CP: Hmm, hmm. What did you think was therapeutic about it?
>
> Trisha: Well, thinking about all my friends, that was nice.
>
> (Trisha, line 130)

Derek was one of two Friendship Event participants who declined to participate in the stones activity. He described, however, how observing peers selecting and talking about retained friendships in this way, had prompted reflections on his own friendships. This led him to question whether his strategy of self-withdrawal needed reviewing:

> Derek: Yes. I couldn't really relate to the stones. Erm, erm, cl- close friends erm, I *don't* have anymore.
>
> (Derek, line 363)

> Derek: Erm, so I, I have since last week I, I have done some serious th- thought, consider it about getting in touch with a couple of old friends who I would call, you know, erm, very, very good friends. Erm, to, to, I, they, erm, … … I'm sure that they would be very understanding. But *now* several years down the line I think, listening to people [*at the event*] I think that yes, I should have more *faith* in others.
>
> CP: And that's something that came out of the, it's a sort of thought that occurred to you after
>
> Derek: [Yeah.
>
> CP: after the day?
>
> Derek: Yeah. Yeah. Yeah. Erm, mmm, yeah.
>
> (Derek, line 303)

Although the project did not aim to probe the views of friends and partners, some Phase 2 interviewees commented on showing Event materials to others. Anthea reported recounting the day to her friends at the residential care home where she lived. Ron showed the booklet to his long-standing friend from the tennis club who visited each week. Gary invited his friend, Jack to the interview where he shared his own responses to the booklet and artwork:

> Jack:     Different literature Gary has provided me, has gone a long way to help me at least appreciate *part* of what Gary is going through. So I can better, erm, be there for him
>
> CP:     Get an insight.
>
> Jack:     Even if it's the *tiniest* little fraction of appreciation what it's like, just to be better erm, better help, better friend. Erm.
>
> Gary:     True.
>
>     (Gary, line 1198)

Shana revealed the more negative side of awareness-raising. Shana became tearful as she viewed her two stones – herself and her ex-partner Danny. He was the only person whom she now felt she could call a friend as he was the only person who knew her from before her stroke and could still connect at a deep rather than superficial level.  Her lone two stones contrasted the clusters of friends identified by others in her small group.

The days seemed to provide a space and some techniques to muse companionably on friendship. Seeing and hearing representations of other people's friendship circles and listening to many diverse stories of friendship loss and maintenance provided a context to think about and talk about friendship. The stories of presenters painted some points on a canvas against which others could begin to map their own experiences. These stories and examples proved useful material in eliciting further material in the Phase 2 interviews.

### 10.3.2 How did participation in the Friendship and Aphasia Events influence engagement of Research Group members with aphasia?

Reflecting both on the Events, and the project as a whole, we evaluated the functions we perceived the Friendship and Aphasia Events to have played (Research Group 18). They had affirmed the importance of the topic, and enriched the pool of diverse friendship stories, providing new examples of positive and creative friendship maintenance as well as the negative impacts of aphasia on the quality and quantity of friendships.  The body of stories of resourcefulness and resilience influenced our decision to add the Humour and

Doing friendships differently branches to the revised Forest of Friendship diagram.

General reactions to the day from Research Group members with aphasia who had attended and led different sections of the day echoed evaluations by Event participants. They commented on tone, the richness and diversity of stories, their perception that the days had met the stated aims of sharing experiences and raising awareness of friendship. One person described the day as 'uplifting', another as 'enjoyable', another as 'empowering':

> 'Did what we said on the tin!'
>
> (Tom, Research Group 18)
>
> 'It was good to meet other people I hadn't met. Because it's nice to talk to other people and they say that's not what I do or it's the same. It sort of …not empowered you …what's the word ...re-affirms. … … But it was very nice and I felt invigorated and ...that spurs you on.'
>
> (Melanie, debrief, March 5, 2012)

Melanie was one of several Research Group members who commented on feeling more directly engaged in this more action-orientated component of the project compared to some of the abstract discussions where she felt she struggled to hold onto all the ideas. One Research Group member commented, however, in an email after the day that he felt 'a spare part'. Despite my observation that he had deftly supported the sharing of stories, and contributed a natural warmth and humour to the atmosphere at his table, he felt that the day could have run just as well without him. All participating Research Group members, however, agreed that hearing the stories of others had been interesting in affirming and extending understandings of friendship expressed by the branches of the diagram.

In summary, all of us, bar one member of the Research Group (Debra) attended one or both Events. We shared a perception that the rich interweaving of participatory processes at the Events facilitated a layering of experience, scrutiny and engagement that dynamically enriched processes of Phase 2 data collection. As Jeff described it this was a process of 'layer upon

layer' (debrief Friendship Event 1) that kept us from over-simplifying a complex and dynamic topic. These experiences interacted with our new iterations of the diagram enabling a second meshing of data, analysis and Research Group discussion.  I noted in my research journals a more active engagement in theorising through participating in the Events (Research Group meetings 18-20). This collaborative grappling with data, which confirmed or added to our model of friendship, enhanced my confidence both about the quality and authenticity of the Events and about the credibility of the Phase 2 data.

## 10.4    Engagement and aphasia: beyond supported conversation

Addressing practical, structural barriers to communication through principles of good communication access undoubtedly supported participation of people with aphasia in the interviews, the Friendship Events and the Research Group meetings (Kagan, 1998; Swinburn et al, 2007). The research also offered strong reminders not to assume that because good communication support is in place, researchers can expect that interpretations and representations of experience are shared. Nind and Seale (2009) and Nind (2011) make a similar point in their attempts to explore access issues with people with learning disabilities. Unchecked researcher bias is an important issue where participants have impaired access to language (Lloyd et al, 2006; Goodley, 1996). In this project two factors were particularly salient to my own attempts at enhanced credibility – time and engagement from the outset.

Time is a well-acknowledged resource underpinning both communication access (Parr et al, 2008) and PAR inquiries (Koch and Kralik, 2006).  However the reality of fully identifying and responding to temporal barriers in everyday life and indeed research practice has been less well addressed (Hewitt and Pound, in press).  In our Research Group meetings, in my one-to-one follow-ups, in the interviews and in the Events there was never enough time. However, the PAR process gave us an opportunity for sustained contact and a stretching of conversations over time.

Exponents of PAR acknowledge the benefits of its flexible approach to collaborative exploration of complex issues (McIntyre, 2008).  A strength of this project was the extended period of time we spent grappling with and developing both the model of friendship and the Events.  A fluid, back and forth movement between abstract concepts, personal stories and the organic mind map ensured we did not rush or trivialise the complex, dynamic dimensions of friendship. For example, we spent three consecutive meetings discussing and revisiting Phase 2 data and it's fit (or lack of fit) with the original version of the Forest of Friendship diagram (Research Group Meetings 18- 20). Similarly we met monthly for over a year to plan, develop, test, edit and rehearse activities for the Friendship Event.

An implication for others wishing to engage in PAR with people with language and/or cognitive impairments is the importance of spending adequate time and space with the data and developmental material, cyclically visiting, returning to and revisiting decisions. Creating communicative space is viewed by Kemmis (2006) as fundamental to mutual understanding and democratic consensus-building that drive the emancipatory aspirations of PAR.

The cyclical long-term nature of engagement, together with its conceptual and procedural flexibility provides richer opportunities for co-researchers in PAR to take ownership and control (Smith and Romero, 2010). Collaborative shaping of focus and aims may also require a willingness to stay with uncertainty and unpredictability. This is a process which Herr and Anderson refer to as 'designing the plane while flying it' (Herr and Anderson 2005:69). Using a slightly different analogy of flight, Tom referred to the voyage of discovery in the Friendship and Aphasia study:

> Tom:    when it begun we didn't know what it was …it's like could be anything really … … I quite like the idea of the unknown you know and it was like, like …Star Trek!
>
> Jeff:    Beyond ! [*laughter*]
>
> Tom:    Yeah …boundaries …the frontiers
>
> (Research Group 21)

Within our Research Group, there were those who enjoyed the creativity and control of the unknown. For some people it affirmed a sense of having control and 'being given the reins' rather than being treated as 'guinea pigs' (Pound, 2010; Research Group 5). For others, the strategic vagueness and evolving, rather than ready-made focus, engendered self-conscious concerns that their aphasia was again a barrier to clear understanding. For one group member, as the plane and mechanics of flying grew in size, she reported the challenge of holding onto all the pieces. Despite the supporting diagrams, accessible notes and frequent recaps she reported feeling overwhelmed with so much information. Only towards the end of the project, when we instigated regular one-to-one Facetime conversations between meetings, did she report that her conceptual grip on the project felt more under control. Asked how she perceived these interactions she hinted at the challenge of balancing engagement with full grasp of the issues.

> 'For me I want to be involved, you want to be engaged. I can see you, I can communicate with you, I can talk with you about some of the issues …It reminds me about it cos I've got all this stuff and I can't quite get hold of it...then I feel more engaged and that motivates me to come to London…I want to be there and I want to be part of that'.
>
> (Facetime conversation with Melanie, February 2013)

In summary, emergent rather than clearly mapped out direction of travel and an overwhelming amount of data, ideas and project 'stuff' challenged full engagement of some Research Group members with aphasia. In this context, enabling Research Group members to initiate questions and actions, and co-own theory-building, required a sense of trust developed from being involved at the outset, and a constant attention to time.

## 10.5   Countering psycho-emotional disablism in research

Psycho-emotional disablism has been introduced in Chapter 3. In contrast to structural forms of disablism, or disadvantage arising from physical and environmental barriers, psycho-emotional disablism refers to the harmful emotional consequences of exclusion and discrimination caused by impairment effects (Thomas, 1999). Reeve (2002) has argued that psycho-

emotional dimensions of disablism are important because they can reproduce experiences of rejection, shame and worthlessness. The negative effects of psycho-emotional disablism are also relevant to the dynamics of research relationships (Tregaskis and Goodley, 2005), particularly where impairment effects relate to language. The presence and impacts of psycho-emotional disablism arose, to my knowledge, at several points in our research journey. I expect it arose on many occasions of which I am less aware.

Two members of the Research Group with aphasia regularly requested if there were ways they could help me with different aspects of the project e.g. preparing talks, investigating contents and materials. Although I responded with a range of tasks and ideas, in practice they often did not carry them through due to difficulties with memory, language or not knowing where to start. Operating alone rather than participating in the creative conversation of the group seemed more challenging. Initiating and carrying through tasks alone didn't play to their strengths, but furthermore it could serve to undermine confidence and reinforce the frustrations of language impairment. Melanie, for example, talked of the 'double edged sword' of wanting desperately to engage and be engaged but re-experiencing the trauma of language inadequacy and the frustration of not matching up to her intellectual capabilities before her stroke (Pound and Laywood, 2012).

Some interview respondents remarked on internalised oppression linked to feeling somehow unworthy of the rich 'communicating friendships' (Little, 2000) described in Chapter 2. Katie, for example, reported questioning whether she was unworthy of being included in rapid group conversation between friends. Binda, although he considered that his friendships were solid, spoke of perceptions of shame and sudden confidence dips. These lurked just beneath the surface, and were still capable 20 years later of catching him unaware. A surprising number of participants in the Research Group spoke of being 'lucky' if they had made or retained friends as if this were somehow unusual or unexpected post-onset of aphasia. Research Group members also discussed how in the early fog of aphasia, the period of 'not knowing', it is easy to be unsure if friends are still there or not.

Perceptions that friendship loss is inevitable may be self-fulfilling. Priya reflected back on a prolonged period of self-questioning which lasted approximately three years. She reported being uncertain during this time whether friends 'were there' or not. A process of recovery and a process of explicitly thinking about friends and friendship during the life of the project had convinced her that friends 'were there' throughout, but she did not always know this:

> 'It's funny my friends were always *there* throughout … erm well my journey [*laughs*] of having a stroke and having aphasia and everything like that but I didn't know they were *there* at first. But it's funny that this is the last meeting now that erm, that I know it's … *cemented* that they are *there* and I *know* it. They were always there anyway but I now know that they were there … I think I was in this, like this cognitive haze or yeah things like that and I didn't know, I didn't actually know they were there but they were there throughout'
>
> (Priya, Research Group 22)

An aspect of psycho-emotional disablism that was apparent during my prolonged relationship with Research Group members was the way the invisibility of their impairment and the absence of their voice seemed to expose them to a constant buffeting by dominant discourses. The two dominant public discourses about disability during the three years of this project were the prominence of the Paralympics and the reform of welfare benefits and associated labelling of benefits claimants as scroungers. Neither of these discourses acknowledged or progressed discussion of disabled identities for people with language impairment. Experiencing communication needs consistently overlooked with family, service providers and welfare systems represented an everyday experience for most Research Group members.

Other insights into psycho-emotional disablism that may be inadvertently perpetuated in academic research and/or professional practice arose in discussions about current research in the area of friendship and social support. For example, research messages about losing friends, needing

psychological support or 'Living successfully with aphasia' triggered powerful reactions in the Research Group. These centred on perceived stereotyping, over-simplification and invisibility of their own more nuanced experiences and identities within research, policy and practice. This motivated a desire to shape and control messages and be able to recognise themselves in the research (Lunn and Munford, 2007). Being 'out' about disability in a way that affirms identity requires attention to language and inadvertent replaying of dominant discourses. Being clear about (unavoidable) impairment effects without perpetuating (avoidable) psycho-emotional disablism (Thomas, 2010) is a fine line (Tregaskis and Goodley, 2005). I fell into this trap on several occasions. For example, preparing for a co-presented talk, one Research Group member asked me to amend a slide explaining the multiple impacts of her aphasia saying she was not prepared for it to be a 'freak show'. In a discussion about the branches of the friendship model, an early suggestion of naming a branch 'holding on' to friends was rejected by several Research Group members with aphasia for reinforcing a perception of victimhood and lack of agency. Other examples were less subtle. For example, on several occasions when we presented at conferences or academic events, co-presenters with aphasia were omitted from conference programmes and speaker biographies. Alternatively, organisers chose to describe them as 'stroke survivors' or 'patients'. On one occasion, a talk about the experience of communication after aphasia was billed as 'Communicating with the damaged brain'.

For me, in my research facilitator role, a key benefit of working with and being accountable to people with aphasia at every stage of the research process was a reminder to be aware of psycho-emotional disablism. This entailed constant monitoring and awareness of my own professional assumptions and discourses. Trusting, honest relationships and taking time together to talk about language, stereotypes and the experience of 'fitting in' were crucial in this project to developing more nuanced and recognisable portrayals of friendship and aphasia.

**10.6    Voice, ownership and authorship**

Issues of dissemination raise questions of voice, and ownership and power within PAR. Emancipatory disability research and Freirean origins of PAR promote empowerment from within rather than power gifted from supportive others (Freire, 1970). Participatory research initiatives with people with learning difficulties illustrate how support from academic allies without learning disabilities, in an interdependent research relationship, is an important pre-requisite to practical involvement in creative research processes (Walmsley, 2001; Booth and Booth, 2003).  However, interpretation and dissemination remains largely under the control of non-learning disabled academics (Aldridge, 2007; Walmsley, 2001). Service users as co-authors remain almost entirely absent from action research studies conducted within social work and nursing (McVicar et al, 2012; Munn-Giddings et al, 2008). These studies underline the challenge of sharing power and ownership of research even where intentions and values fully support participatory practices.

Issues of ownership and authorship have created an ongoing tension for me in this project that also constitutes my PhD research. Early on, authorship and control of the language of the project arose in the writing of Research Group meeting notes. As convener, facilitator and researcher, but also as the group member most able (linguistically) to record, summarise and produce meeting notes, I was charged with recording discussions and decisions from the meetings. Documenting    collective    decision-making    was    relatively straightforward. However selecting illustrative points and quotes to include (or not include) from lengthy three-hour group discussions where individuals held different and sometimes divergent opinions proved more challenging. Contributions that were more lyrical, metaphorical or attuned with my own views invariably stood out for me. Generating notes that offered clear markers of group navigation yet also captured democratically the flavour of individual experience were inevitably under the control of my selecting voice. Producing notes which gave sufficient context to our day-long discussions without overwhelming group members with aphasia with endless pages of dialogue was also a challenge.

Reviewing with hindsight the style and voice of the Research Group meeting notes, I questioned my choice and use of pronouns. From the first group meeting I adopted a convention of 'we', referring to all participants in the Research Group and me. The representations in meeting notes under a heading 'Some of the things *you* said' were an attempt to represent the polyvocal views of group members with aphasia (for example, Research Group 21, Appendix M). The meeting notes also employed multiple forms of 'I': the 'I' of the researcher providing information or training about research process; the 'I' of the practitioner providing insights or understandings about the practice of stroke care and rehabilitation and the 'I' of me as a person with experiences of friendship and disability. The 'we' of these notes therefore concealed the different versions of 'we' as I shuffled between multiple identities and as, over time, we individually and collectively shifted researcher roles and relationships.

Wadsworth (2006) reflected on the shift from the royal 'we' to the 'we' achieved and earned through the work of building trust, sharing understandings and doing the work of PAR. Writing and speaking about the research exposes the competing demands of doing PAR with a commitment to collectivism whilst doing a PhD governed by the rules of individualism (Klocker, 2012). My own confusion about when and whether I was operating inside or outside the group probably did little to clarify the fuzzy boundaries between the participatory project and the production of a thesis. Zuber-Skerritt and Fletcher (2007) draw on Wisker's (2005) schematically represented twin buildings of action research and the action research thesis. Realising that we, as a Research Group, own the project and its outcomes but I, as an individual, own the thesis writing should perhaps have been an earlier insight.

The tension between our process (the project) and my product (the thesis) created more discomfort towards the end of the project as I spent less time with the group and more time in the solitary, distancing process of writing. Frequency of Research Group meetings declined as I spent more time alone, in my thoughts and interpretations of the project, trying to clarify my version of events based on our collective actions and insights. Inevitably, the end game

of writing up also focused my mind on the differences between my co-researchers in the group and me, and on issues of ownership and reward. I will (hopefully) receive a PhD for my efforts, my co-researchers will not. I have been reminded through the grueling process of trying to think clearly, frame ideas in first choice words, read copious material and manage large quantities of words that such 'burdens' are not an option for my colleagues with aphasia. Several members of the Research Group are keen to co-author journal articles and other written features about the project. Aware that an authentic co-authoring of research papers in the context of aphasia will take some considerable time, we have put this task on hold until after the thesis is submitted.

The issue of presenting and writing together is significant in two ways. Writing in qualitative research is widely acknowledged as a process integral to clarifying, questioning and sharpening interpretations of data (Creswell, 2003; Wolcott, 2009). To exclude people with aphasia at this stage is to remove their voice in the important theorising within PAR (Kemmis and McTaggart, 2008). Secondly, greater participation in framing and articulating messages represents a further opportunity for naming the problem and consciousness-raising about friendship (Freire, 1970). Not to participate in this process may diminish opportunities to experience an empowering sense of confidence derived from relational and reflective knowing (Park, 2006). However, expectations of original, critical, student-led PhD research clearly require that I am the author of the final thesis and my voice inevitably will be dominant. Klocker (2012) has asserted, that PhD students wishing to employ PAR methodologies should not be put off by these tensions but should seek institutions and supervisors who are open to exploring the benefits as well as the challenges of engaging in participatory research. Attending to voice and authorship, reflecting on it and raising it explicitly with fellow participatory researchers is integral to PAR.

## 10.7   Research relationships and relational identities

Reflection on research relationships is an important characteristic of qualitative research (Patton, 2002; Silverman, 2006). Sustained reflection on

evolving and long-term relationships in PAR is a defining characteristic of the methodology (McIntyre, 2008; Maguire, 2006).

Stringer (2007) proposed a definition of community-based action research as 'the search for understanding in the company of friends' (Stringer, 2007:214). Conducting research within an ethic of friendship has been widely advocated by feminist scholars who draw attention to the similarities between the qualities of friendship and respectful, reciprocal, research relationships (Tillmann-Healy, 2003; Sassi and Thomas, 2012). There are perils as well as possibilities associated with friendship that again have been well debated within feminist grounded reflexivity. Tillmann-Healy (2003) noted that conversation, compassion, giving, a concern with everyday involvement and vulnerability were all features of research friendships that can enrich relational ways of knowing.

The perils of friendship concern the ease of exploitation and subtle manipulation (Huisman, 2008), the possibility that friendships may fracture (Sassi and Thomas, 2012) and the challenge of responding to friends/co-researchers who are needy within busy lives (Gatenby and Humphries, 2000). These authors have suggested that the formation of friendships is part of the methodological risk taking associated with PAR. Researchers may be unable to respond to and offer the levels of support requested by group members. The PAR group may face criticism for being no more than a support group (Gatenby and Humphries, 2000). Disengaging from projects without abandoning people and communities that have been the focus of research is a contested issue for feminist ethnographers as well as practitioners working within PAR groups (Koch et al, 2002; Stacey, 1988).

My motivations for asking people with aphasia to get involved were practical, political and professional. I needed allies and colleagues to help to design, deliver and disseminate the project. I believe that democratization of knowledge will enhance the quality and impact of the research. Professionally my experience has been rooted in the engagement of people with aphasia in developing training and support initiatives. I wanted to explore this way of

working within a research context. As the project progressed I recorded my own reflections on the benefits of working closely with the Research Group. In addition to challenging taken-for-granted concepts and practical support with research tasks, these included feeling emotionally supported, more confident to address a challenging topic and less lonely on the research journey. These issues were explored more fully in a conference presentation and poster developed in collaboration with the other members of the Research Group (Pound and Laywood 2012; Pound, 2010; Appendix V).

Research Group members had varying motives for getting involved and staying involved. At the outset, individuals in the group voiced a drive to contribute in meaningful, supportive, activist ways to the community of people with aphasia. Individuals wanted to participate in research that they felt passionate about, that had practical outcomes for people with aphasia, that was original and was authentically grounded in the experience of people with aphasia (Research Group 1). Towards the end of the project, group members with aphasia reflected on their reasons for staying involved over three years (Research Group 21, Appendix M). These concerned the pleasure of creative thinking together, the excitement of the unknown, and the experience of feeling that skills and contributions were valued:

> 'the project's sort of intellectual, not just conversation group' (Jeff)
>
> 'just the thinking about something different … not normal
>
> things'(Barbara)
>
> 'it's unusual … its out of the box' (Sarah)
>
> (Research Group 21)

Many of these final reflections openly acknowledged the affirming, relational benefits of working creatively together over time.

> 'Well I think all of us I think we thought … well you got the idea to use
>
> us … and I think we thought wooo … you think we're worth it … and
>
> we thought you're worth it!' (Barbara)
>
> 'being part of something … that you think is radical and … is going to
>
> make a difference' (Melanie)

'because I trust you … and I know that it would … be a laugh!' (Binda)
(Research Group 21)

Like well-balanced friendships, research relationships within PAR emphasise mutuality and reciprocity (Maguire, 2006; McIntyre, 2008). Acts of reciprocity within the Friendship and Aphasia study took many different forms. For example, across the three years working with the group I supported Research Group members with feedback on educational assignments, interview preparation, running sessions at support group meetings, funding social visits to London, providing overnight accommodation and lifts, supporting fundraising activities and campaigns. Group members supported me with humour and encouraging messages as I struggled with thesis writing. One member of the research group baked cakes and muffins to bring to the group, two group members regularly accompanied a group member with mobility difficulties to her travel assist meeting point, another supported group members with access to benefits advice. Relational reciprocity through the constant sharing of humour, emails, and Facebook jokes and information were also commonplace.

Wadsworth (2005) noted that it is not unusual for advisory groups to morph into action research inquiry groups as relationships evolve and naturally become closer. This is reflected within this project as I encountered the dilemma over how to refer to the group of individuals who started as committed advisors and have become Research Group members and friends. The three years of the project have spanned an interesting journey of research but also important milestones and events in our personal lives. These have included illnesses, family bereavements, a marriage, starting a new course, and the sudden death of one of our colleagues in the group. Naturally these events, and the shared emotions which have accompanied them, have forged strong affective components to our relationships. A prevalent topic within my research journals has been the evolving tapestry of relationships that has developed between individual group members, and between myself and other members of the Research Group.

How to end the project well, in the context of evolved relationships and unfinished aspirations became prominent toward the end of our project. We confronted the issue of endings in several ways. Over the last six months of the project it featured in each meeting. I surfaced endings as an agenda item so that collectively we could consider how best to manage the formal ending of the group and different ways of continuing relationships. As I withdrew into writing up and meetings became less frequent several Research Group members commented in phone calls or emails that they were wondering how we might maintain contact without the formal structure of the PhD. Jeff, for example, voiced a view that first I and then the project had acted, within the project, as the trunk of the tree, holding up all the branches. Without the trunk, he perceived that there was a risk that we would lose the support to operate cohesively (Research Group 22). Binda raised his concerns about ending and a desire to keep research relationships going in this email to me as the project was concluding.

> Dear Carole,
>
> I was just thinking of you and hope the your scalp has survived the pulling of your hair in the final lap of your writing long and brilliant study!!
>
> I am so, so lucky to have a close network of friends to provide me with a warm grow of companionship either in person or on the phone. BUT I feel an appreciable emptiness and somehow less fulfilled not having you and the group coming together. Therefore, beyond next month I want to keep in contact with you. I can come down by train and stay at either with John or my nephews.
>
> Do contact me if there is anything I could help with, even a laugh...or a cry! I'm all ears.....which in this weather a distinct disadvantage .
>
> (Binda, Email to CP, January 2013)

We addressed the issue of endings more formally in the final official meeting of the Research Group, where all group members shared what we would miss about the meetings and each other.  Jeff pointed to each person around the table as Tom said, 'Coming here and missing all you lot.' I used this opportunity to be explicit about the support, motivation, energy and friendship I

personally had gained from the group. Interestingly most of the discussion however was already looking forward to future dissemination activities – a writing project, redeveloping the website and future meetings to feed back on what everyone has been doing (Research Group 22)

Tom recalled our much-missed colleague Katie as he summarised the mixed emotions of sadness and achievement as the group process finally drew to a formal conclusion:

> Tom:  I mean I was thinking erm …you mentioned Katie. Yeah I was aware that she was here at the beginning and she was erm, her usual bubbly and energetic self and she was just great to have around … and she just bowed out in a way too early … in the way things are … and I think she'd be erm very pleased, very happy for us cos I think there's been this sort of journey, yes it's kind of got a bit weird and bizarre [*all laugh*] and it has been sort of up and down and in and out and weird and stuff but erm … and yet it's it is sad in one way but … that was part of the deal, always part of the deal that we did this journey together and then it ends and we're all a little unsure about what, where it's gonna go … But this is one part that's ending … it's sad but …its good … and erm yeah it's been … it's been …
>
> Priya:  Epic
>
> Tom:  Good word! [*all laugh*]
>
> (Research Group 22)

## 10.8   Summary

The experience of engaging in participatory action research had implications for the project and for each of us engaged in the project process. These meanings grouped around creativity and engagement over time, raised awareness and identity.  Cycles of reflection and action with a revisiting and reviewing of issues over time gave the project a layered and longitudinal dimension.  Time allowed us to be creative in a way that went beyond the involvement enabled by supported conversation in one-off interviews.  As

discussed in Chapter 9, an over-focus on the provision of supported conversation can underplay the importance of power and the unfettered researcher lens on the interpretation and messaging of research. Extending time together so that issues could be frequently revisited and reviewed in a familiar and trusting space and in a range of creative ways underpinned practical and conceptual developments in this study.

The building of trusting, reciprocal relationships over time enhanced engagement: between Research Group members with aphasia and me, and between individual group members with aphasia who worked on the study. Telling and listening to each others' stories and weaving these with the stories of participants in the Friendship and Aphasia Events was part of the awareness-raising process that allowed each of us to reflect on our own friendships as well as the topic of friendship and aphasia. This raised awareness was also emphasised in our explicit reflection on research relationships and on the transformations that resulted from doing research together. Raised awareness about who our friends were and what was important about friendship alongside a focus on the dynamic and changing relationships between ourselves as co-researchers brought to the surface issues of identity, as individuals and as a group.

The requirement for practical activity and visual representations of the complex, often invisible dimensions of friendship led directly to the development of the Friendship and Aphasia Events and the Forest of Friendship diagram which are two of the key products of our extensive collaborative engagement. The multiple layers of reflection, action and interaction over time, fundamental features of to participatory action research, enriched project outcomes and the overarching quality and credibility of this study.

# Chapter 11
# Discussion

## 11.0    Introduction

This chapter discusses the main findings from the study in relation to current knowledge about experiences of friendship post-onset of aphasia. It considers three sets of findings: firstly, the background context of life with aphasia, secondly, the experience of friendship and aphasia and thirdly, the meanings of doing PAR with people with aphasia. This study enriches previous understandings of friendship and aphasia by making the nature of friendship more visible through the model of friendship, the 'Forest of Friendship' diagram. The chapter describes new understandings about friendship and aphasia illustrated by the eight interacting branches of the diagram. This discussion highlights aspects of friendship and aphasia which have not been well-addressed previously, such as the role of anchoring friends, differentiation between friendship and supportive caring, the blurring of boundaries between friends and family and the association of friendship with reconfiguring of identity post-onset of aphasia. It also discusses implications for practice.

Findings relating to doing PAR with people with aphasia are discussed in the context of debates about the strengths and limitations of communication access within research and the extended forms of knowledge generated within inclusive, participatory methods. The chapter also critically appraises the strengths and limitations of the study design, and evaluates the trustworthiness of the study in relation to benchmarks of quality for PAR inquiries.

## 11.1    Friends and friendship after stroke and aphasia

This study revealed that friendship is a complex, dynamic, idiographic phenomenon. Participants in this study identified friends from contexts of work and play, friends who lived nearby or across continents, friends of long-standing or friends whom they had met and developed since their stroke. A large number of participants also identified family members and paid carers

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amongst their closest circle of friends. Participants described friendships that had endured and in some cases improved, as well as friendships that had ruptured or faded under the pressure of aphasia and changed life circumstances. People with aphasia described friends who performed predominantly support functions offering practical, informational and emotional support as well as friends associated with fun and friendship rooted in reciprocal social exchange. In short, participants in this study described rich personal communities composed of the multiple patterns and types of social, familiar and communicating friendships as described by Little (2000) and Spencer and Pahl (2006) in Chapter 2. These forms of friendship established an important platform for exploring meanings of friendship from the perspective of people with aphasia.

## 11.2   Contextual findings

Individuals in this study made sense of friendship within the pervasive context of life with aphasia. Phase 1 and Phase 2 findings showed that participants did not separate discussion of friendship from the broader impacts of aphasia. As well as loss of work and loss of income following their strokes, many participants described profound changes in lifestyle and sense of self.  The sudden onset of aphasia, at a time of life few associated with stroke or disability, was described as traumatic and bewildering. Many participants described the intense focus on family and rehabilitation in the early days as leaving little space or energy for friends. Some participants also described certain relationships that had changed for the better as time went on, and a sense of appreciation related to new lifestyles and self-learning.

A majority of participants perceived that aphasia and communication changes were not well understood by friends, family or structural systems such as work and welfare. The experience of aphasia imposed different rules of communication, effort and time. Aphasia also altered others' perceptions of competence and expectations of agency. Participants in Phase 1 and 2 of the study as well as the Research Group members with aphasia, revealed how these experiences could dominate relationships with family and friends not just in the short term but for many years after the onset of aphasia. The risk of

being excluded, undermined or under-estimated by friends, colleagues and family was ever-present.

Similar findings are widely documented in the aphasiology literature (Parr et al, 1997; Le Dorze and Brassard, 1995; Parr, 2007; Brown et al, 2010) suggesting that the experiences of participants in this study were similar to those in other studies. However the sustained focus on friendship in this study demonstrated that friendship in the context of aphasia is more complex and nuanced than has previously been suggested.

## 11.3    Contribution of the Forest of Friendship model

The open and participatory methodology of this study added both breadth and depth to previous understandings of friendship and aphasia. The inter-connected branches of the Forest of Friendship model paint a picture that expands the multi-faceted meanings of friendship encountered in Chapter 2. It provides a clear visual map of the different elements of friendship described in the interviews and Friendship Events. It highlights eight distinct but interacting dimensions of friendship. This model challenges previous notions of friendship within stroke and disability studies that make a number of assumptions. These assumptions concern narrow definitions of who friends are, assumptions about the absorption of friendship within the provision of social support, and assumptions about the nature of friendship change, most typically changes associated with friendship degradation and loss (Northcott and Hilari, 2011). The Forest of Friendship model locates the experience of friendship against the powerful impacts of aphasia but also identifies dimensions of friendship associated with agency and personal growth.

Prominent branches of the model that represent new findings in research into stroke and aphasia include:
- Two-way exchange of friendship: power, agency and reciprocity
- Friends as 'anchors'
- Friendship as a means of reconfiguring identity

The diagram's participant-centric perspective creates a more textured and accessible description of the experiences and possibilities of friendship maintenance and development than found in previous studies (Northcott and Hilari, 2011; Brown et al, 2013). These expanded understandings, in turn, indicate actionable strategies for fostering friendships post-aphasia. For example, two linked branches of the diagram explicitly suggest possibilities for supporting friendship maintenance through 'Humour and hanging out' and 'Doing friendship differently'.

The model also reveals that when supporting people with aphasia to be involved and included in friendship activities, it may be important to understand, but not to overplay, communication changes and communication access. 'Communication is only one dimension of friendship' sits alongside another seven themes. This chapter will discuss these themes in relation to previous research and theoretical explanations.

### 11.3.1 Friendship is two-way

A significant finding of this study was that friendship rests on mutuality and reciprocity rather than uni-directional effort and support. The theme entitled 'More than me: friendship is two-way' foregrounded power, balance and the two-sidedness of valued friendships. Participants described friendship as grounded in two-way hard work, conversation and support. Mutuality was associated with shared experience and shared exploration. It was linked to trust and the ability to laugh *with* not *at* one another. Reciprocity and making a contribution within friendship emerged as important aspects both of nurturing friendships and supporting subjective wellbeing. Some participants, such as Melanie and Gary, described pro-actively offering their preserved practical skills, such as baking and DIY, to friends. Jeff noted getting out and attending peer support groups as a natural context to move beyond the natural 'me, me, me' focus of the early years post-stroke. Derek noted, for him, the powerful 'buzz of wellbeing' associated with helping out peers with aphasia by providing lifts to support group meetings.

These findings resonate with key principles of social exchange theory (Blau, 1964) and its emphasis on an equitable give and take of social goods. Several previous studies suggest that loss of reciprocity in post-stroke relationships may be a source of frustration and a reason for social withdrawal (Dowswell et al, 2000; Northcott and Hilari, 2011). Participants with aphasia in a study by Brown et al (2010) highlighted the importance of making a contribution within positive social relationships. Previous studies have tended to underplay the role of reciprocal exchange or focus on changes in communicative balance. Gary, who had no physical difficulties, reported his frustration at friends who thought he was not competent to join in social activities. His motivation for offering DIY help to friends was explained as an explicit desire to demonstrate competence as well as fuel social engagement.

There is a substantial literature on the provision of social support to people who experience stroke and aphasia (Hilari and Northcott, 2006; Natterlund, 2010a). Our Forest of Friendship model emphasises two-way relationship, and inter-dependency, and so rejects simplistic assumptions about individuals within close social networks being cast as either caregivers or care receivers. It encourages increased consideration of the flow of social goods and aid over time and whether social support should be viewed predominantly through the lens of providers or receivers (King et al, 2006). The friendship model challenges the tendency within healthcare literature a) to group 'friends and family' as a single category and b) to pathologise relationships between close friends (and family-as-friends) as relationships of care rather than mutual affection and benefit. This study suggests that a philosophy of friendship, rooted in equity and choice, rather than a particular philosophy of caregiving, associated with duty and burden, may be helpful in thinking about the positive and negative impacts of social relationships on people with aphasia.

This theme, in tandem with the theme 'Doing friendship differently', which highlighted the resourcefulness of people with aphasia and their friends in adapting to and enjoying old and new activities, illustrated neglected aspects of creativity and agency within friendship. These findings contrast with the more passive explanations of friendship change highlighted by Northcott and

Hilari (2011). These authors explain loss of friends as a change in the 'social desires' of individuals with aphasia. Changed social desires were described as 'a sense that many participants were 'closing in' on themselves and wanting to withdraw from the wider world' (Northcott and Hilari, 2011:529). The authors explain this social withdrawal as internally driven, perhaps through experiences of low self-esteem, feeling more introverted or more vulnerable. In our study, although some participants described similar patterns of friendship loss, and changes in self-worth, they did not report changed social desires nor the high levels of friendship loss described by Northcott and Hilari (2011) and Hilari and Northcott (2006). These differences may, in part, reflect the greater length of time post-stroke of the interviewees in this study or their active participation in stroke support networks. The differences may also reflect the input of the Research Group members with aphasia who were critical of understandings of friendship viewed solely through the lens of communication loss and dependent social relationships.

In summary, the constant reminder that friendship is two-way reinforced the importance of mutuality, inter-dependence and agency. People with aphasia wanted to be competent contributors within friendship exchange rather than passive recipients of one-way social support.

### 11.3.2 Friends as 'anchors'

A core finding of this study was that close friends were not experienced solely as buffers to the stress of stroke impairments but more as anchors for negotiating recovery and reconfiguring identity. All but two of the 28 interviewees in this study identified a cohort of existing friends who had stayed in touch. Some of these enduring anchoring friendships provided powerful examples of the possibilities of friendship.

The metaphorical description of 'friends as anchors' surfaced in Binda's narrative. His anchor-like friends offered a sense of grounding and stability in his 'wobbly moments'. Katie and Emily both associated their paid carer friendships with the knowledge that these friends were companions prepared to listen to private troubles that they were reluctant to share with others. These

were also however the friends that shared hilarious incidents of distorted language, mutual 'retail therapy' encouragement on shopping sprees, and outings to nightclubs. Anchoring friends shared the reciprocal fun of friendship as well as being important listeners and confidence buddies.

Anchoring friendships were associated with loyalty, trust and stability. These friends seemed more able to balance making allowances for aphasia with treating their friends with aphasia as competent and as the same person as before the stroke. Like Donna's aunt (and best friend), they listened with empathy rather than sympathy. Participants in this study also provided many examples of anchoring friends who demonstrated a willingness to put in the 'hard work' of consistent friendship. For example, Sarah described her network of close friends who continued to enjoy meeting up for conversation, supper, concerts and holidays as well as weekly visits to support her with paper work. These friends were not frightened off by uncertainty about the future. They were prepared to enter a process of exploration and learning like the 'friends of virtue' and 'communicating friends' described in Chapter 2.

Participants' subjective experience of enduring connectedness and engagement with good friends challenges assumptions that friendship loss is a natural consequence of aphasia (Northcott and Hilari, 2011; Parr et al, 1997). Enduring anchoring friendships contributed powerfully to dimensions of belonging and being (Whalley-Hammell, 2009) as well as the 'doing' of occupational activity more regularly associated with professional constructions of social participation after stroke (Natterlund, 2010a; Reed et al, 2012). The Forest of Friendship model illustrated how each of the dimensions of doing, being, belonging and becoming (Wilcock, 1998) was conceptualised by people with aphasia as underpinning their understandings of anchoring friendship.

### 11.3.3 Friends, family and 'familiar friendship'

A surprising finding in this study was the number of participants who identified partners, ex-partners and family members in a range of anchoring friendships. Derek, Shana and Ron described their ex-partner as their best friend. These loyal friends provided practical support as well as constancy, a deeper level of

communication and, in the case of Ron 'the force' to motivate him to move forward with recovery. A group of male participants (Jeff, Richard, Jack, Grant, David, John, Chris), all of whom had marked aphasia, identified their spouse as their closest friend and confidant. These anchoring friends provided communication access and friendship facilitation, as well as practical and emotional support. For example, Chris's wife, Tina, ensured that friends invited them to lunch rather than dinner to accommodate Chris's fatigue; Grant's wife Sylvana co-ordinated the weekly Skype conversation with Grant's long-standing friend overseas; Karen's best friend was also the sister who supported her to co-ordinate daily carer visits.

Managing the hard work of friendship in the context of aphasia and other stroke-related impairments shows that friends who are also family often take a committed and energetic approach to offering practical, informational, emotional and communication support. But participants described other dimensions to these relationships too. Some emphasised the creativity, and resourcefulness of family-as-friends such as Richard's wife who was helping him play the guitar with one hand and Karen's sister who swapped multiple humorous, chatty text messages and photos about their pet dogs. Other participants described a sense of equity derived by anchoring family friends treating them consistently as competent and as the person they were before the stroke, even though communication changes could make balance in conversation uneven.

As noted, previous studies have highlighted the important role played by family in providing social support to people who experience stroke (Hilari and Northcott, 2006; Palmer and Glass, 2003). Studies of the experience of relatives and partners after stroke and aphasia emphasise the high prevalence of carer depression, anxiety and fatigue (McGurk and Kneebone, 2013). Although the emphasis on carer burden may reflect professional rather than relatives' interpretations of complex role changes post-stroke (Greenwood et al 2009), this portrayal of partners and family members in caring roles rather than those associated with love and friendship reinforces the stereotyping of

social relationships. This positioning reinforces the assumed passivity and dependence of the disabled person.

Participants in this study demonstrated that defining friends and friendship is not clear-cut. No one in this study referred to their partner as their 'carer' but many called partners best friends. This echoes the findings of Spencer and Pahl (2006) concerning the common blurring of boundaries or 'suffusion' of family members as friends within personal communities. It was striking in this study how many men selected partners and spouses as their closest anchoring friend, sometimes alongside other family members such as children, which echoes sociological accounts of gender differences in friendship (Due et al, 1999). Participants in this study described a range of family-as-friends and friends-as-family relationships that blurred the boundaries between friendship and family, reflecting the category of 'familiar friendship' described by Little (2000). This study suggests that the meanings of friendship for people with aphasia are not neatly aligned with the more rigid categorisation of friendship used in studies of people with stroke and aphasia, for example definitions based on kin and non-kin ties (Vickers, 2010; Northcott and Hilari, 2011). It also demonstrates that ignoring the friendship component of 'caring' family relationships and ways to nurture friendship on both sides of the relationship may denude possibilities for mutually engaging relationships.

A further finding relating to family as friends was the importance of the friendship network of anchoring friends and partners. A number of participants in this study described harnessing social opportunities and social capital from their partner-friends. David for example enjoyed holidays with his wife's work friends and Richard's wife Shirley ensured they kept up shared relationships with old musician friends. The emotional and practical support of this 'next layer' of friends, served a dual function. Firstly, they extended and facilitated the net of social opportunities accessible by people with aphasia. Secondly, they maintained important avenues of social connection for friends who were also the designated informal carers. Research findings have associated 'caring' for a partner with aphasia with loneliness, and loss of caregivers' own social contacts (Michallet et al, 2001; Natterlund, 2010b). This study

suggested that just as loneliness and isolation may have a 'ripple effect' similarly the friendship networks of anchoring family-as-friends might contribute friendship capital. Friends can operate as a resource for resilience, health and wellbeing both for the person with aphasia and their family members and partners.

### 11.3.4 Friends with aphasia

A different category of friends, also frequently identified with an anchoring sense of affirmation and belonging, were the many friends and clusters of friends identified within peer support groups. Unlike family-as-friends, where relationships were grounded in long-standing connections, strong friendships within peer support friends were a special category of 'fast friends' (Priya, Chapter 7). In addition to having a recurring presence within the 'friends as anchors' and 'friendship and identity' themes, peers with aphasia frequently personified the two-way exchange and equality of reciprocity. Friendship with a community of people with aphasia was associated with the 'warmth' of welcome and compassion experienced by Katie and Anthea in the culture of Connect, and the solidarity and collective sense of resilience described by Melanie when running her aphasia support group.

Humour was also an important ingredient in the relaxed social space of peer support. In the Friendship Events and in the Research Group meetings, an enhanced capacity to laugh and to listen was rarely far from the surface. This supports the findings of Davidson et al (2008) and Brown et al (2013) about the importance of laughter and humour in friendship conversations between people with aphasia and their friends. Simmons-Mackie (2004) and Simmons-Mackie and Elman (2011) have highlighted the role of humour in aphasia therapy as a means of affirming self, enacting face-saving strategies within clinical discourse, equalising power relations and relieving stress. Humour has also been associated with psychological resilience and the ability to moderate depression (Olson et al, 2005; Nezu et al, 1988). In this study the humour and light heartedness of peer support contexts often contrasted with the intensity of family environments. Participants indicated that in contexts of peer support,

the funny side of aphasia could be embraced and enjoyed as an aspect of aphasia difference and identity.

Many participants in this study described peer support contexts as an empathetic and alternative relational space, marked by different laws of communication, time, mutuality and humour. Differentiating the concept of peer support from friendship, Research Group members suggested that peer support might be considered the first step on the ladder of friendship, a platform from which deeper one-to-one friendships could grow, either in the group or in the wider social world.   In relation to therapy and support initiatives, the Research Group proposed a simple three-stage model of social 'rehabilitation', representing the progression through traditional therapy to peer support to friendship. This is represented in Figure 11.1

**Figure 11.1 Relationship between therapy, peer support and friendship**
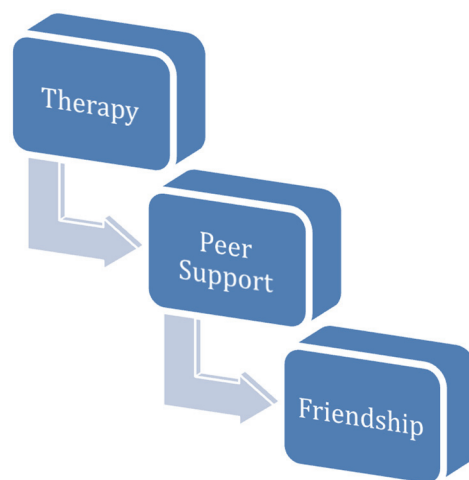


There is a growing body of evidence within aphasiology research concerning the benefits of mutually supportive social groups for people with aphasia. Benefits are known to include: changes in communication skills (Elman and Bernstein-Ellis, 1999), changes in confidence, self-esteem and identity (van der Gaag et al, 2005; Shadden and Agan, 2004; Simmons-Mackie and Elman, 2011), and changes in quality of life (van der Gaag et al, 2005). The value of

peer support in reinforcing access to social activities (Vickers, 2010) and a positive sense of meaningful post-aphasia relationships (Brown et al, 2010; Brown et al, 2013) has also been described.

However, reports in the aphasia literature fail, for example, to document and differentiate between benefits derived from peer-to-peer-support or relationships with non-aphasic therapists and volunteers in the setting. Instead they are often orientated to therapeutic aspects and outcomes of group programmes and do not specifically probe meanings and assumptions about individual and collective definitions of friendship within the groups. Nor do they probe the nature of peer-to-peer relationships outside the structure of support group meetings. In our study, for example, it was relatively rare that people with aphasia met friends with aphasia outside the context of support group meetings. This indicates that many friendships with peers were context-bound and vulnerable to loss if, as was the case for several participants in this study, a local aphasia support group was forced to close through loss of funding.

The meanings and benefits of friendships amongst peers with aphasia can be understood within theories of social identity. Jetten et al (2012) use social identity theory (Tajfel and Turner, 1979; 1986) and its further iteration as social categorisation theory (Turner, 1985; Turner et al, 1987) to explain the positive sense of self and related health benefits derived from belonging to social groups such as family, work, interest-based groups or communities of support. Originally developed within social psychology to explain issues such as intergroup conflict and discrimination, social identity theory offers support for positive social behaviours associated with collective resilience, social capital and solidarity (Haslam et al, 2008). Positively identifying with the collective 'we' of the 'in-group', in this case people with aphasia, may influence people's behaviour in different ways (Jetten, et al, 2012). For example, Sani (2012) reviewed empirical studies that suggest people are more disposed to offer help to people from the same in-group (Levine et al, 2005), respond more positively to reassurance from in-group members (Platow et al, 2007) and find humorous material presented by in-group members more amusing (Platow et al, 2005). These behaviours as well as the creative thinking and positive role

modelling of friendship behaviours were strongly present in the Friendship and Aphasia Events and many narratives describing new friendships enjoyed at support groups.

These findings support social rather than individualistic strategies for supporting people at risk of social isolation and identity change post-illness or trauma (Jetten et al, 2012). Beyond studies of disability, Vernon (2010) takes a philosophical approach to exploring friendship with peers. Likening civic friendship to the social gatherings between groups of friends at Ancient Greek Symposia, or the friendships that arose through political movements such as the Suffragettes, he proposes that these forms of group friendship encourage a celebration of the creativity of friendship. Reflecting together and protesting together, with the in-group, may operate as an important staging post, a bridge between the private and public relational space with their more defined expectations of social relationships. Embracing trust, choice and compassion for equals, may enable some individuals, like many encountered in this study, to practise friendship and citizenship rather than patient-hood (Pound, 2011). This study identifies notions of social belonging enjoyed within peer support with both individual and civic friendship.

In summary, people with aphasia in this study described a range of anchoring friends: old friends, family members and partners who were friends and comrades, and communities of friends within peer support contexts.  These relationships were multi-dimensional and experienced as offering affirmation, encouragement, belonging, courage and fun. The grounding of anchoring friendship also played a significant part in the process of 'becoming' (Wilcock, 1998) as participants shaped new identities after stroke.

### 11.3.5 Friendship and identity

As noted in the contextual findings, many individuals in this study described the strange existential experience of aphasia, and 'identity theft' (Shadden, 2005) as they metaphorically disappeared behind masks, veils and walls, either temporarily or for a period of years. People with aphasia in this study described experiences of being catapulted back to infanthood, of being

stripped naked and rendered vulnerable in the context of lost language. Loss of roles and identities associated with work and the possibility of work were particularly salient for the younger adults who participated in this study. Most recognised that roles within paid employment in the context of their aphasia were no longer an option, partly on account of their language impairments and partly on account of the lack of understanding of communication disability and communication access in the world of employment. Changed and changing sense of self in relation to pre-stroke leisure activities and family roles also featured prominently in the accounts of interviewees.

Some participants also recognised their new pre-verbal state as an opportunity for reviewing who they were after the onset of stroke. Several respondents articulated the experience of aphasia as a catalyst for self-awareness, prompting deep thinking about self, identity and relationships with friends. As noted in Chapter 2, meaningful friendship can both require and engender self-awareness and self-knowledge (Vernon, 2010).

Respondents in this study reported that close friends who, pre-stroke, were viewed as second selves, like Emily's friends from school, could hold up a mirror and reflect stark new comparisons after the onset of aphasia. Sharing the uncertainties of being friends in the context of aphasia, some friends became fellow explorers in the new social territory of aphasia. For example, David talked of how his new friend in America was intrigued by aphasia and how they had intense email exchanges about his altered language. This new friendship led to David and his wife joining his friend for a holiday in Europe. Gary's long-term friend Jack also embraced the personal growth element of deepened friendship, as he and Gary began alternative conversations and social activities together after the onset of aphasia. Trying to understand aphasia led to both parties understanding a little more about each other.

This study confirmed the multiple impacts of stroke and aphasia on identity and sense of self that have been reported in other studies of people living with aphasia and stroke (Parr et al, 1997; Shadden, 2005; Ellis-Hill et al, 2000). Although previous studies have highlighted the importance of social roles and

social activities in relation to identity (Parr et al, 1997; Natterlund, 2010a), they have not analysed the role that friends and friendships play in re-construing identity after aphasia and stroke. Similarly, no attention has been directed to the role of existing, anchoring friends as narrative partners.

### 11.3.6 The role of friends and biographical continuity

Changed sense of self and identity after the onset of stroke has been interpreted in terms of concepts of biographical disruption (Bury, 1982) and biographical flow (Faircloth et al, 2004). Biographical disruption refers to the interruption to a person's life trajectory caused by the sudden onset of disability, and the separation of past self from present self and a previously envisioned future. Biographical flow suggests that a more continuous, coherent sense of self may also be experienced after the onset of disability. Here stroke impairments become incorporated into a life-story that represents a story of transition rather than rupture. For example, Faircloth et al (2004) suggested that stories were often representative of biographical flow as stroke impairments became incorporated into understandings of aging or living with chronic illness such as diabetes.

Leaning towards understandings of illness transitions as disruptions or flow may be influenced by the age at which individuals experience stroke or trauma.   For example, Shadden et al (2008) suggest that those who experience sudden onset of aphasia at an early age may be more prone to the sudden contrast with anticipated health status and sense of disruption.

Narrative theory and narrative identity describes the lived experience of renegotiating identity post-stroke and aphasia. Ellis-Hill et al (2008) use the Life Thread model as a way of making visible the invisible threads of personal, social and cultural identity that may become frayed as stroke alters lives. Within this explanation, friends who are loyal, grounding and anchoring might represent a strong, continuous thread of life when many other life threads, such as being able to fulfil core roles at work and in the family become frayed. In the context of aphasia, the concept of invisibility may combine with the concept of silence to heighten the experience of alienation and isolation.

Some narrative accounts have suggested that people with aphasia may actively withdraw from stressful interactions that confront them with changed communicative competence and the related impacts on identity. For example, Shadden et al (2008) report the experiences of an aphasic man who preferred to spend time alone since he did not experience himself as aphasic when not in the company of others.

Just as friends who stay and friends who go may reinforce or threaten social identities, friendships may represent enduring or frayed threads of narrative self and narrative biography. Many participants in our study recognised that their friends were shocked by physical and communication changes, and often did not know what to do (Chapters 6, 7). Participants acknowledged that aphasia could be confronting of friends' own identities, as well as confronting in the way it tested their responses to and prejudices about disability. So the harmful reactions of friends who avoided or who treated people with aphasia in degrading ways could reinforce negative perceptions of self and the destructive cycles of psycho-emotional disablism (Reeve, 2002; Thomas, 2007). Experiencing shame or feeling unworthy of friendships, through the negative behaviours of friends or cultural expectations that society cannot accommodate friendship difference, may act as a barrier to pro-active attempts to reconnect social threads.

However, participants in this study also described anchoring friendships that provided reassuring and emboldening threads of self and identity. By providing stability and participating in empathic listening, friends could support the co-construction of narratives that integrated illness and biography. Friends could physically represent a thread of continuity and act as a resource to help mend ruptures and weave new biographical stories.

Renegotiation of identity has been described as the greatest challenge that confronts people who acquire aphasia (Shadden and Agan, 2004). This study supports the advocacy of narrative approaches to identity 'therapy' described by Shadden et al (2008) Barrow (2008; in press) and Pound et al, (2000). It also highlights the overlooked role that friends with and without aphasia can

play in supporting narrative reconstruction after aphasia. Narrative based approaches have been critiqued for being difficult to translate into practical 'interventions', particularly in the context of storytellers with impaired language (Bronken et al, 2012; Shadden and Hagstrom, 2007). The Friendship and Aphasia Events developed and evaluated a practical process for sharing and questioning stories of friendship, and utilising these as a means of both raising awareness of friendship and navigating changed lives with friends.  Friends as well as family members and peers with aphasia may act as important facilitators and co-creators of new life narratives that incorporate aphasia and disability. Continuous or evolved relationships with friends can also counter cultural assumptions about friendship degradation post-stroke. This evidence highlights the importance of family and rehabilitation staff having raised awareness of old friends as a resource for narrative coherence and identity work.

The humour, creativity and affirmation of friendship demonstrated within the Friendship Events and their supporting poetry, artwork and activities encourages a view of friendship and aphasia that is not solely aligned with narrative as a process of coping and recovery. Aligned with the affirmative model of disabled identity described by Swain and French (2000; 2008), this study suggests that friendships after aphasia are neither defined by tragedy nor are they about uncomplicated celebrations of connection. The scope and ambiguity of friendship underscores its potential to foster connection and communion in different ways. Our project, through its participatory methodology, offers support for different ways of understanding friendship, of 'being different and thinking differently about being different' (Swain & French, 2008:185).

## 11.4 Findings about friendship: Implications for practice

Participatory action research explores social interactions and practices in order to reduce the way these are experienced as unjust or alienating (Kemmis and McTaggart, 2008). A strength of PAR is its power to translate research beyond the generation of knowledge into actionable outcomes (Herr and Anderson, 2005). A driving motivation of the PAR group in this study was

to produce new understandings about friendship and aphasia in order to enrich the friendship experiences of others living with aphasia. This section discusses the findings from the friendship diagram in relation to their translational value. It focuses on three issues: awareness of friends and friendship; friendship within rehabilitation; and communication support.

### 11.4.1 Awareness of friendship and its importance

'Its about awareness, yes, be aware' (Research Group 22)

Many participants in this study described how easy it was to lose sight of the importance of friendship in the early months and years post-stroke. The drama of stroke, the intensity and different priorities of early rehabilitation, the dominant presence of family, the practicalities of learning to do things differently, and the additional time and effort required to do everything, were all potential barriers to remembering to attend to friends and friendships.

A second difficulty however was finding ways to talk about friendship. This study found that people with and without aphasia tended not to do so. Not talking about friends and taking friendship for granted engendered both a sense of its invisibility and a sense of powerlessness. The Research Group associated being able to have conversations about friends and friendship with an increased sense of agency and control. For example, Melanie described redoubling aspects of reciprocal exchange with friends and targeting a new leisure activity as a way to meet new friends as a consequence of her involvement in the project. Being more aware of the value and intersecting strands of friendship seemed instrumental in both enjoying and managing friendship. This has parallels with principles of 'conscientisation' where empowerment and action is contingent upon heightened awareness (Freire, 1970).

Two major ways of making friendship visible were the Forest of Friendship diagram and the Friendship and Aphasia Events. Both promoted interaction with a range of stories, positive, negative and neutral, underscoring breadth and diversity of experience rather than a single dominant discourse of friendship. The value of listening to friendship stories by others prompted an

expanded map of friendship. Within an on-going phase of dissemination with groups of people who have experienced stroke and aphasia, this map (the Forest of Friendship model) is proving facilitative of stories of recognition and raised awareness. These sessions with role modelling from Research Group members with aphasia and individuals within the group, reinforce the value of a supportive narrative community. Dissemination activity to date (Appendix U) suggests that whilst many individuals attending support groups have experienced changed social relationships and social activities, they have had few opportunities for explicit discussion of friendship experiences and strategies within these support contexts.

### 11.4.2 Friendship and rehabilitation

> 'Dynamic…friendship…my friends and I …it's lot of lot of power'
> (Research Group 20)

In this study, those designated as friends performed a range of functions that service providers might associate with successful community interventions. These included:

- Motivating friends with aphasia to practice rehabilitation exercises
- Taking exercise with friends e.g. swimming, walking, attending Pilates classes, going to the gym
- Supporting a return to driving
- Enabling a move to accessible housing
- Participating in old and new leisure activities, e.g. community gardening, playing bridge, going to the cinema and concerts, attending football and rugby matches, having lunch with friends

However, this study suggested that practitioners are largely unaware of the potential of friends and friendships. Participants in this project perceived that family members were neglected by statutory services, and that friends had virtually no presence in rehabilitation efforts. This supports findings from qualitative studies with relatives of people with aphasia (Natterlund, 2010b) and surveys of aphasia service providers (Johansson et al, 2011) that highlight the perceived lack of contact between friends and family and service providers. In a recent UK survey of 2700 people with stroke and their relatives,

few respondents reported receiving any information or support with the emotional impacts of stroke (The Stroke Association, 2013). Both people with aphasia and their relatives identify maintaining satisfying social relationships as priority areas of rehabilitation (Worrall et al, 2011) and as factors that underpin better quality of life (Cruice et al, 2010), yet much evidence suggests these priorities are not being well met (McKevitt et al, 2011).

Any association of friendship with rehabilitation 'interventions' should be grounded in strong warnings about reducing friendship to a self-help programme. A focus on the self undermines the joint venture of friendship and the fact that it is an exploration not a programme (Vernon, 2010). Similarly the individualism of patient-centred rather than relational-centred approaches to rehabilitation (Ward, 2012), highlight the potential perils of contaminating the essence of friendship with the persisting stroke rehabilitation focus on the individual or the caregiving dyad (Palmer and Glass, 2003). However, these caveats notwithstanding, this study revealed that friends and friendship might offer practitioners exciting opportunities to extend interventions addressing the neglected long-term emotional and social dimensions of life after stroke and aphasia.

Building on heightened awareness of the role of friends and the experience of friendships, this study prompts practitioners to ask themselves questions such as: how might friends provide additional information about a person's identity and long-term wellbeing? ; how could friends be more engaged in real-life goal setting? ; what might be the information and education needs of friends as well as family members?; how could rehabilitation services harness friends to support social rehabilitation and the sustaining of social identities?

This research also encourages practitioners to consider those individuals with aphasia at high risk of losing friends. Haslam, et al (2012:328) advocate a systematic approach to evaluating a person's 'social identity landscape'. They propose firstly, giving consideration to the person's existing group memberships and relationships. Secondly, they advocate assessing the opportunities to maintain continuing social identities or to re-consider group

memberships that are not serving any good or helpful purpose. Thirdly, they suggest assessing and supporting opportunities and contexts to create new social identities.

This study revealed that it was hard to predict who retained or who lost friends after aphasia. Participants indicated that friendship loss was due to personal factors such as confidence and mobility, factors relating to how friends responded, how well family and/or spouse supported or constrained friendship opportunities, social factors such as poverty, and environmental factors such as transport. The Research Group worried about those with more severe aphasia, those who lived alone and those who lacked confidence and peer support. Yet some of these 'at risk' individuals retained rich and fulfilling friendship circles. This study suggests that whilst it is wise to avoid making assumptions about who retains and who loses friends post-onset of aphasia, it is important that service providers ask more questions about friends. Who do people with aphasia describe as friends, what is important about these friendships and what are the perceived internal or external barriers to sustaining these friendships? The status of friendship and social relationships should be a key question at recommended six-monthly review and later follow-up as, for many people in this study, friendships were subject to an ebb and flow associated with time, recovery and the availability of people who could facilitate friendship and social engagement.

Our study also highlights the potential of friends as a player within the process of self-management. Self-management after stroke is grounded in problem solving within relationships of trust and empathic listening (Jones et al, 2013). Enabling relationships that emphasise people with aphasia taking control rather than professionals or carers imposing goals are alert to imbalances of power (Norris and Kilbride, 2013). Based on principles of social learning theory and self-efficacy (Bandura, 1997), self-management emphasizes agency and control rather than helping relationships grounded in dependency. Self-management exercised well, therefore, shares many of the conditions embodied by friendship.

This study showed that people with aphasia derived affirming social cognitions from loyal anchoring friends and peers with aphasia. This study therefore offers tentative support for a more flexible approach to developing self-management interventions, which embrace friends as role models and partners in self-efficacy and self-actualisation (Jones et al, 2013).

A summary of ways practitioners might harness the skills, knowledge and resources of friends is provided in table 11.1. Further examples of suggestions for practitioners, family members, friends and people with aphasia, derived from Research Group meetings and dissemination events, are provided in Appendix T. These locate the involvement of friends in the context of social approaches to the management of people with aphasia (Holland, 2008; Simmons-Mackie, 2008), and social model orientations to therapy and support (Pound et al, 2000; Byng and Duchan, 2005). Building on the findings of this study and the illustrations within the Forest of Friendship model, these suggestions cautiously advocate friends as companions in coping and identity reconfiguration as well as allies who can help circumvent barriers in the external environment and support social engagement in the course of 'doing friendship differently'.

### 11.4.3 Communication access and communication support

> 'In a way, if you're too much communication, it's not prime thing for friendship.'
>
> (Research Group 19)

In this study, the themes 'Communication is only one dimension of friendship' and 'Friendship is two-way' drew attention to the importance of power relationships within the practice of 'supported conversation'. Heightened awareness of power imbalances may get in the way of the business of being friends.

**Table 11.1 Harnessing the skills and resources of friends and friendship in rehabilitation**

**Information and Awareness of friends**

- Encourage friends to stay in touch
- Discuss social networks and important friends within these networks (Jetten et al, 2012)
- Provide accessible information about stroke and aphasia to friends as well as family (Parr et al, 2007)
- Offer basic communication advice to friends as well as family (Brown et al, 2013)
- Consider ways that friends may be involved in goal setting and or goal oriented rehabilitation (Ward, 2012)
- Consider friends as a resource within programmes of self management and self efficacy (Jones et al, 2013: Satink et al, 2013)

**Access as an underpinning principle for getting out and joining in**

Consider the role of friends as:

- Facilitators and enablers in participating in previously valued leisure and social roles activities (Robison et al, 2009)
- Conversation partners and communication access advocates (Kagan et al, 2001, Parr et al, 2008)
- Transport buddies, enabling people with aphasia to get out of the house and negotiate barriers in the external environment
- Supporters in using or learning to use new technology as a way to stay in touch with friends

**Reconfiguring Identity with friends**

- Promote peer support opportunities early on and at regular intervals
- Support people with aphasia to identify and spend time with affirming friends and withdraw or find time out from negative and disabling relationships
- Consider how friends might be involved:

in developing personal websites, portfolios and social networking profiles that help people with aphasia reveal who they are to others (Pound et al, 2000; Shadden et al, 2008); as narrative partners, supporting people with aphasia to tell their story and to start shaping new biographical stories (Barrow, 2011; Shadden and Agan, 2004)

Many people in our study reported that good friends and good communicators had not received formal training in supported conversation techniques (Kagan et al, 2001) yet managed supportive conversation naturally and empathetically. This finding is somewhat intriguing as it suggests that either friends learnt to adapt naturally or that empathy and loyalty trumped formal techniques of supporting conversation. A related issue is that friends with aphasia in peer-run support groups do not practice supported communication techniques, most likely because they are unable to write key words, summarise, or use language flexibly themselves. Slowing down, listening and operating within an ethic of mutuality seemed to be the (untaught) communication skills that were valued in friends as communication partners.

Recent studies of friendship and aphasia have suggested that interventions should target friends for communication partner training (Brown et al, 2013; Davidson et al, 2008). Communication partner training and latterly conversation partner training based on supported conversation principles (Kagan 1998; Kagan et al, 2001) are a popular form of environmental intervention for people with aphasia. People with aphasia in this study highlighted the frustrations of friends who didn't understand aphasia or know how to adapt their own communication, offering some support for these intervention strategies.

Simmons-Mackie et al (2010) carried out a systematic review of 31 studies covering a total of 352 communication partners who took part in a range of communication partner programmes. Only two people were explicitly identified as friends compared to 234 family members or caregivers. The Friendship and Aphasia study suggests that friends should be more frequently considered and encouraged as communication partners within these interventions. However, the Research Group in this project also sounded a note of caution about rushing to provide supported conversation training to friends. They were wary of introducing un-natural therapy techniques, echoing the findings of Simmons-Mackie and Kagan (1999) that the volunteer conversation partners who are most valued by people with aphasia are those who keep

communication natural and value social connectedness above the accurate transaction of information.

This is not to undermine the valuable and effective supported conversation training that works well with service providers and encourages individuals and organisations to be thoughtful in promoting cultures of inclusion (Simmons-Mackie et al, 2010; Pound et al, 2007). However it does suggest that light-touch education and awareness-raising about the importance of connection and communion with friends is where precious therapy time can be well spent with friends.

## 11.5    Findings about doing PAR with people with aphasia

Doing PAR with people with aphasia demonstrated that relational-centred research processes may reveal different layers of understanding about topics that are central to participants' everyday lives.   In this study, research outcomes and research participants were influenced by:

- An obligation to consider creative methods of involving people with marked language difficulties
- An emphasis on relationship as well as communication support
- In-depth understanding of the everyday and enduring reality of impairment effects and psycho-emotional disablism experienced by those who live with aphasia
- Heightened attention to time and communicative space within collaborative work.

During the process of carrying out the research, everyone involved in the Research Group, myself included, identified a changed awareness of friendship and what friendship can mean in the context of lifelong disability. Personal transformations, deeper understandings of the topic of study and enduring actions associated with this new learning are benchmarks of the quality of PAR (Koch and Kralik, 2006). These aspects of quality are discussed more fully later in this chapter.

Previous research has focused on the challenge of allowing people with aphasia a voice as participants, generally through supported interviews or focus groups (Dalemans et al, 2009). Challenges of involving people with aphasia in data analysis and interpretation have not been evident, supporting the view that this is an area of user involvement in research that remains least accessible to people with cognitive and communication difficulties (Nind, 2011). In a study exploring concepts of access with people with learning difficulties, Nind and Seale (2009) concluded that 'one cannot even begin to talk about the concept of access without first and throughout doing a great deal of 'access work'' (Nind and Seale, 2009:285). Our study revealed new methodological findings by engaging in and reflecting on the relationship work as well as the 'access work'.

McKevitt et al (2009) identified the need for stroke research to demonstrate whether and if user involvement enables an extension of boundaries of knowledge, and the degree to which new questions and methods are identified. This research has demonstrated that allowing people with aphasia a voice within question formulation, method design, interpretation and active decision-making throughout the research process can influence research outcomes in multiple ways. Most notably, the Forest of Friendship diagram developed by the Research Group contributes to research in the field by reconceptualising friendship and aphasia.

Drawing on the types of knowledge associated with participatory research discussed in Chapter 3, findings from doing PAR with people with aphasia foreground different types of knowledge and forms of power. Consistent with the principles and ethos of action research this study illustrated possibilities of moving beyond representational knowledge derived from previous qualitative explorations of life with aphasia (Northcott and Hilari, 2011; Brown et al, 2013; Natterlund, 2010a). These studies contribute insider perspectives of interviewees with aphasia but foreground the voice and interpretative power of professional therapists and researchers.

Relational knowledge enhances cognitive understandings through the power of feeling connected to others who share similar experiences. Like friendship, relational power is based on principles of knowing through reciprocity, mutuality and solidarity (Park, 2006). In this study, the leadership of the Friendship Events by Research Group members with aphasia encouraged sharing of a range of stories of friendship that defied stereotyping and simplification.

Finally, reflective knowledge broadens understandings of a phenomenon by engaging in critical reflection and action. In this study, members of the Research Group with aphasia developed the confidence in their understanding of friendship and aphasia to change aspects of their own friendship behaviours and support others to think differently about it also.

Findings on doing PAR with people with aphasia suggested that relational and reflective ways of knowing broadened previous understandings of friendship located in professional understandings, which tend to assume loss of agency and confidence as a natural consequence of language impairment. Comparing and contrasting their stories of friendship at the Friendship Events and in the Research Groups, revealed that some participants took a pro-active approach to distancing themselves from friends in contrast to the passive social withdrawal described by Northcott and Hilari (2011). Others, reviewing the importance of friendships that had endured, described a new sense of affirmation through contemplating enduring, valued friendships. In this sense these findings support principles of participatory research that advocate actions founded on power from within (Freire, 1970; Starhawk, 1987, in Park 2006). These research processes have not previously been described within research with people with aphasia.

## 11.6   Summary

The preceding sections have focused on the new knowledge and actionable outcomes produced by the model of friendship and aphasia and the participatory processes developed in this study. The model of friendship developed in this study suggests that no single theoretical approach to

friendship after aphasia - social support, social identity, or narrative theory - does justice to the breadth of roles and diversity of meanings that people with aphasia describe in relation to friendship. The complexity, ambiguity and taken-for-granted nature of friendship is perhaps a reason for its lack of visibility and understanding within explorations of the social consequences of aphasia. The Forest of Friendship model highlights important aspects of reciprocity, engagement, creativity and reconfiguring of identity that can be accomplished in the company of friends as well as the previously more widely reported aspects of struggle and hard work. The synthesis of findings within the Friendship and Aphasia renders meanings of friendship more visible and accessible. This in turn has created the actionable outcomes required of PAR inquiries. Whilst there is a requirement for friendship 'interventions' not to contaminate the freedom of friendship within rigid structures of rehabilitation, findings from this study suggest greater awareness of friends and ways to have conversations about friendships may be helpful strategies to foster friendship maintenance, development and difference.

## 11.7 Critical Evaluation: strengths and limitations of the study

The remainder of this chapter critically appraises the strengths and limitations of the study and reflects on issues of quality in relation to PAR processes and relationships.

Debates surrounding the quality of qualitative research with people with expressive language difficulties emphasize issues of inclusion and ensuring the voice and perspectives of individuals are directly heard, rather than the views of proxy informants. Including participants with cognitive and communication difficulties in qualitative research also needs to avoid secondary impacts of disempowerment and oppression that might arise from inadequate research methods and the limitations of researcher skills rather than the impairments of interviewees (Lloyd et al, 2006; Swain et al, 1998).

A strength of this study was its commitment to including people with aphasia directly in all aspects of the three-year research process. Involvement of people with aphasia on the research team from the outset of the project

ensured that the rights, dignity and validation of individuals with aphasia involved in the interviews and Friendship Events were kept centre-stage throughout the research.

### 11.7.1 Data collection and data analysis with people with aphasia

A first critique of the study concerns methods of sampling. A majority of Phase 1 and Phase 2 interviewees were connected to activities run by Different Stroke or Connect. Recruitment of participants through support group networks has been recommended where participants have cognitive and communication difficulties and may be subject to gate-keeping or acquiescent behaviours when asked to participate in research (Nind, 2008). Kroll et al (2007) suggest that participants involved in support groups may be better informed about their condition, more confident and more assertive in expressing their views compared with those who do not access support groups. People recruited from self-advocacy groups may belong to more mildly impaired groups, have well-rehearsed arguments and be over-researched (Kaehne and O'Connell, 2010). It is possible that respondents in this study were better informed about aphasia and more proactive in seeking social engagement than younger people with aphasia who are not in contact with support groups. However, the purposive sampling ensured that we included a high proportion of people with very marked language difficulties and who were new to groups or relatively new to aphasia. Only three out of 28 people in this study had returned to very part-time paid work and, despite their relatively young age, few viewed a return to paid work as a realistic option.

A second critique of the sampling is the limited cultural diversity of Phase 2 interviewees. None of the recruits to the first Friendship Event came from minority ethnic groups. In total, three of 12 Phase 1 participants and two of 16 Phase 2 participants belonged to black minority ethnic groups. A strength of the study, however, was the involvement of two individuals on the Research Group from Asian communities. Sensitivity to cultural explanations and understandings of aphasia and illness (Legg and Penn, 2013) as well as cultural differences in the social network structure of different ethnic groups

(Spencer and Pahl, 2006) should be borne in mind when considering the relevance of these findings to more ethnically diverse populations.

Apart from Debra, who joined after year one, and the loss of Katie and Stephen, the Research Group remained consistent throughout the three years. Homogeneity in terms of the professional background of most members of the Research Group is a potential limitation of the study. However, the Research Group also possessed collectively a depth of experience and breadth of skills, including those of Debra and myself who do not have aphasia but who brought different experiences of long-term disability to the group. Tregaskis and Goodley (2005) highlighted the enriching benefits of trust and interdependence based on insider/outsider skill mix in disability research.

This study prioritised time with people with aphasia and did not manage, as originally anticipated, to extend cycles of reflection and action to include other stakeholder groups such as friends or healthcare professionals. Early on, the Research Group considered interviewing people with aphasia in a dyad with their friends. This presupposed knowledge about who people might identify as friends and why. It also raised ethical dilemmas about whether people without aphasia would be honest in front of their friends and whether issues might be raised that posed a risk to the foundations of friendship, for example, friendships framed within sympathy and dutiful commitment rather than fun and reciprocal exchange. One-to-one interviews were considered more apt to give the person with aphasia a safe and confidential space to identify their friends and talk about them openly.

The challenges of conducting interviews with people with aphasia include the credibility of accounts where, for example, individuals have memory impairments or a tendency to acquiesce to direct questioning (Heal and Sigelman, 1995). The use of visual material within supported conversations may also be subject to interviewer bias and to constraining or closing down responses (Lewis and Porter, 2004). Questions about the quality and richness of the data generated (Paterson and Scott-Findlay, 2002; Luck and Rose,

2007) and the risk of researchers imposing their own unchecked interpretation (Goodley, 1996) may also arise. In the Friendship and Aphasia study, adaptations to interviewing techniques followed those described by Luck and Rose (2007) and Carlsson et al (2007) and the adaptations and cautions adopted by researchers who interview respondents with learning difficulties (Booth and Booth, 1996; Nind, 2008).  The rich pool of contrasting friendship experiences offered by Research Group members and participants at the Events ensured that the 'leading questions' required to probe individual perspectives were sufficiently varied and open to elicit a breadth of experience.  Similarly these alerted me, as interviewer, to the range of possible interpretations where respondents had minimal expressive language. Issues of credibility and researcher interpretation were also monitored through a process of constant review within the Research Group (Patton, 2002).

Despite using a range of adaptive strategies in interviews as described in Chapter 4, not all interviews were as productive as I would have liked. In Phase 1, the interview with Sam left many questions unanswered. Even after the member check interview where I revisited in detail any responses I was unsure about, I was unconvinced that we had always fully understood each other. In Phase 2, the interview with Martin was also of questionable quality. Martin seemed uncomfortable in the interview and his responses to my questions seemed based on acquiescence and a desire to get out as soon as possible rather than a more thoughtful reflection on issues of friendship. Extracts from these two interviews are provided in Appendix Q. Across the study I associated poor interviews with an over-use of props, an excess of unproductive rather than creative, expressive silences (Booth and Booth, 1996), and a perceived sense of awkwardness either on my part or that of the interviewee.  However, a major strength of the study was the inclusion of participants with severe aphasia, approximately one third of all participants, in both the Friendship Events and interviews.

Although we chose not to use repeated interviews as a method of addressing the slower pace of interviews, I visited all Phase 1 interviewees before their research interview to get to know them and their communication preferences

and afterward to check I had understood their responses to interview questions. With Phase 2 interviewees, the one-to-one interviews followed our shared participation in the Friendship and Aphasia Events, which again provided me with the time to familiarise myself both with the person and their specific communication strengths and challenges. Despite the lack of longitudinal data from individual respondents, prioritisation of time to revisit and review issues arising in data collection and analysis with the Research Group injected an interesting temporal dimension into the study. For example, Research Group members commented at the end of the project how their perceptions of friendship had changed over the three years of the project.

Strategic attention to communication access in Events, meetings and interviews was a further strength of the study, including making discussions of the theoretical model of Friendship and Aphasia as accessible as possible to individuals with language and memory difficulties. The organic, thematic mind map has also supported the dissemination of findings in a clear and actionable way (Sandelowski and Leeman, 2012).

In summary, whilst the presence of aphasia necessitated the use of non-traditional methods of data collection and data analysis, it also heightened sensitivity to issues of credibility, the quality and nature of interviewing and my own skills in eliciting data and cautiously searching for meanings. These are core to questions about the rigour and quality of all interview-based qualitative research. In many ways interviewing and theorising with people with aphasia puts the spotlight on critical issues of communication, participation and inclusion that are the key principles of action research (Stringer, 2007).

## 11.8    Rigour and trustworthiness in qualitative research

As noted in Chapter 4, trustworthiness in qualitative research requires attention to matters of credibility, dependability, transferability and confirmability (Holloway and Wheeler, 2010; Lincoln and Guba, 1985). Credibility is thought to be the most important aspect of trustworthiness (Holloway and Wheeler, 2010), since it questions whether the data convincingly and accurately describe the phenomenon being studied.

Research Group members with aphasia contributed to questions of credibility through an on-going process of respondent validation (Barbour, 2001) or a repeated review and revisiting of data and data interpretations. Preparation of co-presentations about focused aspects of the findings gave further opportunities for individuals with aphasia from the Research Group to question data, findings and interpretations.

The Research Group also sought wider verification that people with aphasia recognised the issues and found our interpretations meaningful and believable through an accessible mid-project update sent to all Phase 1 interviewees (Appendix S). A proto-type website to enable people with aphasia who had supported the project, and their friends and family to have greater access to the project discussions and findings has also enhanced credibility. We have given presentations and run feedback / learning sessions at Different Strokes, The Stroke Association and Connect at the request of people with aphasia who attended the Events (Appendix V). Review of findings by inquiry participants and inquiry audiences is an important aspect of the credibility of participatory inquiry (Patton, 2002).

Dependability and confirmability have been addressed by providing detailed description of research processes and decision-making. Illustrations of these are provided in the methods chapter, appendices and findings on the process of doing PAR presented in Chapter 10. Original recordings of all interviews and Research Group meetings are available in addition to transcripts of data, and audit trails of the process of analysis.

Transferability requires that findings generated in one context can be transferred to a similar situation or group of participants. This study prioritised the perspectives of working age people with aphasia whose biographies have been described in appendix D. Careful documentation of the materials and processes employed in the Friendship Events means these are readily transportable to different contexts.

**11.9 Questioning quality in participatory action research**

Reason (1994) identifies the twin aims of PAR:

- to produce knowledge and action which is directly useful to people
- to empower those involved through a critical consciousness raising

It has been argued that appraising the validity of PAR inquiries requires evaluations that are not only based on criteria of trustworthiness but also encompass outcomes relating to action and transformation (Herr and Anderson, 2005).

Koch and Kralik (2006) have proposed critically appraising PAR projects and processes by asking a series of questions based on Reason and Bradbury's series of 'choice points' (Reason and Bradbury, 2006:344). These five questions are addressed below in relation to the Friendship and Aphasia project:

- Questions of relational practice
- Questions about outcomes and practice
- Questions about plural ways of knowing
- Questions about purpose and significance
- Questions about enduring consequences

**11.9.1 Relational practice**

This question addresses adherence to the values of democracy and the quality of the relationship between the research initiator and research participants. People with aphasia were involved as full and active participants in the Research Group. Reviewing Stringer's (2007) working principles, Relationships, Communication, Participation and Inclusion, Research Group meetings were characterised by working together, mostly, in harmonious, co-operative support relationships. The group members valued different opinions and experiences in a manner reflective of the diversity of experiences of friendships. Effective communication and participation were underscored by principles of good communication access whether within group meetings or through supporting the inclusion of others with aphasia in events and interviews.

Challenges to relational practice arose in relation to knowing what less communicative members of the Research Group were thinking. For example, one group member was unable to use email and one attended meetings but rarely responded to communications between meetings. Those who had more marked aphasia were less able to be in touch via electronic communication.

Two academic presentations documented the perceived two-way benefits of relational research practice (Pound, 2010; Pound and Laywood, 2012; see Appendix V). Benefits for me included the motivation, energy and confidence derived from Research Group meetings and the different aspects of personal support offered to me by Research Group members with aphasia. For example, Research Group colleagues would email or telephone to offer emotional support when I was struggling with administrative tasks or the toil of writing up the thesis. The presence and passion of group members also gave me the confidence to experiment with different methods and ways of presenting information. For example, I have included a dance sequence as a metaphor for changing relationships in presentations to academic audiences. Practising being a friend to people with aphasia enriched my own understandings of friendship and aphasia.

Research Group members with aphasia described a range of benefits they perceived from our relational practice. All commented positively on a sense of emotional and intellectual engagement with 'the joy of the topic' (Pound, 2010). Most described deriving confidence and affirmation from the experience of having ownership and control of a project they perceived to be dynamic and influential. Melanie and Binda commented on changed coping skills, whilst Priya reflected at the end of the project that she had learnt more about aphasia and developed greater compassion for others with aphasia through participating in the project. Jeff appreciated the creative energy of the group as a way of being able to talk in more depth about friendship and achieve collaborative sense-making that went beyond what he felt he could achieve individually (Research Group 21).

As within friendship, there were moments of relational strain too. At times I felt frustrated that social conversation took priority over research objectives in precious meeting time. Two people in the Research Group reported that participating in the academic work of the project highlighted their impairments of language and memory. In their less demanding day-to-day activities these were less apparent to them.

### 11.9.2 Outcomes and practice

Reflecting on the benefits of participating in the Research Group, all group members, including myself, reflected on a deeper understanding of friendship and heightened awareness of the value of their own friendships. Some members of the group have re-established contact with old friends during the course of the project. Others have talked about re-evaluating the importance of friendship personally and for the communities they work with. Two people talked of feeling more secure about their friendships now and therefore feeling less worried about being apart from their friends. All, including me, have begun to highlight friendship more frequently in support group, training and advocacy work. We have reflected on our own friendships, including those that have strengthened and those that have been lost or have faded in recent years. However this has been with a more critical eye about whether these changes were the result of natural attrition across the life course or prompted by acquisition of disability.

Personal transformations in relation to raised awareness of friendship are illustrated in a segment of dialogue from the final meeting of the Research Group.

> Binda: I'm saying that erm it's er, erm doing this project has enriched me. Kind of immensely and er, erm … I wanted to use a different word than … confidence … it's just erm … em*powered* me
>
> Melanie: yes I'd say that as well. Before my stroke I didn't really think about friends that much … But as a result of this and everything, I'm thinking about my friends. I'm thinking about

>               other people and their friends…and it is, it is erm given me
>               a lot of *strength* this group and just the whole process. And I
>               feel a lot *better* about *my*self. And it's just been a very …
>               erm not community … relationship between us … its very
>               special, very special.
>
> Barbara:      And of course I think all of us feel …cos you think about
>               friends before and after that group but after that for me I
>               feel, I feel I want to get message *out* to other people.
>
> Melanie:      Yes
>
> Jeff:         mmm yea
>
> Priya:        Yeah, yeah
>
>               (Research Group 22)

In discussing the benefits of the project findings for others, we highlighted the
simple key message about the usefulness of raising awareness of the value
and meanings of friendship.  We are currently embarking on a series of
meetings with people with aphasia, their friends and family members and
those who provide services to them. These will help us to evaluate their
perceptions of the Forest of Friendship model and its practical application in
supporting conversations and awareness building.

Highlighting the invisibility of friendship and its potential within rehabilitation
settings has emerged as a key message for professional audiences. Following
a presentation to a predominantly professional audience, we have had
requests to present the model and methods of exploring friendship at a
training day for staff working in a brain injury unit and dancers exploring
movement and narrative identity with people with neurological conditions. A
member of the Research Group who volunteers at a group for adults with
acquired brain injury also noted the relevance of heightened awareness of
friendship on her work:

>               'well for me erm … I think the thing about making a difference … that's
>               really important. I also think that it's been about informing the other
>               voluntary work I do [at Headway] … …really what it's all about at its

bottom …It's about how to make friends with people.'

(Debra, Research Group 21)

### 11.9.3 Plural ways of knowing

This question asks how well the project is situated in participative ways of knowing and what it has added conceptually to what is known about friendship and aphasia. The study has been well-grounded in the experiences of the 28 interview participants, some of whom had marked language impairment. It has also been longitudinally informed by the experiences, personal and professional, of Research Group members, enabling us to explore the topic iteratively and dynamically over three years rather than present a 'snapshot' view framed through the lens of professional researchers. Group-based interaction with participants in Phase 2 and group-centred analysis has guarded against the danger that respondents become reduced to textual subjects (Doucet, 2008) and has promoted a layering and temporal dimension to reflexivity (Mauthner and Doucet, 2003).

Conceptually, the Forest of Friendship diagram has, we believe, contributed to new ways of thinking about friendship after aphasia as well as helping to make findings accessible and actionable (Sandelowski and Leeman, 2012). Experiential knowing has been enhanced by methodological innovations in data collection such as the use of the coloured stones to represent friends, feelings about friendship and relational change. Exploration and elaboration of findings and interpretation of findings within the Friendship Events and the repeated spirals of action and reflection in the Research Group has gone beyond conventional 'member checking' and promoted deep intelligibility and resonance of the findings with a skilled team of aphasia experts.

A limitation of the considerable time spent developing the Events and reflecting on the Forest of Friendship model was that we ran out of time to engage with other stakeholder groups such as friends, family members and healthcare workers in new spirals of action and reflection. This will be a priority of future dissemination activity.

### 11.9.4  Purpose and significance

This question asks whether studying friendship in the context of aphasia has purpose and significance for people who live with aphasia. In determining the focus of this study the Research Group prioritised matters of relationship because social relations with others mattered to them as a topic that held universal and radical appeal and was deeply rooted in everyday experience. Motivations for studying friendship were discussed and recorded in Research Group 2. Friendship was seen as:

- Relevant to everyone with aphasia
- Especially relevant to people with severe aphasia
- Egalitarian in attending to equal relationships rather than those skewed by power and status
- Potentially relevant to relationships with family and work colleagues both of which had been other 'front runners' in our top issues to research

As Tom expressed:

> 'Aphasia for me is all about relationships…the core of the struggle and the triumphs.'
>
> (Research Group 2)

My research journal entries early on confirmed a sense of excitement that friendship as a topic connected to so many of the important living with aphasia themes raised by my friends and colleagues with and without aphasia. Conversations with professional experts confirmed my perception that friendship was almost completely invisible within stroke rehabilitation agendas and the academic literature on aphasia.

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**Box 11.1 Reflection**

Good feeling about friendship, particularly after conversations with B [academic in Australia] and supper with S [person with aphasia]. Both a bottom-up and top-down affirmation that friendship is almost completely invisible in practice and the academy. And a fit with my own professional

---

experience about the prioritisation of family and assumptions that 'next of kin' are best placed to be the voice and conduit to who you are.
(Research Journal, February 2010)

### 11.9.5 Enduring consequence – is the work sustainable beyond the project end?

How participatory action research spirals and their outcomes recycle into the future is often uncertain as projects conclude (Koch and Kralik, 2006). Next steps in engaging policy makers in conversations about friendship are not yet clear. However, taking a bottom-up approach to change, we have already identified and initiated several small-scale projects. Research Group members intend to stay in touch with each other, beyond the project end. For example, we have agreed a meeting in Summer 2013 to update the project website, disseminate accessible versions of the findings to participants and review forthcoming presentations, writing and advisory projects.

Melanie, with Debra as a support 'buddy', has undertaken a project to establish a local disabled cycling group. She described this as motivated by creating a new set of friends around a leisure pursuit that has developed during the project.

> 'It's made me think about friendships and want to do friendship in lots of different ways, different for different people. That's why I want to do the cycling group. I'm trying to set up the cycling and that's because I'm energised. Your research has made me think I can do it with other people.'
> (Facetime conversation, Feb 2013)

Sustainability is also likely through the work of individuals in the support groups they work within. Barbara, Sarah and Jeff have already integrated small awareness raising activities into their practice at local support groups. For example, Barbara reported that since her involvement with the project she always asks new people with aphasia at Drop-In sessions about their friends and follows up on the availability of and access to friends with their relatives (Research Group 22).

**11.10 Summary**

This study revealed that friendship is not easily talked about and is rarely on the 'radar' of people with aphasia, their family or therapists. A major contribution of the Forest of Friendship model is the way it makes friendship and its component features visible and more accessible to conversations. Findings from this study extend earlier work in this field that have tended to emphasise loss of friends after stroke (Nothcott and Hilari, 2011), the nature of interactions between friends (Davidson et al, 2008) or the benefits of social relationships (Brown et al, 2013), without describing the multiple meanings of friendship as understood by people with aphasia.

This chapter reviewed salient themes of the friendship and aphasia model that enrich previous understandings of friendship and aphasia. These included the important role of social exchange rather than one-way social support as a mechanism for exercising competence and agency. This located friendship as a place to practice citizenship and contribution rather than being subsumed within an ethic of sympathetic caring.

The discussion of friends as anchors revealed the high value placed on loyal friends who offer the stability and belief for people with aphasia to explore new relationships and new identities post-stroke. The blurring of boundaries between family members and friends challenges dominant discourses within healthcare that diminish complex social relationships through their tendency to categorise relatives as 'carers'.

Participants in this study perceived anchoring friends, with and without aphasia, as companions to explore new lives and identities in the context of acquired language loss. This study and the methods used within the Friendship and Aphasia storytelling events, revealed the possibility of friends as narrative partners in the challenging work of reconfiguring identity and reaffirming friendships.

Findings from doing PAR with people with aphasia emphasised the emergence of different forms of knowledge including the benefits of relational

and reflectional learning in translating findings to new awareness and actions. The chapter highlighted the practical ways new understandings represented in the Forest of Friendship model can offer novel solutions for maintaining and developing friendship in the context of aphasia.

The second half of the chapter reviewed the strengths and limitations of the study and appraised issues of quality. Scrutiny of interview methods confirmed the call for greater inclusion of people with communication difficulties, including those with more severe aphasia, in research about the complexities of life and relationships. This study suggests that the challenge of co-constructing knowledge with people with aphasia heightens the focus on issues of credibility and trustworthiness and promotes the need to develop accessible, non-traditional methods of inquiry. In this study, for example, the peer-led learning events, balanced awareness-raising with mutual support in broaching a complex topic. Cycles of action and reflection within the PAR group enabled the Research Group to pilot more collaborative, user-led processes for analysing and interpreting data as well as being interview participants.

Review of quality issues relating to PAR suggested that undertaking PAR with people with aphasia echoes some of the processes and requirements of participating in friendship with people with aphasia. These include investing in committed, long-term, trusting relationships, thinking about equality and reciprocity, communicating creatively and stretching time and communicative space together. Personal awareness-raising, and reflection on identity may be important outcomes to journeys through PAR as well as journeys through friendship.

# Chapter 12

# Conclusion and recommendations

## 12.0    Introduction

This concluding chapter summarises the study, highlighting new knowledge both from findings concerning friendship and aphasia and from using a participatory methodology to conduct the research. The chapter outlines the practical implications of the findings and suggests possible future actions relevant to people living with aphasia, their friends and family members, practitioners and policy makers. Finally, it suggests possible directions for future research.

## 12.1    Overview of the research

People with aphasia are systematically excluded from many stroke studies which rarely include people with marked language impairment (Brady et al, 2013). As a consequence, understanding of how people with aphasia experience relationships and social participation is limited. No research to date has explored what friendship actually means for people with aphasia. This study therefore set out to answer the research question:

> How do working-age adults with aphasia define, experience and understand friendship?

The other unique aspect of the study was its use of a relational, participatory methodology with people with aphasia. A second research question was therefore:

> What are the meanings of doing participatory action research with people with aphasia?

## 12.2    What the findings revealed

This study shows that meanings of friendship are diverse, nuanced and dynamically influenced by personal, interpersonal, cultural and structural factors. Interviews with 28 people with aphasia, two peer-led Friendship and Aphasia Events and a three-year programme of action and reflection with a

PAR Group led to the development of a model of friendship and aphasia. This 'Forest of Friendship' model synthesises the friendship experiences of people who were young or middle-aged adults when they acquired aphasia. The model's eight interacting branches represent participants' stories of friendship loss, gain and change, incorporating the experiences of those living the early years of life post-stroke as well as those who drew on several decades of friendship experiences since the onset of aphasia.

This study supports previous work (Northcott and Hilari, 2011; Natterlund, 2010a) showing that people with aphasia face challenges relating to communication change, managing other impairments and managing the reactions of others. Similarly this research reinforces past findings that people with aphasia value time, humour and the companionship of peers with aphasia (Davidson et al, 2008; Brown et al, 2010; 2013). However, the study's explicit focus on friendship and the engagement of people with aphasia in shaping the model created new understandings rooted in mutual relationships. Key new understandings are: the two-way hard work of friendships, the evolution and attrition of friendships across time, and the role of creativity and resourcefulness in maintaining friendships in the context of aphasia, also underpinned by joint endeavour and shared agency. The central involvement of individuals with aphasia resulted in a detailed examination of the impact of aphasia on identity and the relevance of identity issues within friendship. The two main branches of the friendship model: friends who anchor and friendship as identity work, create an axis which asserts the powerful relationship between friendship and identity, something which has been neglected in previous work into relationships in the context of aphasia.

Findings about doing PAR with people with aphasia highlight the importance of time, communicative space and the need for constant revisiting, reviewing and reframing of evolving theoretical understandings. Reflections on doing PAR together also suggest that relational methodologies, which of necessity reflect on power, voice, and the balance in relationship, are highly appropriate for qualitative explorations of social relationships. The repeated cycles of action and reflection implicit in PAR inquiries contributed to the innovative and

action-oriented research outputs. In addition to the model of friendship, these included a replicable Friendship and Aphasia Event, a website reporting findings from the study, and a body of resources from the 22 Research Group meetings. The group-based interactions of PAR underscored the transformative learning or catalytic validity required in PAR inquiry (Herr and Anderson, 2005). At an individual level Research Group members reflected on positive personal transformations in thinking about friendship. Collectively, the study motivated participants to advocate more forcefully for awareness-building about the benefits of friendship post-onset of aphasia.

## 12.3    Contribution to knowledge and practice

New contributions to evidence about friendship and aphasia relate to the range of roles and functions played by friends with and without aphasia. The study reveals that friends are not a homogenous category and may include family members, partners and paid carers as well as non-kin confidants and other more distant social connections. Some friends acted as important 'anchors' in the uncertainty of post-stroke lives, grounding friends with aphasia and giving them the confidence to explore emerging identities. In addition to offering practical social support in the early days of recovery, friends offered opportunities for social exchange and fun, termed by some, as an experience of 'fresh air' away from the intensity of families and rehabilitation. The study highlights friendship as an important context for agency and citizenship by contrasting mutual exchange, two-way resourcefulness and collaborative learning with the uni-directional giving and receiving of care and social support. People with aphasia identified peer support as an arena to make 'fast friends', re-experience mutual social engagement and, explore post-stroke identities. For some people, these experiences helped develop the skills and confidence to engage in other social relationships and activities. For others friends were a source of affirmation and continuity.

Methodologically, the study created a range of innovative tools for 'talking about' and exploring friendship in the context of communication difficulties. In addition to the visual model of friendship and aphasia these tools include a peer-led group event constructed around sharing personal narratives of

friendship and aphasia, poetry and art-work on the theme of friendship and a website aimed to support people with aphasia and their friends. Learning from doing PAR offered insights into the twin benefits of collaborative reflection, the generation of knowledge grounded in experience and the personal empowerment derived from participating in and owning research interpretations of friendship and aphasia.

The detailed methodological and substantive findings from the study deepen understandings of friendship and aphasia and provide a robust evidence base for making recommendations to a range of stakeholders.

## 12.4    Recommendations

This study delivered compelling evidence for harnessing the range of positive experiences associated with friends and friendship after the onset of aphasia. Three key messages emerged as important and relevant for all parties interested in supporting friendships after aphasia more effectively. These were:

- Friends and friendship are really important – for reconnecting with self, others and life
- Friendship maintenance and development requires awareness of the importance of friendship and its multiple dimensions
- Friendship is distinct from social support

## 12.4.1 Recommendations for people with aphasia, friends and family members

Many participants in this study described how easy it was to lose sight of the importance of friendship in the context of the intense and varied events and activities in the early months and years post-stroke. The central recommendation here is for finding ways both to keep friends on the social 'radar' and also to talk openly about friendship.

Participants in the interviews and the Friendship and Aphasia Events, some many years post-stroke, talked of reflecting on friendship for the first time. Using stones to think about, identify and discuss friends proved a helpful and

practical introduction, especially for sharing stories of friendship amongst peers with aphasia, which many described as affirming. For others, the conversations challenged previously untested perceptions of friendship loss. Other participants, who had encountered less favourable reactions from friends, described how conversations with peers who had faced similar relationship challenges helped them to feel less alone.

The project also has clear messages for family members of people with aphasia. Participants identified relatives as people who either facilitated access to friends or acted as gate-keepers to seeing friends:

> 'my family have been so protective, they've kind of tended to push my friends to the side.'
>
> (Research Group 18)

This suggests that relatives and partners would benefit from increased access to education and awareness-building about friendship and the important role they have as friendship facilitators.

Findings also indicate that family members, particularly partners, should continue to value their own friendships. Participants considered that close relatives or partners who nurtured their own friendship networks obtained personal support at what was also a time of stress and uncertainty for them. This secondary network of friends also provided opportunities for the person with aphasia to sustain and in some cases develop friendships.

### 12.4.2 Recommendations and implications for practitioners

> 'For me, nobody talk about friends at all.'
>
> (Research Group 20)

The above points regarding awareness, information and communication also have implications for health and social care practitioners, including third sector support agencies. In many cases, practitioners merely need to stop and think about how their service or practice can ensure friends and friendships are visible in the landscape of rehabilitation, which is not happening currently. As other studies have shown (Johansson et al, 2011; Natterlund, 2010b), most participants in this project perceived that statutory services neglected their

family members, and that friends had virtually no presence in rehabilitation efforts.

This research encourages health and social care workers to embrace the opportunities that friends offer for long-term self-management and explorations of emerging identities amid the multiple changes of life with aphasia. Service providers should be aware of potential roles for friends as communication partners, narrative partners and access enablers. Findings also warn practitioners not to reduce friendship to rigid individualistic programmes of therapy.

### 12.4.3 Commissioners and policy makers

This study reveals the important role friends can play as buffers and anchors for people who experience aphasia. Findings support social policy that highlights the contribution of friends to wellbeing and resilience (Watts et al, 2010) particularly where people receive limited help from statutory services. Commissioners and policy makers could support and harness the health benefits afforded by friends, for example, as resources within self-management initiatives and networks of peer support. However, policy makers should avoid stereotyping social relationships with friends and relatives as relationships defined only by caregiving, burden and one-way support (Bowers et al, 2011). Social innovations founded on friendship require a more sophisticated understanding of the impairment effects of aphasia and a dignified, non-exploitative approach to harnessing reciprocity and mutuality.

### 12.5    Suggestions for future directions in research

Friendship can be explored from the perspective of the individual, the dyad or the social network. This study prioritised the perspective of individuals with aphasia mainly because as a group they have so little voice within stroke research. A natural extension of this study might explore the experiences of non-aphasic friends within identified friendship dyads or networks. Qualitative explorations of friendship from these perspectives might illuminate how and why some friends adapt and remain in mutually satisfying relationships whereas others choose to leave or transform friendship into caring.

It might also be interesting to probe further into the role of work and the effect of the age of onset of aphasia on friendship. The participants in this study were all of working age, but only three were working in new part-time roles and most were not optimistic about working again. Larger scale studies might probe the friendship networks of those who acquire aphasia before they are able to establish long-term intimate relationships.

Longitudinal studies might also be productive, for example, investigating whether and how people with aphasia are more able to re-connect with former friends once they emerge from the cognitive fog of the early months and years post-onset of aphasia. Longitudinal studies could also investigate the forms of personal and social resources that enable people with aphasia to sustain friendships over time. Such studies might illuminate which people are most at risk of social isolation or the negative consequences of ambivalent or problematic relationships over time.

Research into interventions for people with aphasia might also be informed by these findings. This study suggests that friends can play roles as communication partners, motivators, problem-solvers and transition bridgers. Studies exploring quality of life, post-stroke coping and social integration could investigate both the impacts of friendship and the role of friends in supporting other interventions relevant to the long-term consequences of stroke. It is important that future studies take care to unpack the meanings of terms such as 'family and friends', 'informal caregivers' or 'social support', so that the place of friends and friendship is clear and not subsumed within simplistic assumptions of social relationships and social support.

The innovative, participatory methodology of this research also has potential for future research. This approach enabled the productive engagement of people with aphasia, and also facilitated lasting transformations for some of the people with aphasia involved in the research and for non-aphasic research collaborators like myself. As Bradbury and Reason (2006) and Park (2006) also point out, PAR is an exciting way of building new research capability

whilst simultaneously contributing to the flourishing of human potential and relational ways of knowing.

People with aphasia are often marginalised within health and disability research. The PAR principles and techniques used in this project suggest that future studies might utilise PAR with other groups of people with cognitive and communication difficulties, for example people who experience traumatic brain injury, multiple sclerosis, Parkinson's and the early stages of dementia. Friendship remains under-investigated within these groups (Grose et al, 2012; Ward et al, 2012). One fruitful exploration, for example, might be how people with different acquired neurological conditions respond to the 'Forest of Friendship' model.

## 12.6    Final reflections

This research journey initially set out to explore communication access issues in order to develop new knowledge and practice for involving people with aphasia in work, education and social life. The inclusion of people with aphasia as Research Group members resulted in changes to the research focus and the choice of PAR as a methodology, and this began a three-year relational research process. Exploration of friendship with people with aphasia extended my research skills in diverse and unexpected ways. The research journey has required that I cross disciplinary lines, blur the boundaries between research relationships and friendship, and reflect critically on the narrow social gaze of neuro-rehabilitation. Embracing Freirean principles of consciousness raising and empowerment from within, the Research Group became a creative and supportive context to reflect on personal skills and social identities. The added value and extended ways of knowing of a participative worldview have underpinned the practical, theoretical and methodological outcomes of this study. Importantly, as individuals we are also taking away a little more insight into ourselves and into our own friendships.

> 'I definitely value my friendships more, I've thought about how friends help keep me on an even keel…It's made me think about it differently…feeling a bit more secure, thinking about your identity. Particularly in my wobbly moments.' (Research Group 22)

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## List of Appendices

# Appendix A

## Ethical approval

**Brunel**
UNIVERSITY
WEST LONDON

School of Health Sciences and
Social Care

**Research Ethics Committee**

School of Health Sciences and
Social Care
Brunel University,
Uxbridge
Middlesex UB8 3PH
Telephone: +44 (0)1895 274000
Web www.brunel.ac.uk

11 June 2010

Proposer:    Carole Pound – PhD Student

Title:    Aphasia, Friends and Friendship : A pilot study

Reference:    10/05/PHD/06

## Letter of Approval

The School Research Ethics Committee has considered the amendments recently submitted by you in response to the Committee's earlier review of the above application

The Chair, acting under delegated authority, is satisfied that the amendments accord with the decision of the Committee and has agreed that there is no objection on ethical grounds to the proposed study. Approval is given on the understanding that the conditions of approval set out below are followed:

- *The agreed protocol must be followed. Any changes to the protocol will require prior approval from the Committee.*

NB:

- Research Participant Information Sheets and (where relevant) flyers, posters, and consent forms should include a clear statement that research ethics approval has been obtained from the School of Health Sciences and Social Care Research Ethics Committee.

- The Research Participant Information Sheets should include a clear statement that queries should be directed, in the first instance, to the Supervisor (where relevant), or the researcher. Complaints, on the other hand, should be directed, in the first instance, to the Chair of the School Research Ethics Committee

- Approval to proceed with the study is granted subject to receipt by the Committee of satisfactory responses to any conditions that may appear above, in addition to any subsequent changes to the protocol.

- The School Research Ethics Committee reserves the right to sample and review documentation, including raw data, relevant to the study.

David Anderson-Ford
**School Research Ethics Officer**
**School of Health Sciences and Social Care**

**Brunel**
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School of Health Sciences and
Social Care

**Research Ethics Committee**

16 November 2011

Proposer:      Carole Pound – PhD Student

Title:         Friendship and Aphasia: Phase 2

Reference:     12/11/PHD/01

## Letter of Approval

The School Research Ethics Committee has considered the amendments recently submitted by you in response to the Committee's earlier review of the above application

The Chair, acting under delegated authority, is satisfied that the amendments accord with the decision of the Committee and has agreed that there is no objection on ethical grounds to the proposed study. Approval is given on the understanding that the conditions of approval set out below are followed:

- *The agreed protocol must be followed. Any changes to the protocol will require prior approval from the Committee.*

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- Research Participant Information Sheets and (where relevant) flyers, posters, and consent forms should include a clear statement that research ethics approval has been obtained from the School of Health Sciences and Social Care Research Ethics Committee.

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- Approval to proceed with the study is granted subject to receipt by the Committee of satisfactory responses to any conditions that may appear above, in addition to any subsequent changes to the protocol.

- The School Research Ethics Committee reserves the right to sample and review documentation, including raw data, relevant to the study.

David Anderson-Ford
School Research Ethics Officer
School of Health Sciences and Social Care

# Appendix B

# Participant information and consent forms

# Phase 1

Aphasia, Friends and Friendship – A Research Project

Information sheet for participants

**Thank you** for your interest in this project. This information sheet tells you about the project.

## Who is involved in the project?

The project is part of a **PhD research project** at Brunel University. **Carole Pound** is co-ordinating the research. Carole is a Speech and Language Therapist by background. Carole used to work at Connect the communication disability network.

Carole is working with a **team of people with aphasia** to guide the project. These people all have personal experience of living with aphasia.

Three researchers from **Brunel University** are supervising the project: Frances Reynolds, Peter Beresford and Bella Vivat.

## About the project

This research project aims to explore the **friendship experiences** of **younger people (under 65) with aphasia**. We want to find out **what friendship means** to people with aphasia. For example we want to ask people with aphasia:

- who their friends are

- any significant changes to their friendships ?

- what's important to them about their friends and friendships?

**Research** shows that having a **good network of friends** and **social support** can be very **helpful** after a stroke or head injury. But **very little is known** about **friendships and aphasia**.

We hope the **findings** from the project will be **useful** to people living with aphasia/ communication disability, friends and family members, rehabilitation service providers and policy makers.

**What happens if I want to be involved?**

If you want to be involved Carole will **meet you** to tell you more about the project and answer **any questions** you have. If you still want to be involved Carole will ask you to sign a **consent form**.

*Interview 1*

We will arrange a **convenient time** to interview you about your friendships. All the interviews will be carried out by Carole. If you agree we will **audio or video record** this conversation.  .

**The interview** will last about **one and a half hours (90 minutes)**. We can do the interview in your **own home** or at the **Connect centre** in Southwark.

The interview is **<u>not</u> a test** or an assessment. It is to find out your thoughts and stories about friendship.

*Interview 2*

This second interview will be about an hour to an hour and a half long. It will be either:

- in a **small group** with other project participants at **Connect**

- or, if you prefer**, one to one** with Carole **at home.**

This interview will give you a chance **to go over** the main points from the first interview. You can also **add any new thoughts**

If you agree we will **audio or video record** the session.

We will pay for any **travel expenses** you incur at any of the stages above.  We will provide **refreshments** at group meetings.

**What happens if I'm not sure about the research as it progresses, or have questions to ask?**

You can **talk to Carole or someone** on the **research group** at **any time**.

If you have a **complaint** about the project you can contact Betty Cassidy from Brunel University Ethics Committee

**What happens if I change my mind or need to drop out for any reason?**

You can **opt out** of the project at **any time**. You do not need to give a reason. If you choose to leave the project it will not affect any of the services you receive or activities you go to.

We will <u>not</u> use any material from your interviews if you do not want us to.

**What are the benefits to me ?**

Your thoughts and experiences will contribute to **improving understanding about aphasia** and ways to live with communication disability.

If you are interested you will have the chance to **meet and talk with other people** with aphasia who are involved in the project.

Many people find taking part in research interesting.  This is a **research project**. It is **not direct therapy** involving exercises and rehabilitation.

**How will you use my contribution to the research?**

Your contribution will become part of the **project findings**.  We will use the project findings to **tell others about friendship and aphasia**.  We will do this by :

- Giving **presentations**

- Writing articles in **academic journals**

- Writing articles for **websites and newsletters**

Sometimes people are worried that what they say in an interview might be sensitive or might offend someone. **Everything you tell us** will remain **anonymous**. When we report our findings we will not use your real name or let people know who said what.

If we use your **quotations and stories** from your interview we will <u>not</u> reveal your name and details.

## I have difficulty talking – how can I tell you my experiences?

We are very keen to talk to people who have communication difficulties. We will use a number of **different ways** to make sure you have your say:

- We will use **different communication strategies** – pictures, writing, photos, other visual aids

- We will give you **plenty of time** to think about the questions

- We will **send you the questions** before the interview

- We can get **support** from an **advisory group member** who also has aphasia

- You can **tell us** before the interview what **communication support works best** for you

**Thank you** very much for your interest in this research

**Any questions about the project**

**Researcher** : Carole Pound   **Supervisor**: Frances Reynolds
School of Health Sciences & Social Care
Brunel University,  Uxbridge UB8 3PH

Telephone: 07821 374661                    Telephone: 01895 268826
Email: carole.pound@brunel.ac.uk        Email:Frances.Reynolds@brunel.ac.uk

Any **complaints**
Betty Cassidy,
School of Health Sciences & Social Care,
Ethics Committee

Telephone: 01895 268736
Email: Elizabeth.Cassidy@brunel.ac.uk

**Brunel**
UNIVERSITY
WEST LONDON

# Aphasia, Friends and Friendship – A Research Project

**Brunel**
UNIVERSITY
WEST LONDON

## Participant consent form

Yes 👍    No ✋

**1.** I have seen the project **information sheet**
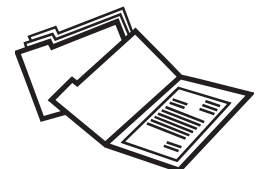
**Yes** ☐    **No** ☐

2. I have had an **opportunity to discuss the project** with Carole and **ask questions**

Yes ☐    No ☐

3. I understand **my name will not be used** in reports and talks about the project:

Yes ☐    No ☐

Yes 👍 No ✋

4. I agree that my **anonymous quotes and stories** may be used later in articles and presentations

Yes ☐  No ☐

**5.** I understand **I can opt out** or withdraw from the study **at any time**

Yes ☐  No ☐

6. I understand **I don't need to give a reason** if I withdraw

Yes ☐  No ☐

7. I agree that **my interview** can be recorded on **audio tape**

Yes ☐  No ☐

**8.** I agree that **my interview** can be recorded on **video tape**

Yes ☐  No ☐

9. I **agree to take part** in this study

Yes ☐  No ☐

| Signature | Date |
|---|---|
| | |
| Name in capitals | |

# Appendix C

## Communication resources

## Phase 1 interviews

# Who are your friends?

Work colleagues

???

Family

Interest / hobbies

Carers/ Support workers

Past school / college

???

# Think about Friends

Who are Your friends

Things you do together

What's important for you

Your friends

Your friends

Your friends

Sam

Advice to other people

Your friends

Your friends

Any difficulties

changes since your stroke
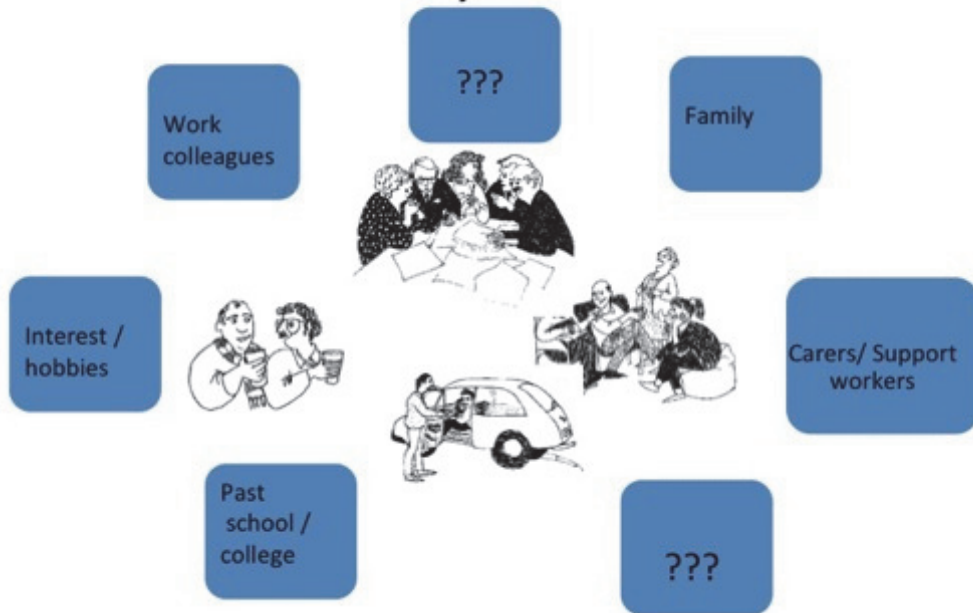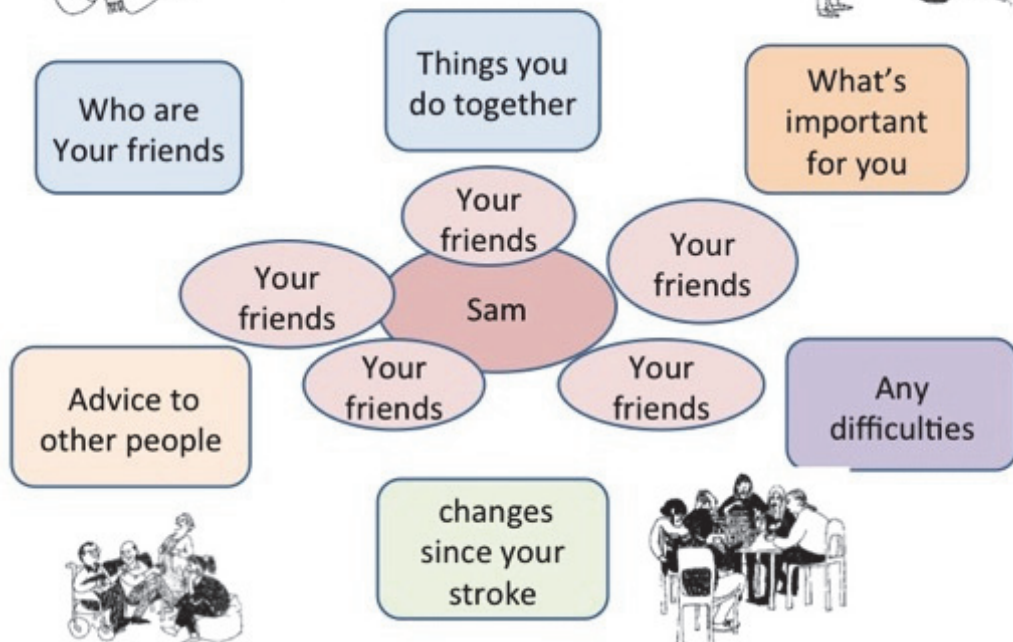
# Friendship – what other people say is important

| | |
|---|---|
| Doing things<br>Going out<br>Holidays<br>Interests<br>Work | Humour<br>Trust<br>Respect<br>Honesty<br>Getting along |
| **Friendship** | |
| Hard work<br>Keep trying<br>Time<br>Understanding about stroke & aphasia<br>Walking, getting around | ???? |

Scale A–1

411
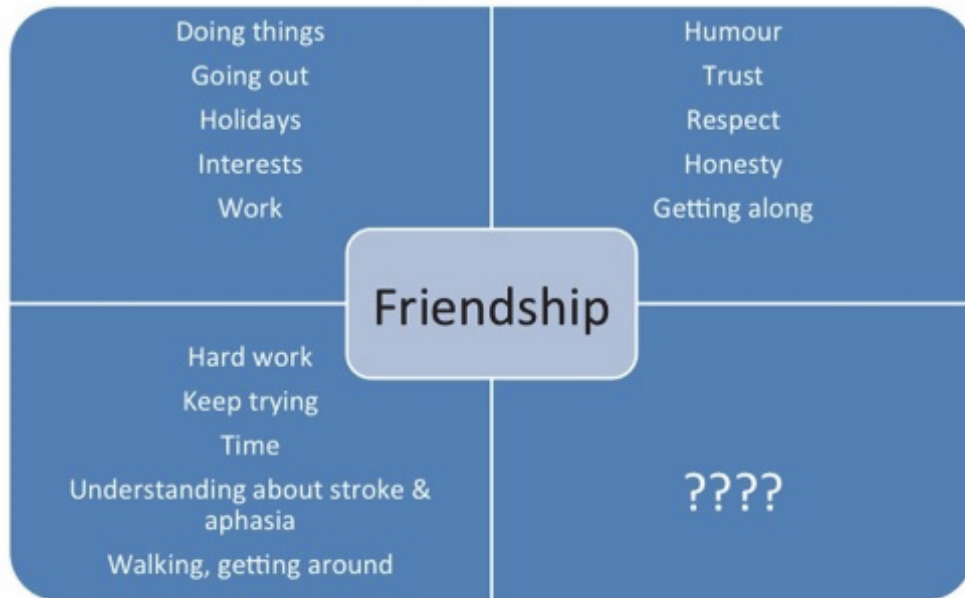
# Appendix D

## Participant biographies

**Biographies - Phase 1 participants**

**Binda** is in his late forties. He is single, having divorced shortly after his stroke, and lives in Yorkshire. He had a stroke 18 years ago whilst working as a deputy head teacher. In addition to aphasia he has epilepsy and difficulty using his right arm. He has not worked in paid employment since his stroke. He has a strong interest in the arts and international politics. Until recently he was a Trustee of Connect. He has also volunteered at a local stroke support group.

**David**, in his mid fifties, lives in a semi-rural setting with his new wife. They married recently, after the onset of stroke. He has two adult children living away from home. He worked as a project worker in the I.T industry until his stroke four years ago. He is now medically retired. David spends time on the internet and enjoys socialising with former work colleagues, bridge friends and his wife's friends and work colleagues. David has a marked right hemiplegia and, although he can walk unaided, relies on a driver, most usually his wife, to get around.

**Donna** is in her mid thirties. She experienced a stroke following a traffic accident. She lives with her teenage son. Her partner left them following her stroke. Donna used to work as a dinner lady, a job she enjoyed. She occasionally attends a local stroke support group though is dependent on the organiser driving over to pick her up. Several members of her family live locally and provide support with shopping and practical help. Donna has difficulties with balance and use of her right arm. In addition to word-finding difficulties her speech is significantly distorted requiring careful listening and questioning to aid comprehension.

**Emily** experienced a stroke aged 18, while sitting her A-levels. She has no visible effects of stroke but marked expressive language difficulties affecting spoken and written language. She lives at home with her mother, father and two cats. She has an older sister living locally. Three times weekly Emily sees a paid carer, employed directly by the family. Her carer has become a close confidante and friend. For example, they go horse-riding and clubbing together as well as participating in activities associated with rehabilitation. Emily had planned to go to University before her stroke. She currently works part-time in a supermarket, stacking shelves.

**Grant** is from Nigeria. He travelled widely before his stroke, working as an engineer and consultant in the company he co-founded. Now in his early sixties, he had his stroke almost 20 years ago. He lives with his wife on a large housing estate. They moved here reluctantly when money ran short. He has three grown-up children, two of whom live in London. Grant has not worked since his stroke though, for the last seven years, has attended a gardening group run by a charity. He continues to attend a local stroke support group. Grant has severe aphasia affecting all aspects of spoken and written language.

**Jack** lives with his partner Dawn, and two teenage children in London. Prior to his stroke two years ago, he worked as a van driver. He has been unable

to drive since his stroke. Jack has very marked spoken language difficulties though no apparent physical difficulties. He enjoys football and taking the dog for a walk. He attends a university therapy clinic for ongoing Speech and Language Therapy. His partner Dawn is also unable to work due to ill-health and they report struggling to make ends meet particularly following a recent review of their benefits.

**Jeff** is in his mid forties. He was working as a university lecturer and tutor and undertaking PhD studies when he experienced a stroke four years ago. He lives with his wife and two of his three children. After some difficult negotiations with his former employers he was medically retired. Over the past two years Jeff has worked with local and national stroke charities mainly on a volunteer basis. He set up and leads a branch of Different Strokes that meets weekly. He enjoys watching rugby.

**Katie** worked as deputy head teacher in a primary school. She was a keen fitness enthusiast, enjoying playing and coaching hockey. Katie had a stroke in her early fifties. At the time she lived with her partner and two teenage sons. Katie had a dense right hemiplegia and had slowly recovered much of her speech and language though her conversation remained hesitant and, reduced in fluency and flexibility. Three years into her recovery Katie began to attend, and later, volunteer at local stroke charities. For example, she led a 'Getting out and about' Group at Connect and was Chairperson of her local stroke service user group. She had her stroke five years before joining the Research Group. Sadly Katie passed away in year one of the project following a second stroke.

**Melanie** was in her late twenties went she experienced a severe stroke. Subsequently she developed aphasia, some memory difficulties, and had paralysis of her right arm and leg. She lives alone in a flat within a housing association. At the time of her stroke, eighteen years previously, she was working for a charity as a policy officer. She has not been able to work since. Melanie set up and ran a local stroke support group for ten years, eventually resigning because she felt 'burnt out' and keen to develop contact with people without aphasia. She continues to support local stroke training initiatives in the East Midlands where she lives.

**Priya** had just finished training as an optometrist when she experienced a stroke in her early twenties. She lives with her parents and has an older sister. Two years post-stroke Priya has been trialling a part-time return to work in a reduced capacity. She has also taken first steps to completing a part-time psychology degree. She maintains contact with many of her old university and work friends. She has made a relatively good language recovery though is very aware of the differences between her pre and post-stroke language skills. She enjoys shopping, travelling and partying with friends and family.

**Sam** previously worked shifts in a printing firm. He lives with his elderly mother in a high-rise tower block in Central London. He had a stroke in his early forties and has very severe aphasia with no usable speech other than

'yes' and 'no'. He is able to use some drawing and occasional letters to support communication. He has a dense right hemiplegia affecting his right arm and leg. He is able to walk independently and travels alone to Connect where he attends the weekly music group. He also enjoys watching motor-racing and football and previously socialised with friends in some favourite South London pubs. He currently spends most of his time at home.

**Sarah** experienced a stroke nine years ago in her late forties. At the time she was working as a lawyer. She is single and lives in her own house in South London. She remains in close and regular contact with friends from university days and friends from work. They enjoy socialising over supper, going to concerts and dance. Sandra is an only child and has elderly parents living on the south coast. She has a carer who visits one day weekly to help with house work and shopping. Sarah resumed driving after five years though travels around London by train and tube. She has marked language impairment and although able to read, requires help to use email and with correspondence. Sarah travels to Connect twice weekly where she co-facilitates a conversation group and supports activities at the Drop-In sessions.

**Biographies - Phase 2 participants**

**Anthea** had a stroke in her mid forties. At the time she was working as a nurse in a London hospital, though she trained in the West Indies. After a period of rehabilitation, Anthea's partner left her and she went to live in a residential home where she has remained for the last nine years. Anthea is a regular churchgoer and also enjoys socialising with people in her residential home and at Connect Drop In sessions. She is able to travel independently and use public transport though she has some residual mobility difficulties and paralysis of her right arm.

**Cherry** worked in charity management. She had a stroke 22 months ago, shortly after giving birth to her second child. She was in her late thirties at the time. She lives at home with her partner, and two young children. She is able to walk independently but still experiences difficulty using public transport. She continues to attend speech and language therapy where she is working on sentence construction and writing. Her speech is dysfluent with considerable word-finding difficulties. She has help from her parents and parents-law though she reports this causes some tensions relating to attitudes to her competence as a parent. She describes herself as a resilient person shaped partly by experiencing cancer as a young adult.

**Chris** lives with his wife and two dogs. He worked as a postman prior to a stroke twenty months ago when in his early forties. He has very severe aphasia, epilepsy, post-stroke fatigue and paralysis of the right side. Some years previously Chris and his partner Tina ran a pub. They remain in close contact with many of these friends and also have a close network of family living locally. Chris spends time on the computer reviewing the spreadsheets of the family finances and also, encouraged by Tina, has a daily programme of home-based rehabilitation working on his right arm.

**Derek** worked as a farrier after leaving the army. He is separated from his wife and now lives alone. He enjoys tending the chickens on his small holding and has recently taken up drumming as a strategy to relieve stress. He had a stroke just under three years ago, when in his late forties. He also experiences epilepsy and visual difficulties though he has recently recovered his driving licence. He attends two local stroke support groups where he now acts as a volunteer driver as well as group participant.

**Frank** experienced a stroke four years ago as a consequence of a heart condition. He was in his early fifties at the time and working as a hospital porter. He lives alone since the death of his mother several years ago. He enjoys football and has recently begun travelling to matches again. He also enjoys acting as a volunteer at Connect Drop In sessions and using Facebook as a means of sharing jokes and news items.

**Gary** worked as a delivery driver prior to his stroke a year and a half ago. Congenitally deaf, Gary managed to communicate well with signing and speech before the onset of aphasia. Post-stroke his speech has many distortions and additionally, he has difficulties with word finding and writing. He lives alone, a few streets from his mother and step-father. He enjoys spending time with best friend Jack, whom he now describes as his informal support worker. They watch films, play video games and enjoy going to the pub together.

**Joan** lives with her husband and teenage son. Prior to her stroke, she worked as a manager in car sales. She was in her forties at the time. Joan has mild aphasia and some persisting balance difficulties. She enjoys going shopping and spending time with a small group of long-standing friends. Joan attends Connect Drop In as well as an adult education group for people with aphasia where she also supports a befriending scheme.

**John** lives with his wife, adult daughter and her partner. He has virtually no spoken language other than 'yes' and 'no' but is a skilled IPad user, drawing on photos and google maps to elaborate his descriptions of people and places. He previously worked as a Director within a small I.T. company and remains hopeful that he may return to work in the future.

**Karen** had a stroke following a skydiving exercise in her late twenties. At the time of the research interview, 17 months post-onset of marked aphasia, she had just moved into her own adapted flat with her two small dogs. Paid carers visit daily to help with housework and personal care. She is in texting contact with her older sister multiple times daily, exchanging news about the dogs and practical arrangements regarding care visits. An avid Facebook user, Karen remains in regular contact with good friends locally and several former colleagues from the office where she worked as an administrator.

**Martin** works as a travel consultant and is currently on sickness leave. He lives with his wife and their family of three teenage children. He experienced a stroke eighteen months ago in his mid forties. He enjoys watching the local football team play and watching other TV sport. He has no apparent

physical difficulties though his speech is dysfluent and characterised by marked word-finding difficulties.

**Richard** lives with his wife. They have two grown-up children. He has very severe aphasia and marked mobility difficulties following a stroke six years ago in his mid sixties. At the time he worked as a musician travelling around England to play in pubs and small venues, often accompanying a dance troupe. His wife gave up her job at a young offenders centre to be able to spend more time with him after the stroke. Richard is dependent on her for transport. They continue to enjoy music, travelling to pubs and local gigs with friends.

**Ron** lives alone and worked as a service fitter before he experienced a stroke in his early sixties. Ron's dysfluent speech is characterised by multiple attempts at words and correcting frequent mis-sequencing of sounds and syllables. He has a difficult relationship with his only son and lives alone. His closest friend is a woman he has known for over twenty years who has been his main support since his stroke just under three years ago. Ron enjoys sudoko, word puzzles and most TV sport.

**Shana** was in her late twenties when she experienced a stroke. Originally from Australia, at the time she was living with her boyfriend and working as an administrative assistant. She split up with her boyfriend but they remain in close contact and she currently lives in the flat below him. Shana has tried unsuccessfully to find work since her stroke and now volunteers one day weekly on the reception at Connect. She holidays abroad twice a year, meeting up with friends from previous visits.

**Sonya** has very severe aphasia and right-sided paralysis. She worked as a hairdresser prior to her stroke ten years ago in her late thirties. She lives with her daughter and grandson. Her social life includes weekly visits to the Drop In sessions at Connect as well as a local disabled person's resource centre where her support worker is based.

**Terry** was working as a salesman when he experienced a stroke 13 years ago in his late thirties. He separated from his wife several years later and has been living alone since that time. He currently works as a volunteer in the office of a stroke support group. He also enjoys spending time in the pub with friends and watching TV.

**Trisha** lives with chronic pain from a back injury sustained in an accident. She experienced a stroke two and a half years ago in her mid-thirties. She was working as a mechanic at this time. Trisha lives with her partner and reports a close relationship with her parents and siblings, including a twin sister. She is in regular contact with her family, most of whom live relatively nearby who live fairly nearby. Trisha occasionally goes to Drop In at Connect and the adult education session at a stroke support group. She often goes with her friend, Joan, above. Trisha enjoys Tai Chi, art and drinking with friends down the pub.

# Appendix E
# Topic Guide Phase 1

**Aphasia, Friends and Friendship – a research project**
**Topic Guide for phase 1 interviews**

1. **Introductions**
   - About the research and the research team
   - Purpose of the interview today – how people with aphasia define friendship; how they talk about friendship experiences

2. **Background information about you** ( details sheet ahead of interview)
   - Age
   - Living arrangements
   - Date of onset of aphasia
   - Cause of aphasia
   - Other disabilities
   - Impact of aphasia on understanding, talking , reading ,writing

3. **Background context - Impact of disabilities on life**
   - Roles
   - Relationships generally
   - Work, interests, activities
   - Social changes – housing, finance etc

4. **Friendship**
   - Who are your friends?
   - What do you do with them?
   - What's important about your friendships?

5. **Changes in experiences of friendship**
   - Examples of changes
   - Reasons for changes
   - Changes after onset of aphasia
   - Changes over time
   - Turning points

6. **Barriers and facilitators to friendship**
   - What gets in the way of developing and maintaining friendship
   - What helps develop and maintain friendship
   - Any help received in relation to developing and maintaining friendship

7. **Advice**
   - Your advice to people with aphasia about friendship
   - Your advice to friends of those who have aphasia
   - Advice to the research team – e.g. important issues to think about

## 8. Round up

Anything else you want to add
Summary and what happens next
If relevant information and contact details for support


**Probes**
Non kin friendships if discussing friendship and family
Your own friends and 'second hand' friends

Examples of strong friendships
Examples of difficult friendships

Existing friendships
New friendships

Changes in friendships and changes in you

Impact of communication disability
Impact of other disabilities

Technology and friendship eg social networking, email

Some people say …
Losses
Gains

# Appendix F

## Participant information and consent forms

## Phase 2

**Aphasia, Friends and Friendship – A Research Project**



**Information for Research Day participants**

**Thank you** for your interest in this project. This information sheet tells you about the project and what we are asking you to do.

## Who is involved in the project?

The project is part of a **PhD research project** at Brunel University. **Carole Pound** is co-ordinating the research. Carole is a Speech and Language Therapist by background. Carole used to work at Connect the communication disability network.

Carole is working with a **team of people with aphasia** to guide the project. These people all have personal experience of living with aphasia.

Three researchers from **Brunel University** are supervising the project: Frances Reynolds, Peter Beresford and Bella Vivat.

The project has received **ethical approval** from the Research Ethics Committee, Brunel University.

## About the project

**Health research** shows that having a **good network of friends** and **social support** can be very **helpful** after a stroke or head injury. But **very little is known** about **friendships and aphasia**.

This research project aims to explore the **friendship experiences** of **younger people (under 65) with aphasia**. In the **first stage** of the research we interviewed 12 people with aphasia. We asked them:

- Who their **friends** are

- **What 's important** to them about their **friends and friendships?**

- About any **friendship changes** after their stroke and aphasia?

We have used these stories to produce some **different ways** to talk about experiences of friendship and aphasia e.g. videos, poems, artwork.

**Now** we want to **share these stories** with a wider group of people with aphasia. We want to see **how you respond to these stories** and to hear about **your own experiences** of friends and friendship when you have aphasia.

**What happens if I want to be involved in the project?**If you want to be involved Carole or Basia or Jerry (project advisors in London and Northampton) will **meet you** to tell you more about the **project** –

- about the **Friendship and Aphasia Research Day**
- about the **follow up interviews** after the research days

We will answer **any questions** you have. If you still want to be involved we will ask you to sign a **consent form**.

We will invite you to come to a **day** either in **London** or **Northampton**.

## About the Friendship and Aphasia Research Day

The day will be run by Carole and the project advisors, who all have aphasia.  We will:

- tell you **what we have found out** so far about **friendship and aphasia**
- **ask** you about **your own friends and experiences of friendship**
- **ask** you **what you think is important** about friends and friendship.

The day will **start at 10.30** and **finish by 3.00**. There will be **12-15 participants with aphasia at each day.**

Several members of the project advisory group and some communication supporters will also help us on the day.

We will discuss things in a **large group** and in **small groups**.

We will **take notes** about what different people say.

If you agree we will **record** the session on **video** and **audio tape** and take some **photos**. This will help the project team to remember what you say and capture the main themes of the day. We will not use your stories and pictures if you want to keep anything confidential.

We will pay for your **travel expenses** to the day and provide **refreshments.**

## About the Follow Up Interview

We will invite people who come to the Research Days to a feedback interview. Carole will arrange to meet up with you about **2 weeks after** the Research Days. This meeting will be in your **own home** or at **Connect/Different Strokes**. She will ask you:

- Your **reactions and thoughts** about the **day**

- if you have had any **further thoughts** about your **own friendships**.

The meeting will take up to **1 hour**.

We will send you **some questions** to think about ahead of this interview.  For example we will ask:

- what you thought about the research day

- do you have different experiences of friendship and aphasia

- has your thinking about friends and friendship changed

- what advice might you offer to other people about friends and aphasia

The group and individual meetings are **<u>not tests</u>** or therapy sessions. They are a way to find out your thoughts and stories about friendship.

## What happens if I'm not sure about the research as it progresses, or have questions to ask?

You can **talk to Carole or someone** on the **research advisory group** at **any time**.

You can **pull out** of the **Research Day** and follow up **interview at any time**. You do not need to give a reason for opting out.

If you choose to leave the project it will not affect any of the services you receive or activities you go to.

If you have a **complaint** about the project you can contact Dr Simon Bradford (Head of the Research Ethics Committee, School of Health Sciences & Social Care, Brunel University).

## What are the benefits to me ?

Your thoughts and experiences will contribute to **improving understanding about aphasia** and ways to live with communication disability.

You will have the chance to **meet and talk with other people** with aphasia who are involved in the project.

Many people find taking part in research interesting. This is a **research project**. It is **not direct therapy** involving exercises and rehabilitation

**How will you use my contribution to the research?**

Your contribution will become part of the **project findings**.

We will use the project findings to **tell others about friendship and aphasia**.

We hope the **findings** from the project will be **useful** to:

- **people living with aphasia**/ communication disability

- **friends** and **family members**

- **rehabilitation service providers** and **policy makers**.

We will tell people about the project by:

- Giving **presentations**

- Writing articles in **academic journals**

- Writing articles for **websites and newsletters**
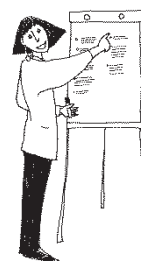
Sometimes people are worried that what they say in a group or in an interview might be sensitive or might offend someone. **Everything you tell us** will remain **anonymous**.

If we use your **quotations and stories** from your interview we will **not reveal your name** and details. We will ask **your permission** to use **any photos or film** of you and tell you clearly how we would plan to use any images.

**I have difficulty talking – how can I tell you my experiences?**

We are very keen to talk to people who have communication difficulties and may have difficulty talking. We will use a number of **different ways** to make sure you have your say:

- We will use **different communication strategies** – pictures, writing, photos, other visual aids

- We will give you **plenty of time** to take part

- We will **send you questions** to think about before the event

- We can get **support** from an **advisory group member** who also has aphasia

- You can **tell us** before the day what **communication support works best** for you

**Thank you** very much for your interest in this research

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**Any questions about the project**
**Researcher** : Carole Pound       **Supervisor**: Frances Reynolds
School of Health Sciences & Social Care
Brunel University, Uxbridge UB8 3PH

Telephone: 07821 374661          Telephone: 01895 268826
Email: Carole.Pound@brunel.ac.uk    Email:Frances.Reynolds@brunel.ac.uk

**Any complaints**
Dr Simon Bradford, Head of the Research Ethics Committee, School of Health Sciences & Social Care, Brunel University, Kingston Lane, Uxbridge, Middlesex, UB8 3PH.
Telephone: 01895 267143
Email: Simon.Bradford@brunel.ac.uk

# Friendship and Aphasia – A research project



## Participant Consent Form – Research Day

Yes     No 

1. I  have seen the project **information sheet**

   **Yes** ☐    **No** ☐

2. I have had an **opportunity to discuss the project**  with Carole and **ask questions**

   Yes ☐    No ☐

3. I understand **my name will not be used** in reports and talks about the project:

   Yes ☐    No ☐

4. I agree that my **anonymous quotes and stories** may be used later in articles and presentations

   Yes ☐    No ☐

Yes 👍 No ✋

**5.** I understand **I can opt out** or withdraw from the study **at any time and do not need to give a reason**

Yes ☐ No ☐ **EXIT**

6. I **understand** that **photographs, audio and video recordings** may be taken during the Friendship and Aphasia Day

Yes ☐ No ☐

7. I **agree** that **photographs, audio and video recordings of me** may be taken at the Friendship and Aphasia Day

Yes ☐ No ☐

8. I agree that **my feedback interview** can be recorded on **audio and video tape**

Yes ☐ No ☐

**9.** I understand that **any visual material** identifying me will only be used with my consent

Yes ☐ No ☐

10 . I **agree to take part** in the Friendship and Aphasia study

Yes ☐ No ☐

| Signature | Date |
| --- | --- |
| Name in capitals | |

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# Appendix G

## Topic Guide Phase 2

**Draft Topic Guide for Phase 2 interviews (after Friendship and Aphasia Research Day) with participants with aphasia**

(NB this is likely to evolve in response to what happens on the Research Days and participants responses to the early set of interviews)

**Introduction**
- Reminder about the research aims
- Brief recap of personal story (e.g. employment and family, date of stroke, impact and changes)
- Brief recap of key friends and friendship issues raised at Research Day (using photos of stones / notes from Research Day to support communication)

**General Impressions of the Friendship and Aphasia Research Day**
(Using the programme / Takeaway booklet/ Feedback sheet to support discussion)
- What did you think of the day?
- Any parts of the day you found particularly interesting/useful/memorable? Why?
- Any parts of day you found particularly upsetting or difficult? Why?

**Your experiences of friends and Friendships**
- Your responses to the main themes of day
- What's important/ different for you about friends and friendship?
- What have you found helpful / unhelpful?

**New thoughts and actions relating to friends and friendships**
- Have you had any new thoughts or ideas about friendship since the research day?
- Have you done anything differently since the research day?

**Any advice to others**
- about friends and aphasia
- about developing / nurturing / sustaining friendships when you have aphasia

Anything else you wish to add

Thanks and information about next steps of project

# Appendix H

## Communication resources Phase 2 interviews

## Who are your friends?

1. Pick a stone to represent you
2. Pick some stones to represent your friends now
3. Tell the group about your friends – who they are, how you know them, why you are friends

**Discussion and feedback :**
•Who are your friends now ?

•**What's important** to you about your **friends and friendships**?

•**Any changes** to your friends and friendships **since your stroke / aphasia**?

## Your friends and friendships

**XXXXX** talked about:
•His **jobs before** the stroke
•**Losing lots of work friends** / colleagues after his stroke
•**Making new friends** through **volunteer work** and **new jobs**
•What he **likes** about his old and new friends

My stroke, my friends
-Northampton University
- At the hospital
- Cards, flower, fruit ...
- Visiting my colleagues
- After recovery, at home
- Long time : 18 months
- No email
- No colleagues
- Good speech therapy
70                    20++11
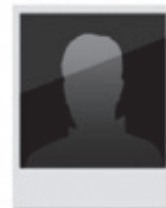
**Discussion and Feedback:**
•What are your **reactions to Jerry's story?**

•Do you have any **similar experiences**?
•Do you have any **different experiences**?

•What has **helped**?
•What has **got in the way**?

## Your friends and friendships

**XXXX and XXXX** have known each other for a long time. They talked about their friendship:
•Some things are the **same** and some things are **different**
•It can be **hard work** – on **both sides**
•XXXX thinks its important to **think laterally** and enjoy things that don't always involve speech
•They still **have fun** together



**Discussion and Feedback:**
•What are your **reactions to XXXX and XXXX's** story?

•Do you have any **similar experiences**?
•Do you have any **different experiences**?

•What has **helped**?
•What has **got in the way**?

## Your friends and friendships

**XXXX** talked about:
•**Dance** being a good way to think about friendship – a **visual language**
•Friendship is **dynamic** and **open-ended**
•Friends can **anchor you** and **ground you**
•And XXXX feels he is an **anchor to his friends** – he gives them **time and space**



**Discussion and Feedback:**
•What are your **reactions to XXX's story**?

•Do you have any **similar experiences**?
•Do you have any **different experiences**?

•What has **helped**?
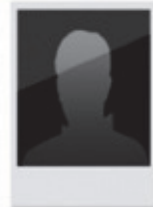•What has **got in the way**?

**Suggestions (from Friendship Day March 5th) to help maintain and build friendships**

- Time, time, time

- Always be there

- Respect

- To and fro, give and take


- 'leave it'

- Give it time – for friendships to get back on track

- Think of ways to manage 'heightened communication state'

- Communicate creatively – write it down, drawings

- Read poetry – 'I feel like that but cant say it'

- Advice for therapist – music, poetry, post card e.g. something different – a way to talk about emotion


- 'get beyond the baggage – I'm still the same'

- 'lighten up'

- Don't personalize it – remember there's a lot going on inside

- Relax - don't be embarrassed

- Allow us to just 'be'


- Talk about 'who you are' e.g. job etc

- Bringing photos to help you talk early on about your friendship and shared experiences

- Advice for friends and family - Read Better Conversations – lots of good advice for family and friends – how to communicate; reassuring

| **Thought Board Ideas 5th March** |
| --- |

- Trust – loyalty goes 2 ways

- I'm happier now

- Emotional

- Different group today

- Going out

- More vulnerable – but vulnerability can give depth to friendships

- They think there is no problem – don't understand

- Open up – keeping it simple

- You can't argue

- My friends followed me to this country from Jamaica!

- Beautiful friends – Beautiful – better now than before stroke

- Brought friends closer

- Able to share new activities with friends

- Harder to keep in contact when people are further away

- You don't go out so much ...its tiring

- Changes the way we interact with friends

- Like you for *what* you are

- Like you for *who* you are

- Hard work!

- Respectful relationships

- Creative adjustments BOTH!

# Appendix I

## Friendship Event materials

**Friendship and Aphasia Project Research Day:**

**An event for people with aphasia**

**Friday 24th February – Northampton**

## Programme

10.00 **Coffee**

10.30 **Introduction** to the day
- About the research
- About the research team
- About the day

11.00 **Who are your friends?**
- These are my friends – video demonstration
- Your friends – small group activity

11.45 **Working and friends**
- Video story 1
- Changes and challenges for you

12.30 **Lunch**

1.30 **Friendship and aphasia: What's important**
- Video stories 2 and 3
- Small group discussion
  - What's important for you?
  - Ideas for other people?

2.45 **New insights and next steps**

3.00 **Finish**

Confirmation Letter

Dear                    ,

**Re: Friendship and Aphasia Research Project Day –**

**Monday 5th March**

Thanks so much for your interest in the project. We are looking

forward to seeing you on Monday March 5th.


The day will be:

**At:**          **Connect** , 16-18 Marshalsea Road, London SE1 1HL

**On :**          **Monday 5th March**

**Time:**          **10.30 start – 3.00 finish**          **Coffee** from **10.00**

               **Lunch provid**ed


I am sending you a **programme** for the day.

Also could you fill in a few **brief details** on the **About You** form.  And

bring this along to the day.


I look forward very much to meeting you on **March 5th**

Do get in touch with me or XXXX if you have any questions or concerns.

Best wishes


Carole Pound

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Briefing for helpers

**Friendship and Aphasia Research Day  – Briefing for helpers**

Thank you so much for agreeing to help at the **Friendship and Aphasia Day in Northampton/ London /** on Friday 24th Feb (Northampton) / Monday 5th March (Connect London) .

The days are part of the **Friendship and Aphasia research project** which has been researching the meaning of friendship from the perspective of those who live with aphasia. So far we have interviewed 12 people with aphasia about their friends and friendships. The project is also guided by the experiences and views of an advisory group of people with aphasia.

We now want to **check out the findings** from the project so far with a wider group of people with aphasia. And **hear about** their own **stories of friendship and aphasia.** The **people attending the workshop** today are people with aphasia we have recruited from Northampton and London.  We expect about 12 people on each day.

Your **role as helper** will be to work with us to:

- Run the day, ensuring a friendly, welcoming, supportive **atmosphere**

- **Support communication** and communication accessibility

- **Document** as many stories and experiences as possible

- Make sure **everyone is included**

Please read the **Information Sheet** about the **Friendship and Aphasia Days**.

The **main aims of the day** are:

- To **highlight and emphasise** the **importance of the friendship relationship**

- To **share experiences and stories** about friendship and aphasia – from the 12 interviews.

- To **explore / acknowledge/ recognise/ discuss/discover** issues people have with their friends and the changing dynamics of their friendships

- (To **discover who you are** though your friends)

The **role of the helpers** today is to:

| | |
|---|---|
| **Welcome, practicalities & ambiance** | • Support the practicalities of the day e.g. room set up, badges, sign in, lunch, travel expenses, taxis <br><br> • Help create a friendly, welcoming , positive atmosphere |
| **Communic-ation support** | • Support communication on a 1 to 1 basis with any group members requiring communication support <br><br> • Support discussions by ensuring people have adequate props and pictures |
| **Record & document** | • Act as a scribe in small group work e.g. key points, quotes, stories on flipchart <br><br> • Help document (by means of verbatim quotes) comments, stories, reactions relating to the main aims of the day and the different activities. <br><br> • Help with cameras, recorders and equipment that we use to capture what people say |
| **Feedback from you** | • Help document any useful strategies or challenges in managing the day <br><br> • And give your personal feedback on the content and process of the day |

Whilst it may be helpful to contribute your own personal examples to facilitate group discussions the main focus of the day is to elicit and document the reactions and experiences of people with aphasia.

Any questions do please ask any of the advisory team: xxx, xxx, xxx, xxx, or Carole

At the **end of the day** it would be helpful to gather **your own reflections** on the event using the attached form. You can also send any post event thoughts and reflections to me later at carole.pound@btinternet.co.

Huge thanks for your help                             The Project Team
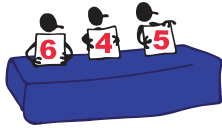
**Helper Feedback on Friendship and Aphasia Research Day**

**Name** **Date**

## Content and impact

1. How would you **sum up** the day in one or two words?

2. Do you think the day **achieved the aims**?

3. **What struck you** about the stories and experiences you heard?

4. Any **new thoughts and reflections** about Friendship and Aphasia **for you**?

**Running the day**

5. What do you think **worked well**?

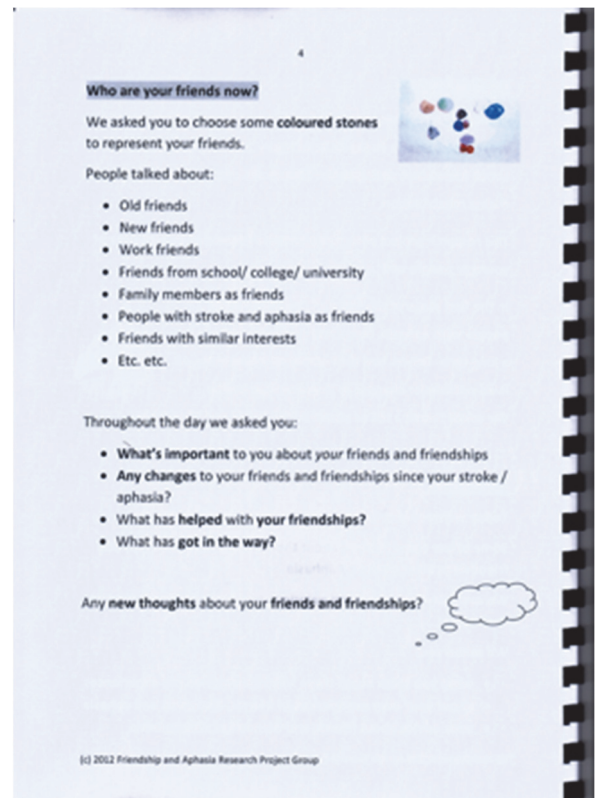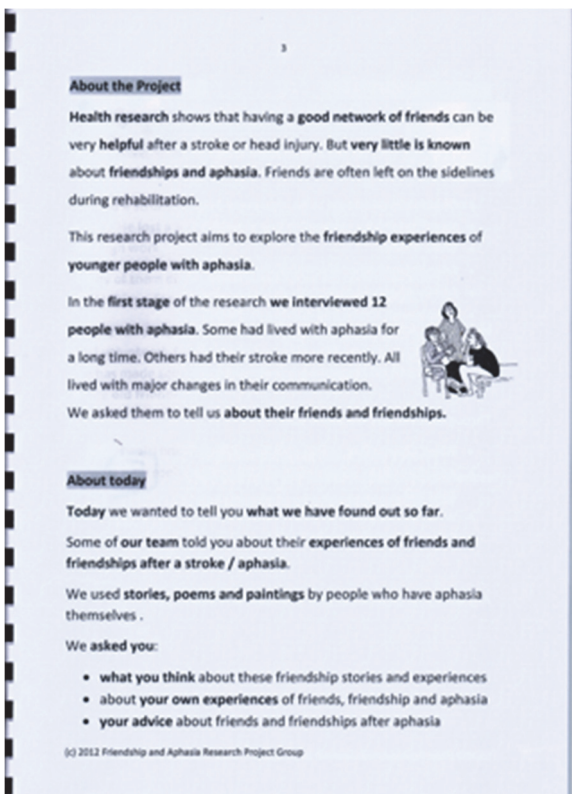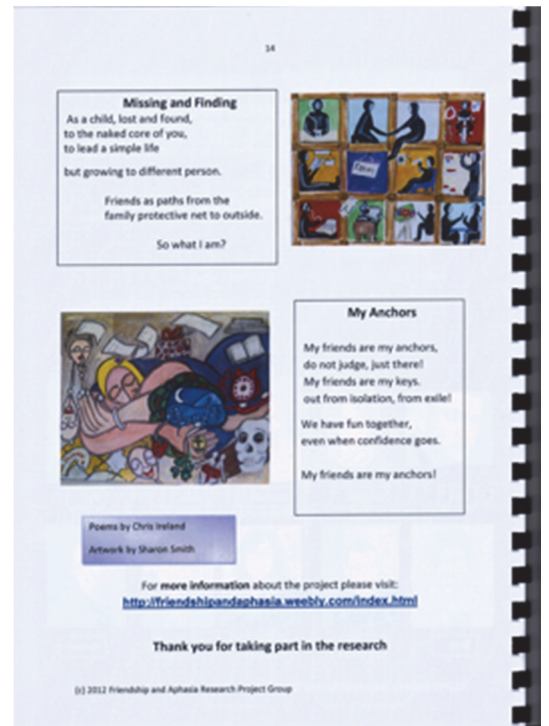6. **Any challenges**?
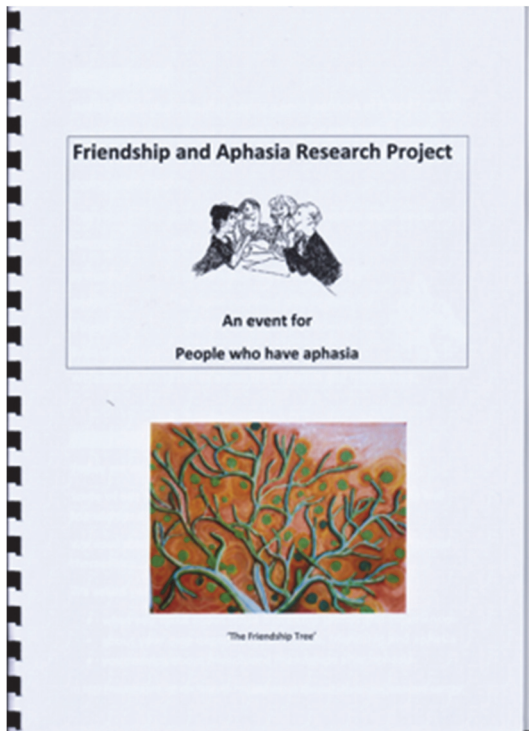
7. **Any changes** next time?

  **Less** of …
  **More** of …
  **New ideas** …

**General**

 8. **Any other comments** about the day or the project?

Takeaway booklet: sample pages

**Friendship and Aphasia Research Project**

An event for

People who have aphasia

'The Friendship Tree'

---

14

**Missing and Finding**

As a child, lost and found,
to the naked core of you,
to lead a simple life

but growing to different person.

Friends as paths from the
family protective net to outside.

So what I am?

**My Anchors**

My friends are my anchors,
do not judge, just there!
My friends are my keys,
out from isolation, from exile!

We have fun together,
even when confidence goes.

My friends are my anchors!

Poems by Chris Ireland
Artwork by Sharon Smith

For **more information** about the project please visit:
http://friendshipandaphasia.weebly.com/index.html

Thank you for taking part in the research

(c) 2012 Friendship and Aphasia Research Project Group

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3

**About the Project**

**Health research** shows that having a **good network of friends** can be very **helpful** after a stroke or head injury. But **very little is known** about **friendships and aphasia**. Friends are often left on the sidelines during rehabilitation.

This research project aims to explore the **friendship experiences** of **younger people with aphasia**.

In the **first stage** of the research **we interviewed 12 people with aphasia**. Some had lived with aphasia for a long time. Others had their stroke more recently. All lived with major changes in their communication.
We asked them to tell us **about their friends and friendships**.

**About today**

**Today** we wanted to tell you **what we have found out so far**.

Some of **our team** told you about their **experiences of friends and friendships after a stroke / aphasia**.

We used **stories, poems and paintings** by people who have aphasia themselves .

We **asked you:**

- **what you think** about these friendship stories and experiences
- about **your own experiences** of friends, friendship and aphasia
- **your advice** about friends and friendships after aphasia

(c) 2012 Friendship and Aphasia Research Project Group

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4

**Who are your friends now?**

We asked you to choose some **coloured stones** to represent your friends.

People talked about:

- Old friends
- New friends
- Work friends
- Friends from school/ college/ university
- Family members as friends
- People with stroke and aphasia as friends
- Friends with similar interests
- Etc. etc.

Throughout the day we asked you:

- **What's important** to you about your friends and friendships
- **Any changes** to your friends and friendships since your stroke / aphasia?
- What has **helped** with **your friendships**?
- What has **got in the way**?

Any **new thoughts** about your **friends and friendships**?

(c) 2012 Friendship and Aphasia Research Project Group

## Stories of Friendship

### 1. ▓▓ and work – Friendship and Change

▓▓ talked about his **different jobs** as a **University lecturer and tutor.**

He had a stroke about 4 years ago. After his stroke ▓▓ couldn't work. He **lost a lot of friends and colleagues** whom he knew through work.

Many of them **didn't understand** about his communication difficulties – for example, it was very hard to use email.

Slowly ▓▓ began to do more. Now he does **several new jobs** (paid and volunteer). For example he works with several stroke charities. He has made some **new friends** and **developed his friendships** with some **old friends.**

- Any **new thoughts** about ▓▓'s story?
- Do you have any **similar/ different experiences?**
- Any changes in your friendships after your stroke?

### 3. ▓▓ – Friendship is two way

▓▓ had a **stroke about 2 years ago** in her early 20s.

She was just starting work as an **optometrist.**

**At first** friends came to visit her at home and stayed in touch.

But some friendships began to feel **one – sided** – her friends asked lots of questions but she wanted to know about them too.

**It took time** to build up her **confidence** and **self esteem.**

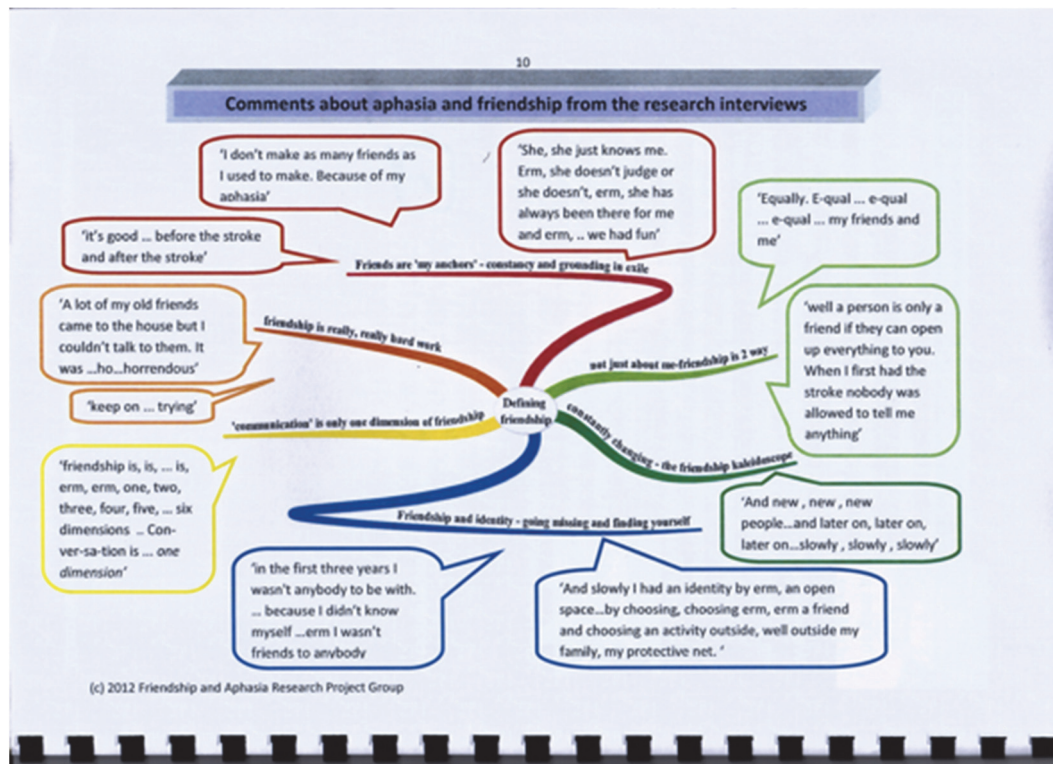She talked about the importance of **2 way relationships.**

And a **realisation** that 'the world doesn't revolve around me!'

She thinks it's important to **give friendships time** to get back on track.

- Any **new thoughts** about ▓▓'s story?
- Do you have any **similar/different experiences?**
- **Whats important** in your friendships

## Comments about aphasia and friendship from the research interviews

'I don't make as many friends as I used to make. Because of my aphasia'

'it's good ... before the stroke and after the stroke'

'A lot of my old friends came to the house but I couldn't talk to them. It was ...ho...horrendous'

'keep on ... trying'

'friendship is, is, ... is, erm, erm, one, two, three, four, five, ... six dimensions ... Con-ver-sa-tion is ... one dimension'

'in the first three years I wasn't anybody to be with. ... because I didn't know myself ...erm I wasn't friends to anybody

'She, she just knows me. Erm, she doesn't judge or she doesn't, erm, she has always been there for me and erm, .. we had fun'

'Equally. E-qual ... e-qual ... e-qual ... my friends and me'

'well a person is only a friend if they can open up everything to you. When I first had the stroke nobody was allowed to tell me anything'

'And new , new , new people...and later on, later on, later on...slowly , slowly , slowly'

'And slowly I had an identity by erm, an open space...by choosing, choosing erm, erm a friend and choosing an activity outside, well outside my family, my protective net. '

Friends are 'my anchors' - constancy and grounding in exile

Friendship is really, really hard work

not just about me-friendship is 2 way

Defining friendship

'communication' is only one dimension of friendship

constantly changing - the friendship kaleidoscope

Friendship and identity - going missing and finding yourself

# Appendix J

## Artwork and poetry developed for the Friendship Events

**The money tree**
Originally it's a friendship tree.
Chinese origins. Buddha – he grows the tree and snaps bits off and
they grow.

It made me think about trees and friendship – you take a bit and you
need to water and nurture it to make it grow.
Symbolic of *giving* to someone. Sometimes we take quite a lot.
Friendship and giving  ...a giving thing... passing it along

Look at it the other way up  – it could be the roots of a system of the
tree – like the Friendship diagram.
The twists and turns  - a testimony to the long lasting bond we form
over the years.

Its boxes in the way of being *in control.*
I like being on my own with music.  This is me with my reading...the
computer...go away leave me alone I wanna watch the tv.
And ones Gone Fishing – that's funny ...painting ...on the phone
...there's people like this in Drop In. It's a mixture of different things –
there's someone doing his keep fit. And someone doing work.

If you notice the box is the person and ...they're stepping out ...that
one has actually gone out to see this one.
It doesn't mean I'm in my little box, it's the opposite ...it's a secure
place you come in or out but it's *your* decision

Its a happy scene it's not bad scene... They don't have to be people
with aphasia ...it's a mixture of *my* friendship.

**6 trees**

Some men, some women.

Trees with different sexuality

The forms -  trees - people

Each one is separation isolation

but the roots branches blend to one

and on and on.

Each tree is connected to the last tree.

It's all entwined and intertwined.

A tree it's growing, its strong, its firm, its loyalty.

**Whats in my brain**...this is me ...all around me. From the centre this is me here with a ... a handkerchief people used to put their belongings in...I put my house and home in it. My hand with my anchor on the coin...it's my luck my marriage my relationships. The death of my past.

The masks are my personality I wear a mask with different masks for different people I'm with. There's a puzzle which is friends and family but some pieces are missing cos you do lose some.
A letter which ...my spelling is terrible ...you do it again and again...I don't mind its wrong but i want people to understand it. My diaries and I have the past , now, and the future. And the phone I leave off the hook 'cos I don't always get what people are saying. Night because it's my favourite time of day.

Commentaries by the artist, Sharon Smith, who has aphasia
 Poetry developed to reflect the six themes from Phase 1

**1.**          **My Anchors**

My friends are my anchors,
do not judge, just there!

My friends are my keys.
out from isolation, from exile!

We have fun together,
even when confidence goes.

My friends are my anchors!

**2.**          **Hard Work!**

No speech is not everybody cup of tea!
Old friends came to my home
but could not talk to them,
was horrondous, enormous effect.
HARD WORK!

Doesn't see them too much,
they are busy with everything,
That is HARD WORK too!

**3.**          **Two Ways!**

Two demensions, my friends and me,
Friendship is not only about me.
          Two ways!
They talk seventy percent and I talk thirty percent!


Friends can open up everything to you,
          to the darker side.
But love share humour,
          laughter together.

We have a vision , so
          THANK YOU

## 4.　　　　The Kaleidoscope

Friendships is constantly changing,
　　some before and some after,
　　　　　different.........
　　New friends,
　　　　　new, new, new people
　　　　　slowly, slowly,
　　　　　fainting, faintly,
　　as fast friends, sharing and bonding,
　　as a painting, that is never finished.........


## 5.　　　　Missing and Finding

As a child. lost and found,
to the naked core of you,
to lead a simple life
but growing to different person.

Friends as paths from the
family protective net to outside.

So what I am?


## 6.　　　　Communication

To try and reach out,
as together.......

Enchance friends, not only is communication,
other ways, as just walking,

Just together......


Poetry by Chris Ireland who has aphasia

# Appendix K

## Friendship Event evaluation report

**Friendship and Aphasia Events – Summary Evaluation**

As described in the Phase 2 Methods in Chapter 8, the approach to evaluating the Friendship and Aphasia Events was multi-faceted and drew on multiple perspectives. Informal evaluations draw largely on data gathered on the day from multiple informants, more formal evaluations draw on the semi-structured interviews from event participants with aphasia.

**1.0    Informal evaluations**

Informal evaluations, incorporated views of people with aphasia who attended, Research Group participants who both participated and facilitated the event, and non-aphasic participants who attended as communication supporters and helpers. They group around three key questions:

How well did the Events succeed (or not) in meeting the stated aims?

What aspects of the process worked well or not so well?

What was the learning from the day for different participants?

**1.1    Participants with aphasia**

Sixteen of the eighteen participants with aphasia completed on-the-day evaluations. Examples of feedback forms are provided at the end of this report. Information on these forms is typically sparse given the writing impairments of most participants and, for some, the impact of fatigue at the end of a full day. There are methodological issues with interpretation of this feedback data as often participants with aphasia required help from communication supporters to complete forms. Communication supporters may have mis-understood or (over) interpreted responses. There is also a possibility that participants felt obliged to score sessions favourably in the presence of people they perceived to be organisers of the event.  However, approximately half of the Event participants completed forms independently. By differentiating sessions with ticks, crosses and, in 1 case, numbers, most individuals appeared happy to judge content and process in a discriminating manner. Comments describing the day were overwhelmingly positive. These included: 'Good'; 'Very good and good';  'Fantastic'; 'Very interesting'; 'A very good day – talks, articles make you want to think'  (Comments from

participant Evaluation forms 24.2.12, 5.3.12).Less favourable evaluations, generally signalled by the absence of ticks or inclusion of question marks included a questioning of the purpose of the dance, not quite seeing the point of the stones activity (2 people) and different preferences for smaller (1 person) or larger (2 people) group discussion.

Impressions about the days, were probed in more detail in the semi-structured interviews.

## 1.2 Supporters without aphasia

Helpers on the days included volunteers without aphasia who worked at stroke support groups (including a trained Occupational Therapist, a trained rehabilitation assistant, and a person with direct experience of stroke though not aphasia), two speech and language therapy students, a stroke support group coordinator, and a former administrator within an aphasia charity.

General feedback from helpers in the debrief sessions and in follow up emails was that the day met all its stated aims. Helpers commented on their perceptions that activities and materials had worked well in stimulating discussion and thinking about friendship.

Comments from evaluation forms, completed independently and confidentially on the day of the Events, included the following:

- 'People were able to think about what defined their own friendships and discuss how this was similar/ different to other peoples experiences ' (RW evaluation sheet)
- Thought the whole day worked well. Thought the stories worked very well. Thought the dance provoked thought' (SC evaluation sheet)
- [Do you think the day achieved its aims?] 'Definitely! Everyone was able to contribute their own experiences' (LC evaluation sheet)
- Well, all very different experiences. I wondered if the day should/could have had more discussion about where relatives fit in on the 'friend' spectrum. Can your husband/wife be a friend? Do they become more of a friend and less of a partner? John seemed to have a supportive wife

who helped him keep his friends. Whereas Gary appeared to have a Mum who was protecting him so much and almost colluding with his friends to make him feel 'disabled'. He said his friends asked her if he was alright - not him. I wonder if there could/should have been more discussion about spouses/relatives as friends. John said he had more friends now - but he also seemed to have quite a lot of confidence. (CC email).

Suggestions for improvement included:

- Creating more communication props to help the inclusion of people with more severe aphasia
- Including a stronger focus on strategies and actions which participants could take away
- Making time to discuss the poetry and artwork

In relation to their own learning, all helpers commented that they had found the day interesting - it prompted them to reflect on their own friendships as well as those of the participants with aphasia. One helper, an experienced rehabilitation worker reflected how, just knowing he was going to come on the day had prompted him to pay more attention to the friendship experiences of clients on the stroke unit where he worked:

'I've started listening to the people I see in hospital...there's quite a lot of people I'm very worried about ...stroke is such a big life changing event ...the support you get from your friends is so very important'
(Debrief session 24.2.12)

Several helpers reflected on the absence of reflection on friendships generally:

'striking that we don't often analyse our friendships'
(Debrief session 5.3.12)

Several helpers who were health care workers commented on their surprise that the day generated so many positive stories:

'surprised by so much positivity'        (Debrief meeting 5.3.12)

## 1.3    Evaluations by members of the Research Group with aphasia

Members of the Research Group with aphasia who had facilitated sessions and participated in small and large group discussions unanimously agreed that the day had met its aims – 'did what we said on the tin' (Barbara, Research Group 18). They reflected on the positive, inclusive ambiance, the ease with which participants with aphasia engaged in discussion and activities, and the range of diverse experiences and stories that arose in response to the materials we had developed.

Their comments on procedural aspects of the day included a range of observations. These included:

- A disappointment that there was no explicit attention and time to study the artwork and poetry

- A concern that several participants may have had difficulty following more abstract components of the day, e.g. the dance sequence, the stones activity

- A worry that several participants were becoming tired towards the end of the day

- A concern that those attending the day were more representative of people with aphasia who proactively seek out and engage with peer support rather than individuals who may be harder to reach, or less confident

Their reflections on how the days had impacted on their own learning tended to focus on two main issues. Firstly, these reflected more personal, emotional responses, for example how they had found the day 'invigorating' or personally affirming or 'empowering' (fieldnotes, 24.2.12; debrief interviews 24.2.12; 5.3.12).  Secondly responses reflected insights about friendship and aphasia. These related to further evidence about everyone being different and another affirmation about the complexity of the topic, or as Jeff described it the 'layers into layers' (Research Group, 18).

## 2.0    Event evaluations in the semi-structured interviews

Evaluations of the Friendship Events within the interviews probed individual reflections on the day and its different components.   Illustrative comments are reflected in sections 2.1-2.3 below.   Table 1 summarises the responses to stories and activities on the basis of a thematic review of individual transcripts under activity headings.

## 2.1    Overall impressions of the day

Across participants the positive evaluations from informal evaluations were borne out. Feedback was overwhelmingly positive with comments relating to the people, the tone and the content.

'I erm, I I think erm, (...) erm, as a general , I think it was a, a very, very *successful* day. Erm, for, for who, for *everybody* really. For, for, for the sake of *research*, erm, for volunteers, you know, who are purely interested, erm, and for, for *stroke survivors* and so on. It was, it was erm lovely get their views and to find out just how, you know, how important friendship is, you know.'

(Derek, line 54)

CP: Generally what did you make of the day ?

Cherry: Erm, very s- *good*. Erm, erm group. Erm, yeah, very good. Erm,(3) erm, (...) positive, you know.

(Cherry, line 22)

Trisha: It was *good*. It was fun.

(Trisha, line 11)

**Table 1  Summary of responses to stories**

| Participants in Northampton | Participated in Stones activity | Jeff's story | Sarah and Sandra | Priya's story | Binda and dance | Reviewed Booklet and artwork |
|---|---|---|---|---|---|---|
| Derek | No | ✓ | ✓ | x | x | Yes |
| Ron | Yes | ✓ | ✓ | ✓ | ✓ | Yes |
| John | Yes | x | x | ✓✓ | ✓ | Yes |
| Terry | Yes | x | ✓ | ✓✓ | x | No |
| Chris | Yes | x | ✓✓ | x | x | No |
| Gary | Yes | ✓ | ✓✓ | ✓✓ | ✓ | Yes |
| Karen | Yes | ✓ | ✓✓ | ✓ | x | No |

| Participants in London | Participated in Stones activity | Jeff's story | Sarah and Steph | Priya's story | Binda and dance | Reviewed Booklet and artwork |
|---|---|---|---|---|---|---|
| Shana | Yes | ✓ | ✓ | ✓ | x | No |
| Sonya | Yes | ✓ | ✓✓ | ✓ | x | No |
| Anthea | Yes | ✓✓ | ✓✓ | ✓ | x | Yes |
| Richard | No | x | ✓✓ | ✓ | ✓ | Yes |
| Martin | Yes | ✓ | ✓ | ✓ | x | No |
| Frank | Yes | x | ✓✓ | x | x | No |
| Joan | Yes | ✓ | ✓✓ | ✓ | x | Yes |
| Cherry | Yes | x | ✓✓ | ✓ | x | Yes |
| Trisha | Yes | x | ✓✓ | ✓ | ✓ | Yes |

*x* no strong identification: ✓ identify with some aspects of story; ✓✓ identify strongly with story

Only one person implied that the day had focused her mind on friendship in a more negative way.  Shana was the only person who became visibly upset during the day, as she described having only one person she considered a real friend, since her stroke 10 years ago:

> CP:    I mean, just anything that struck you about the day (..) as sort of memorable or interesting or terrible or (..)
>
> Shana: Well, it was fr- friendship and *aphasia*. That's it. Can't talk at all. Well, can, you know.  But (..) is (3 )  for *me* erm, (...)small (…) friends (…) *small.*
>
> (Shana, line 41)

Other less favourable comments addressed the challenge of talking and explaining when you have aphasia rather than the nature of the day.

### 2.1.1   Reflections on aspects of process

Many comments reflected positive views on the range and variety of activities and people. Some people had a preference for smaller group activity, whereas some, including those with more severe aphasia such as Sonya, Richard, Karen and John, reported enjoying the larger group interaction. Most participants enjoyed the mix of both.

### 2.1.2   Reflections on the activities and materials

Most respondents suggested that they enjoyed the stones activities and the video stories, sometimes highlighting a particular story or discussion as being particularly meaningful to them. For example, John and Cherry were intrigued by the video of Priya, commenting on her youth, her positive approach and her impressive recovery of speech. This led John to ask for a copy of the video stories to show his wife.

A highlight for many respondents was the video of Sarah and her friend Sandra in conversation.   Joan's comments demonstrate her own clear sense of connection to Sarah's coping style as well as the joy of ongoing connection with good friends. Asked what she thought about the Friendship Event she replied:

Joan: Lovely. *Beautiful.*

CP: Yeah.

Joan: It was just like me and my friends.

CP: You and your (…)

Joan: My friends.

CP: Yeah, yeah.

Joan: And I thought that was *lovely*.

CP: That reminded you then, seeing Sarah and Sandra chatting together, having a bit of a laugh (…)

Joan: It was (...) Yeah. [*laughs*]

CP: Yeah, yeah. That really, that's like you when you're chatting with Teresa.

Joan: Yes, that's, that's, That is about me, yes, lovely. I thought that was *lovely.*

CP: Hmm.

Joan: Her, Sarah it was very much like me. That's how I felt like her. Lovely.

CP: Say a bit more, why did you feel like Sarah, you think.

Joan: Because I've got a smile on my face now.

CP: Right. So you identified with her, she was laughing.

Joan: Yeah.

(Joan, line 1017)

People with more severe aphasia seemed to find connections to their experiences also. For example, Sonya, who had severe aphasia, seemed to draw parallels with the experience of her own two loyal friends:

CP: Erm, yeah, and the last thing that Sarah and Sandra said that was really important was erm, (**…)** friends who are very loyal. [*writing – artefact 8*]

Sonya: Yeah.

CP: And persevere and keep, keep going.

Sonya: *Yeah*. That's it, yeah.

CP: That's a big smile and a big thumbs up.

Sonya: *Yeah.* [*laughs*] Yeah.

CP: So and it sounds like people like [*mentions two of her friends*] and your family they, they do this [*points to 'keep going'*], they keep going every day.

Sonya: Yeah.

CP: Very reliable.

Sonya: Yeah.

(Sonya, line 1579)

Opinion was more divided in response to the inclusion of the dance sequence. Some respondents (Gary, Richard, Trisha) loved it. Others described feeling unclear about its relevance or worrying that they had not understood what it was all about. The strong negative reactions to the dance from some participants was an interesting demonstration that respondents were not simply acquiescing in being positive about all aspects of the Events.

In relation to the takeaway materials, nine of the 16 participants reported reviewing the materials after the event. Joan stuck the postcards on her fridge as a reminder of the day. Some participants (Gary, Anthea, Richard, John, Ron) reported showing them to friends and family. For example, Anthea described showing the booklet to her key worker (and long standing friend) and residents (and friends) at the residential home where she lived. She described her own thoughts on revisiting the Tree of Friendship postcard and the image of the six entwined trees on another postcard from the Event:

Anthea: No. I waited until when I get home. Then I erm, look at the (..) photograph, the erm, (..) before it (…)  Yeah, this one.

CP: That one. [*Postcard of friendship tree*]

Anthea: And it was, erm, *real interesting*.  … …

CP: What did you find interesting about it. So this is one of Sharon's paintings of the friendship tree.

Anthea: Yeah. Yeah. For me when you look at the tree is like the friendship is going on different directions. Yeah. … …

CP: Mmm. And any (…) So this one in particular you (…) That occurred to you that that was about friendship.

Anthea: Yeah.

CP: How about any of these other ones? [*both scan the 4 postcards*]

Anthea: Also the erm, you know, [*points to card with 6 intertwined trees*] it was interesting as well with the, erm, the trees because what do you call it   [*weaving gesture with hand*]

CP: Yes, it's intertwined.

Anthea: Yeah, yeah. So it's like friends and family and everything is involved together, yeah. Yeah.

(Anthea, line 1210)

Gary showed the booklet to his friend Jack, who commented that he found all such material useful to increase his understanding of Gary's experience of aphasia:

Jack: The erm, booklet, I found this one particularly fascinating…

…I've greatly appreciated *everything* that Gary has provided me to read, because whilst I haven't got a chance of ever understanding what it's like for Gary and Gary of course can't explain to me in any way that I can appreciate what it's like for him, all these people's different, erm, ways of describing what it's like for them, …  …has gone a long way to help me at least appreciate *part* of what Gary is going through. So I can better, erm, be there for him … … just to be better erm, better help, better friend. Erm.

Gary: True.

(Gary, line 1198)

Others, such as Martin, indicated the materials had not made any significant impact:

CP: … did you show the booklet to anyone or did you put it on the shelf or (…)

Martin: I, I, I put it o- in the, the, you know (…) Oh yeah.

> CP: Did your wife have a look at it or not?
>
> Martin: Erm, not really.
>
> (Martin, line 1795)

## 3.0    Advice for others

The final section of the Events and the semi-structured interviews asked participants to reflect on advice or suggestions that they might want to pass on to others about friendship and aphasia. Suggestions arising from the Events were documented and uploaded onto the project website. These suggestions were reviewed and, in some cases amplified in the semi-structured interviews. A full list of suggestions from the Events are included in Appendix T.

# Appendix L

## Overview of Research Group meetings

**Overview of Research Group meetings**
**Phase 1**

| Exploratory | Content of meeting |
|---|---|
| RG 1<br>January 2010 | • Introductions<br>• Groundrules<br>• Ways to be involved<br>• Priority issues about life with aphasia<br>• Research training: PhD requirements; methodologies |
| RG 2<br>February 2010 | • Decision-making about involvement<br>• Decision-making about research focus<br>• Ethical considerations<br>• Research training: aphasia research literature |
| RG 3<br>March 2010 | • Friendship experiences<br>• Design issues<br>• Models of disability; project values<br>• Research training: social support and aphasia literature |
| RG 4<br>April 2010 | • Meeting with Brunel supervisors<br>• Shaping research questions and methods<br>• Decision-making about sampling<br>• Developing information materials |
| RG 5<br>June 2010 | • Preparation for interviews – topic guide; communication support; emotional support<br>• Reflection on involvement benefits and challenges<br>• Key messages for talk to rehabilitation conference |
| RG 6<br>July 2010 | • Feedback on first wave of Phase 1 interviews<br>• Methods: resources to support people with severe aphasia<br>• Decisions about involvement in analysis<br>• Research training and discussion – data analysis<br>• Desired esearch outputs |
| RG 7<br>October 2010 | • Preliminary analysis of Phase 1 interviews<br>• Emerging themes – discussion and experiences<br>• Discussion of first version of friendship diagram<br>• Research training: phases and cycles of participatory action research |

**Overview of Research Group meetings**
**Phase 2**

| Innovation | Content of meeting |
|---|---|
| RG 8<br>January 2011 | • Analysis and interpretation – review findings from 2nd set of Phase 1 interviews<br>• Review and revise Forest of Friendship diagram<br>• Begin to design Friendship and Aphasia Event<br>• Meeting with poets |
| RG 9<br>February 2011 | • Review of Forest of Friendship diagram<br>• Develop aims of Events and possible products<br>• Develop brief for artists and storyteller<br>• Meeting with artists and poet |
| RG 10<br>March 2011 | • Planning for Events<br>• Design materials for Events – stories to friendship themes, interactive activities, role of humour<br>• Meeting with artist |
| RG 11<br>May 2011 | • Planning for Events<br>• Review of materials – art, storytelling<br>• Meeting with storyteller<br>• Feedback on artwork |
| RG 12<br>August 2011 | • Review of purpose of Events<br>• Planning for Events: designing 'activities', videos, programme<br>• Develop key messages for conference presentations |
| RG 13<br>September 2011 | • Planning for Events<br>• Design of takeaway materials<br>• Recruitment process and materials<br>• Review of website structure and artwork |
| RG 14<br>October 2011 | • Development of website materials<br>• Event planning: data collection and evaluation<br>• Designing and piloting activities |
| RG 15<br>November 2011 | • Review of website<br>• Event planning: recruitment materials and ethical procedures<br>• Developing video stories<br>• Pilot and finalise activities |
| RG 16<br>December 2011 | • Event planning: recruitment process; briefing for helpers<br>• Review of materials<br>• Training and problem solving: facilitation at Events<br>• Research reflection: Doing PAR |
| RG 17<br>January 2011 | • Event planning: dress rehearsal<br>• Recruitment update<br>• Planning communication access at the venues<br>• Practical preparations, roles at Events |

**Overview of Research Group meetings**
**Phase 3**

| Evaluation & elaboration | Content of meetings |
| --- | --- |
| RG 18 April 2012 | <ul><li>Review of Friendship and Aphasia Events</li><li>Analysis and interpretation of Phase 2 interviews: new issues arising</li><li>Revisiting the Forest of Friendship diagram after the Events</li><li>Dissemination: developing feedback materials for participants</li></ul> |
| RG 19 June 2012 | <ul><li>Analysis and interpretation : Forest of Friendship diagram</li><li>Dissemination: website review</li></ul> |
| RG 20 September 2012 | <ul><li>Analysis and interpretation: Forest of Friendship diagram</li><li>Reflection on methods and diagram</li><li>Dissemination: key messages and audiences</li><li>Update on thesis writing</li></ul> |
| RG 21 November 2012 | <ul><li>Final Forest of Friendship diagram</li><li>Dissemination: prioritising opportunities</li><li>Reflection on participation and involvement</li><li>Endings: planning ways to stay in touch</li></ul> |
| RG 22 February 2013 | <ul><li>Update on thesis writing</li><li>Endings: reflection on achievements and learning</li><li>Reflection on project outcomes and future priorities</li><li>Plans for dissemination events</li></ul> |
| | Celebration drinks and supper |

**Appendix L  Additional meetings and contact with Research Group members**

- Interviews with six individuals (June-July 2010)
- Meeting with Katie to run training session (July 2010)
- Member check meetings with all interviewees (September 2010)
- Meeting with Jeff to develop presentation (September 2010)
- Katie's funeral (October 2010)
- Training session at Different Strokes organised by Jeff (October 2010)
- Training sessions at Brunel University with Priya (October 2010; January 2011)

- Meeting with storyteller and Melanie (February 2011)
- Experimental storytelling workshop with 12 individuals with aphasia including Research Group (June 2011)
- Meetings x 2 with Melanie to write blog piece (September 2011)
- Meetings x 2 with Barbara to plan and present at Human Sciences Research Conference (July 2011)
- Meetings x 2 with Priya to plan and present at British aphasiology Society Conference (August; September 2011
- Meetings with Priya, Sarah, Melanie to plan and film video stories (October-November 2011)
- Meetings x 2 with Binda to plan dance presentation (September, October 2011)
- Visits to Northampton and London to check Event venues and discuss Phase 2 recruitment with link RG members
- Running of Friendship and Aphasia Events (February; March 2012)

- Meetings x 2 with Melanie (+ Facetime conversations) to write article and plan conference presentation (September, October 2012)
- Meeting with Binda (+ Skype conversations) to plan and run conference presentation at UK Stroke Forum (November, December 2012)
- Meeting with Jeff and Stephen to discuss dissemination events at Connect (February, 2013)
- Meeting with Barbara to plan and run dissemination event for Stroke Association in Kettering (April, May 2013)
- Meeting with Binda to plan talk and workshop for Different Strokes Symposium (May, 2013)

# Appendix M

## Examples of Research Group notes

**Friendship and Aphasia Research Project
Meeting 21**

**Thursday 8th November 2012 at Connect**

**10.30** **Coffee in the cafe**

**Agenda**

**11.00** **Updates**

**11.15** **Telling people about our findings**

- **Review of key messages & audiences**

**Conferences and talks:**

- I**NVOLVE** – How does participation of people with aphasia make a difference?

- **UK Stroke Forum** – How can stroke services support people with aphasia with their friendships?

- **Different Strokes** – ideas needed

**12.45** **Lunch**

**1.45** **Endings**

- What difference has the project made?

- Hopes for the future?

**3.00** **To do list and final meeting**

**3.15** **Finish**

# Friendship and Aphasia Research Project
# Notes from Advisory group 21

# Thursday 8th November 2012 at Connect

## People

**Present:** Sarah, Barbara, Melanie, Debra, Binda, Jeff , Priya, Tom, Carole

## 1. Update - Revisiting Forest of Friendship Diagrams

Carole recapped the **changes** we agreed last time:

- 'altruism' – now changed to 'making a contribution'
- power – the branch swirls around to encompass the other sub-branches
- reconfiguring identity – now at the top of the diagram - aspirational

Carole has also now **numbered the branches / themes** – to help group some of the themes and structure the writing about a complex subject:

- Theme 1 My friends are my anchors
- Theme 2 Communication is only 1 dimension of friendship
- Theme 3 Friendship is really, really hard work
- Theme 4 More than me : friendship is 2 way
- Theme 5 Time, time, time
- Theme 6 Humour and hanging out
- Theme 7 Creativity: Doing friendship differently
- Theme 8 Friendship and identity

Binda's nephew asked for a copy because it felt very relevant to his own friendships.  It's good that it's helping other people to think about and talk about friendships

The diagram is proving **helpful** in **developing talks** too.

**Evaluating** the final **diagram** you said:

- ✓ 'its fantastic…its there'
- ✓ 'and also shaping it all'
- ✓ 'Very good …were …proud' – about diagram
- ✓ 'it's a little …a little masterpiece'

## Confidence

Priya asked about **confidence**. It's not a separate branch. But it comes into:

- • Background context chapter
- • Reconfiguring identity – identity evolves as confidence develops
- • Hard work – Managing other impairments

We talked about the **importance** of confidence. And also about **not wanting to overplay** it. Sometimes we thought healthcare professionals latch onto confidence, over-simplifying it and over-emphasizing it. Jeff talked about the danger of confidence, like language, becoming a superficial concept and simplistic 'intervention'. We decided not to label it as a separate branch but be aware of its importance

Some of the things you said:

- ✓ 'it's only word …like verbs '

✓ 'confidence is everywhere and nowhere …its part of friendship, part of everything really, part of self esteem …its one of those things like power …that …is always present but not spoken about'

✓ 'The speech therapist at the hospital… a little talk and …an activity…mostly cards and ..countries and cities…and second a holidays and lots of pictures..[pulls face] well its good  [grimaces] but its only the surface not not not …its fine …but…'

## 2.  Participation and involvement

We reviewed your thoughts about **being involved** in the project

Carole asked **what motivated you** to:

- Get involved with the project
- Stay involved with the project over 3 years!

You said:

✓ 'Its unusual …its out of the box'

✓ 'just the thinking about something different …not normal things'

✓ ' positive idea …yeah.

✓ 'the projects sort of intellectual…not just conversation group'

✓ ' it stimulates you'

✓ 'Well I think all of us I think we thought…well you got the idea to use us …and I think we thought wooo …you think were worth it …and we thought you're worth it!' – the l'Oreal effect (swish of hair) !

✓ 'a bit like …a think tank'

- ✓ 'when it begun we didn't know what it was …it's like could be anything really'

- ✓ ' I quite like the idea of the unknown you know and it was like, like …Star Trek!'

- ✓ I think what's been created is …unique, and I also thought …being Connect and being involved …I liked the project being in tandem with Connect ethos'

- ✓ the creative process of thinking together and not quite knowing what would come from our collective thinking

- ✓ 'for me that was a bit challenging but it has been good'

- ✓ ' being part of something …that you think is radical and …is going to make a difference'

- ✓ 'because I trust you …and I know that it would …be a laugh!'

- ✓ 'well for me erm…I think the thing about making a difference … that's really important. I also think that its been about informing the other voluntary work I do (at Headway) … …really what its all about at its bottom its about how to make friends with people.'

- ✓ Has relevance at a wider, more strategic level - beyond the community of people with aphasia, relevant to influencing policy makers more widely

- ✓ 'although it was difficult it was still acknowledging that you have hopes and ambitions… and with that acknowledgement of skills and experience which is very important, I think as well for me , and this is not altruistic…it was about status '

✓ fits with being an ambitious person – like being involved at PhD level

✓ your experience and your skills given the status they deserve

✓ 'it's been hard but I wouldn't have it any other way …but coming out of that it makes you positive and you can cope better'

What have you **learnt**:

✓ 'About myself …beyond the subject as well'

✓ Other ways to manage

✓ 'learning to be a bit more compassionate towards other people with aphasia and other people with disabilities.'

✓ Friendship is missing from government health papers – thinking about how to get friendship into government policy documents

**Changes for you during the project**

✓ 'For the past 3 years this …learning will not be taken away …and the erm …self esteem or …self affirmation and , and er … you know little bit of self knowledge that erm , you know …erm no one can erode '

✓ 'I think change for me is like I know what …participation research is and now I very …critical other research like you know you have research and they say 'ooh you know we have to do focus group' to erm like like …'consult people …I don't like that …lots of research its just guinea pig, guinea pig aren't they '

- ✓ 'well I feel a far richer person , I do [ CP: why?] well erm …richer in that I've met good people, richer for the whole experience, because that point about …somebody said about erm the …experience being a very holistic one'
- ✓ Enjoyed making cakes for the group
- ✓ 'I went 1 conference with you and I enjoyed that …you get part of this thing outside '
- ✓ 'being at the conference with you I get like my public speaking skills … this was another jump towards my speaking skills'
- ✓ The anger with professionals who say 'you're alright you're fine'

We talked about different levels of involvement in research, a **continuum** between **consultation, collaboration and control**.

Different people indicated the level of control they felt they had during the project. For most people it was on a pendulum between collaboration and control, changing a little with different stages of the project:
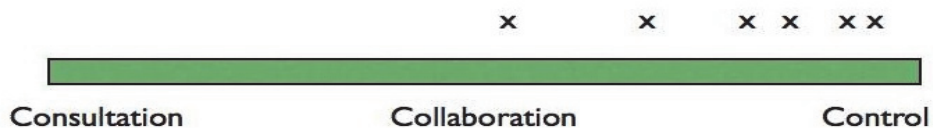


**Advice re Participatory Action Research as a way of doing research:**

- ✓ Do it!
- ✓ Pace and patience is required – what you do unravels over time]

✓ Important to record with camera and audio and summaries
– (Barbara talked about a project where there are no
summaries)

✓ Being involved at the outset of the research was important –
Barbara talked about wanting to know where the original
research question had come from when she helped other
research projects – the researchers or people with aphasia

✓ Importance of trust with the researcher – some people said
knowing Carole a little from before was helpful

✓ 'An important part for me is you give ownership back and
that's very important for me'

✓ Priya said she thought it was important that Carole had her
own experiences of disability.

---

### 3. Dissemination – Telling others about the Friendship Research

**We recapped the different audiences and key messages.** We agreed clear, simple messages are best!

| Audiences | Key Messages |
|---|---|
| **All (people with aphasia , friends, family , health and social care workers, academics and policy makers)** | ✓ Friendship is **really important**<br>✓ Be **more aware** of **friendship** and the **importance of friends**<br>✓ Friendship can play an important **role in reconfiguring identity, autonomy, wellbeing** |

| People with aphasia | ✓ **Don't forget your friends** (even if its hard to think about them at first) |
|---|---|
| Friends | ✓ **Stay in touch** <br> ✓ People with aphasia **value their friends** in **the long term not just in hospital** |
| Family | ✓ **Don't leave out friends** <br> ✓ **Family** are **very important** and **Friends can be too** |
| Health & Social Care staff <br> Stroke teams | ✓ **Don't just focus on family** <br> ✓ Think **beyond 'health and social care'** <br> ✓ Friendship is **not a tick box** exercise <br> ✓ Friendship is **'naturally holistic'** – about real life <br> ✓ Friends are an **untapped resource** <br> ✓ Friends and friendship lead to **better health outcomes** <br> ✓ **Ask yourself** - How can I or other people make sure friendship gets addressed? <br> ✓ Think **out of the box** – not 'therapy' but real life <br> ✓ **Don't medicalise friendship** |
| Policy Makers | ✓ **Think about cost** –it will be **cheaper** for you <br> ✓ Friends and friendship **can save money** – don't need other help e.g. |

| | |
|---|---|
| | no pills, no psychology, no doctors, fewer appointments, no carers<br>✓ Friends **enable better health outcomes**<br>✓ Our research/ model is **relevant to other groups** |
| **Academics and researchers** | ✓ People with aphasia **can participate** in Action Research<br>✓ Involvement needs to be **creative and long term**<br>✓ Ideas from our project that might be useful for **other research projects** (eg involving people with dementia, mental health conditions) |

Carole and XXXXXX ran through the talk planned for the **INVOLVE conference** in Nottingham. INVOLVE promotes **greater user involvement** in health and social care research. This talk focuses on the **involvement** of people with aphasia **as co-researchers**, the **way we have worked together** in the advisory group. The title 'Friendship is like a painting that's never finished' – to emphasize that you never quite know what's coming next with participatory research.

The talk highlights **the difference involvement has made** to:

  ✓ The **data** – the stories we gathered, the range and differences

  ✓ The **findings** – the way we have interpreted what people said; shaping our model of friendship (the diagram)

✓ The **outcomes** – what we will do with the research

We talked about how the **research** might have been **different without your involvement**:

✓ **Different starting point** and different research question – Carole might have pursued a research question about communication access not friendship

✓ 'I feel we are **more direct** …this group has more direct understanding of what it is to live with aphasia'

✓ a good combination of the inside ( your personal experience) and the outside (Carole's experience and understanding of aphasia) – this gives the project 'a seal of **authenticity'**

✓ The **methods were different** – e.g. developing and using the Friendship Events – this was a way out of a more medicalised view of friendship; using the stones was an example – 'its absolutely physical…it does not require language. You can see the outcome. Its individual seeing. Its individual…and democratic'

✓ Tom thought the work sat nicely along with the **ethos of Connect** and the social model – 'its about how you live with it and …the effects on you, your family and friends and everyone who comes in contact with it'

✓ Debra thought that the **impact** could be **deeper** because the project involved' greater and **deeper experience and understanding'**

- ✓ **Positive tone** and **creative stories** from the events – this led to theme 6 Humour and theme 7 Creativity, being added
- ✓ Stronger advocacy for **people with severe aphasia** so more people with severe aphasia included in the project
- ✓ **The diagram – 'more aphasia friendly'**; you thought without the diagram …'maybe you have more list' and 'more difficult to take things out'
- ✓ The nature of the research was a bit like a **shoal of fish** (or flock of swallows) travelling along together but suddenly changing direction. The **change of direction comes 'from within'** – i.e. not a linear process like some research

We talked a little about **different perspectives on friendship research**. Involvement in, for example the friendship events, meant that we avoided medicalising the topic.

Priya asked whether Carole's disability had had an impact on the project too.

We talked about some different approaches in recent research on Friendship e.g.:

- Analyzing conversations between friends
- 'Living successfully with aphasia' – you thought this was a strange title:

Your reactions to this:

- 'Makes me laugh [laughs]'
- 'Fantastic lets go!' – simplifying what its like
- 'all those are kind of …helicopter' – looking from the outside not starting from the inside

**Other talks and dissemination opportunities**

Carole and Binda are going to the **UK Stroke Forum** – this talk will focus on what healthcare professionals can do to help people with aphasia maintain and sustain friendships – see key messages above. Binda worried about encouraging people to 'hang onto' friends if they want to go.

See key messages above: Other things to say:

- **Think outside the box** – use stories from the interviews to illustrate
- Think about **beyond 'therapy'** and health / social care – 'living with it'
- '**your family only knows one part of you'** – do you really want your family to be telling the therapy team 'who you are'
- think about **who people's friends are** – not just long term friends, maybe neighbours
- can you **involve a friend** in …a therapy session; in goal setting etc
- tell them they don't need to keep 'talking, talking, talking' – a **different culture** of friends from the culture of therapy. Friends don't feel the need to fill the silence, they know you and therefore can respect the silence

**Different Stroke Northampton** (audience people with aphasia) Barbara to meet up with Carole to plan the session. Main focus on telling them what we found and thinking about best ways to disseminate the findings.

Carole and Barbara to produce a **little flyer** inviting friends and family and telling them what we will do.

We discussed trying to get a lecture on **TED** *('TED (Technology, Entertainment and Design) is a global set of conferences …formed to disseminate "ideas worth spreading.")*. 'Celebrity - style' lecturers record a lecture and its watchable on the internet/ Youtube. Priya will investigate. Carole also suggested filming some good soundbites next time from the advisory group to go on the website or Youtube.

After the meeting Debra suggested **Radio 4 'The Listening Project'** – for a conversation between friends.  Carole to investigate

## 4. Endings

**Next meeting** will be the **last**!! Hardly seems possible we have been meeting for 3 years!
We agreed to have the meeting in the afternoon, then celebrate after the meeting with a drink / supper together.
We talked about wanting to **mark the ending** properly – **acknowledging contributions and successes**. And thinking about **future projects and opportunities** to work together on talks and chapters. Before we finish we also want to:

- Have a process for responding to **requests to talk** about the project

- Work out who might go to **Australia** – quite a few interested speakers!

- Think about **writing the book** with Bronwyn in Australia – this is with psychology Press.

- Think about how to get the findings to the **wider world** too – eg Sociology, Media outlets eg Laurie Lee programme, Mark Vernon (philosophy); maybe talk to XXX and XXX

- Produce a standard **set of powerpoint slides/ standard presentation** so that anyone from our group can talk about the project

- Review and properly update **website** – maybe some new talking heads, making it more interactive eg a blog. We need a process for doing this

- XXXX suggested an **email update** every couple of months might be useful – to keep regular contact and share ideas

**Actions**: Could you all have a **think about**:

- Getting our ideas outside to the wider world
- Plans for beyond the project
- Ways to stay in touch
- Any agenda items for next time
- Any ideas for restaurants!

**Date of Next Meeting -**
**Monday February 18th 2013 at Connect at <u>2 pm</u>**

**Friendship and Aphasia Research Project  -**

**Summary of Meeting 21 Thursday 8ᵗʰ November  2012**

## 1.      Reviewing the Forest of Friendship diagram

We reviewed the changes since last time & the role of confidence

We evaluated the role the diagram played in summarizing

many aspects of the project

## 2.      Participation and involvement

We talked about how the research was **different**:

The **topic** was different – friendship

The **way** we did the research (e.g. using the stones and

Friendship Events) and the **Findings** are different too. We talked

about a **continuum of involvement** – from collaboration to

control. And **personal changes** for you through being involved.

## 3.      Dissemination – Telling others about our research

We reviewed **key messages** for **different audiences**.

Carole and XXXXX ran through the **INVOLVE presentation**.

We discussed messages for the **UK Stroke Forum**

## 4.      Endings

 Next meeting is the last official meeting! But we talked

about **plans** for **staying in touch** and **more communication**

about the project in the future. We discussed TED talks, radio

programmes, writing together etc. We need to plan this next time.

## 5.          Final meeting

Next meeting at Connect **Monday 18ᵗʰ  February 2013** at

**Connect**

**NB Later start at 2pm** Then pub and early supper together**.**

# Appendix N

# Research Group resources and materials

Diagrams used to support Research Group discussions
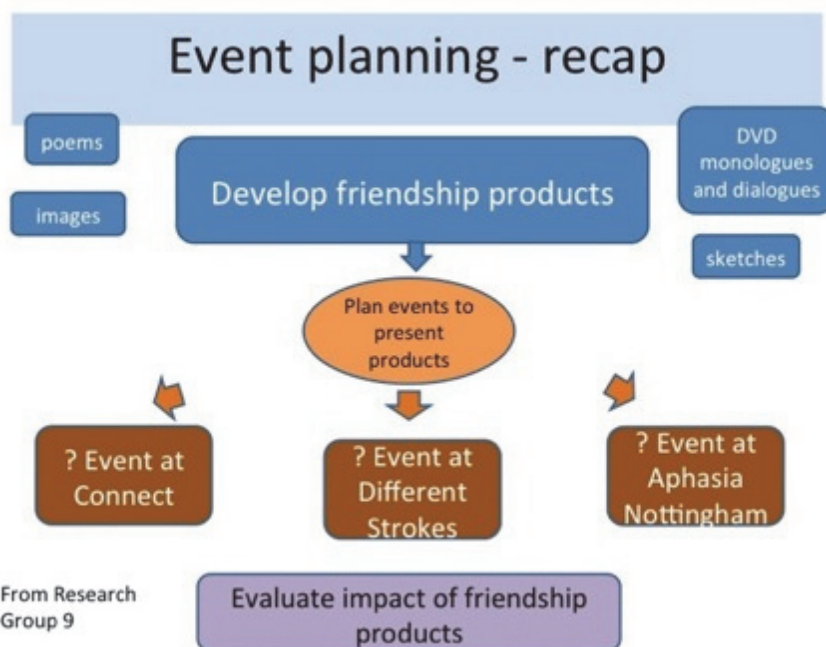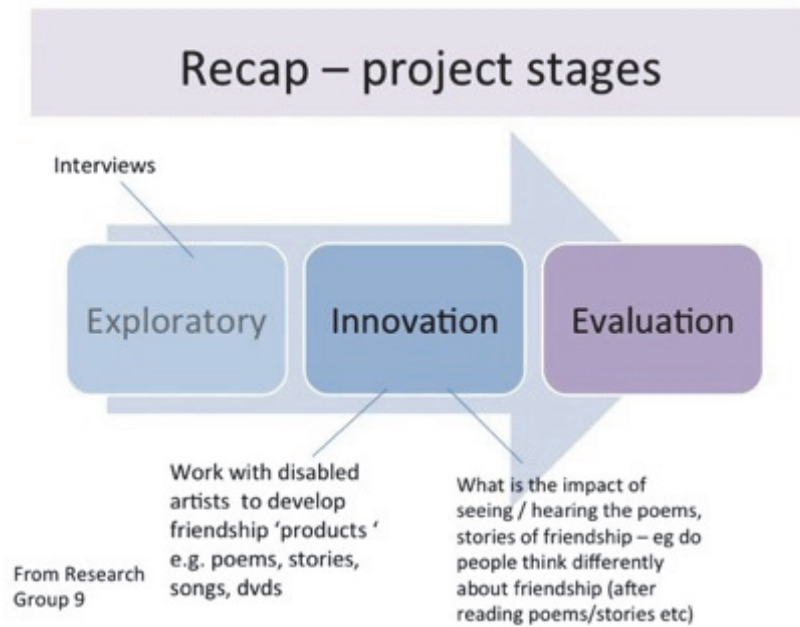
# Revisiting the diagram

- Check branches
  - New branches (Time; Humour; Creativity)
  - New positions & colours
  - New look



- Check wording
- Check meanings
- Check for gaps

From Research Group 20

# Appendix O
## Transcript notation

**Transcript notation**

| | |
|---|---|
| (..) | a brief pause |
| (…) | a slightly longer untimed pause |
| (4) | a pause measured in seconds |
| *italics* | indicates emphasis |
| <u>*italics*</u> | italicised and underlined text indicates slightly stronger emphasis |
| **bold** | bold text indicates very strong emphasis |
| [ talk | indented talk beginning with a square bracket indicates overlapping talk |
| bu- | a dash indicates speech that ends abrubtly |
| ho:me | a colon indicates an extension of a sound |
| Hhhh | audible out-breath |
| .hhh | in-breath |
| . | indicates a stopping fall in tone |
| ? | indicates a rising inflection |
| ! | indicates an animated  or emphatic tone |
| (?word) | indicates best guess at  unclear material |
| (?) | question mark in single parentheses indicates unclear speech |
| [*writes*] | italicised text in square brackets provides explanatory information and other non-verbal features of talk |
| ... … | horizontal elipses indicate talk omitted from the data segment |

Notational conventions slightly adapted from Gail Jefferson's system (see Atkinson and Heritage, 1984) cited in Wood and Kroger (2000).

# Appendix P

## Transcript extracts Phase 1 and Phase 2

Example of Phase 1 transcript – Katie

Interview 1 – 14-06-2010  Katie – F - 57 – 23.11.03

1013    affect your friendship at all?

1014

1015    K: No. No. Because, erm, it is only me who notices

1016    that I am having a bad day.

1017    Erm, I am always going to be

1018    'Good afternoon. Hi, how are you doing?',

1019    and use all the common words that I use anyway. So.

1020

*Comment [c126]: So maybe here strategy of being upbeat conceals this to others. Much easier to deal with a consistent friend than one who is moody and inconstant – thinking of Debs and Jude and how hard to stay a friend when you are faced with vaiation. A real skill being able to cover up moods. Thinking of Troutie too and how we are exercised and bamboozld by inconsistency because it makes it harder work on the friend*

1021    CP: What do you think people value

1022    about you as a friend?

1023

1024    K: [pauses and sighs] Well, I suppose

1025    I am always honest. Erm, no, I don't, erm,

1026    I never ever tell lies.

1027    Erm, the odd wee white fib. [laughs]

1028    But erm, because life is too short.

1029    I mean, I don't know, I felt if tomorrow is tomorrow

1030    but I'm going to make sure I am okay

1031    and I give it the best I can. So I mean,

1032    I give the best I can to everything.

*Comment [c127]: Philosophy of life – part of narrative and maybe very important part of knowing someone and what you can expect from them as a friend. Less tested before stroke?*

1033    Sometimes I feel so tired and wish that I had

1034    more energy but ... No, I do, I think I really ...

1035    I think friends will ... [sighs] I hate to say this.

1036    Erm, they don't have like

*Comment [c128]: Fatigue as a theme*

*Comment [c129]: Yes being a friend is 'really really hard work'*

1037    'Oh, your have, oh, look and listen to her voice,

1038    haven't you improved. Oh, what a clever girl. Oh...'

1039    That is, I mean, that is what comes

1040    for everybody because we don't like

37

Interview 1 – 14-06-2010  Katie – F - 57 – 23.11.03

1041   to see people in a bad state.

1042

1043   **CP: So people do that to you a lot now,**

1044   **sort of slightly patronising?**

1045

1046   K: Yeah. Well, I don't find it patronising

1047    but when I think about it, it is patronising.

1048

1049   **CP: But when they do that**

1050   **'oh, aren't you doing well',**

1051   **how does that affect your friendship**

1052   **with those people?**

1053

1054   K: Erm, well, it generally is a,

1055    to feeling of how I am doing which is fine.

1056    I don't, I don't reply. Just 'Oh, thank you' or something,

1057   and move on to the next thing.

1058   But it makes them feel better.

*Hard work of managing this*

1059

1060   **CP: And how does it make *you* feel?**

1061

1062   K: Erm. [pauses]

1063    It makes me sad for the people

1064   who don't have such a, which die alone.

1065    Is sad for them. But not for me.

1066   Because I can see in Charlie and in Hilary

1067   and the people, erm, erm …

1068   Basia, has really, really come on

38

495

Interview 1 – 14-06-2010  Katie – F - 57 – 23.11.03
_____

1069   since she started your programme.

1070   Hmm. Just a thought.

1071   I noticed a terrific difference in her.

1072   It is because I think we all grow in confidence

1073     through being given something concrete to do

1074     like we're doing now.

1075

1076   CP: You, you implied before that confidence

1077     is quite a big thing for you

1078

1079   K: yeah, yeah

1080

1081   CP:  and how you feel about yourself

1082     and how you interact with friends.

1083

1084   K: Yeah. Yeah. [laughs] Yeah. It is.

1085   Also because, erm, you know that Jethro …

1086   Here's the question, there is a very long passage of time

1087     before you get the answer.

1088   I was like that about three years ago.

1089   I'm not like that anymore. So comes quite quickly.

1090   Erm, and like yesterday I was in … [very loudly]

1091   'When is it my turn?'

1092   because, erm, they were very quick, the girls.

1093   Oh, [imitating girls speaking very quickly].

1094   Advising my …

1095   And I said 'Listen! You want to hear me?'

1096

**Comment [c132]:** Being given something concrete to do as important

**Comment [c133]:** The role of confidence in building self and maintaining/ developing friendship. My lack of friends in early depressed days – nothing to offer

**Comment [c134]:** Confidence to claim a turn literally. Otherwise invisible in a crowd?

39

Interview 1 – 14-06-2010  Katie – F - 57 – 23.11.03

---

1097    CP: That was with your house guests.

1098    You were confident to sort of ...

1099

1100    K: Yeah. Yeah. Just, yeah. Is it my turn now.

1101

1102    CP: What would you say

1103    thinking about things that help friendship.

1104    Either help keep them going

1105    or help develop new friendships.

1106    So confidence, how confident you feel

1107    sounds one thing.

1108

1109    K: Yeah. Yeah.

1110

1111    CP: Are there other things

1112    that you feel help friendships?

1113

1114    K: If you go out.

1115

1116    CP: Go out?

1117

1118    K: Yeah. For a meal or a drink.

1119    Just a quick drink, a coffee or something.

1120    Yeah? Erm, like the girl I met through the Connect,

1121    she was a volunteer when you were there.

1122    She is doing another degree in speech therapy.

1123    Erm, and I go up to see her.

1124    Because we are very ...

> **Comment [c135]:** Going out maintains/ develops friendship.

40

Interview 1 – 14-06-2010  Katie – F - 57 – 23.11.03

_____

1125  And she said oh, and 'you are a star'. [laughs]

1126  Yeah. So that is the kind of thing.

1127  It doesn't take much, just to have a coffee and a drink

1128  or a meal to …

1129  Because that gives time to grow the friendship.

> **Comment [c136]:** Time to grow the friendship is a nice phrase

1130

1131  CP: So doing something together so that that …

1132

1133  K: Yeah. Yeah.

1134

1135  CP: … grows the friendship.

1136

1137  K: Yeah. Yeah.

1138

1139  CP: Does it matter what you talk about

1140  or what you do?

> **Comment [c137]:** Regardless of topic or activity thy are only a conduit

1141

1142  K: No. No. Not at all. Talk about anything.

1143  I always said that isn't me

1144  [imitates somebody speaking very, very fast

1145  so that individual words become indistinguishable].

1146

1147  CP: So it's just about spending some time,

1148  sort of hanging out together. Yeah.

1149

1150  K: Yeah. Yeah.

1151

1152  CP: Anything else that in your opinion

41

498

Example Phase 2 interview- Richard

| | Interview 11 | | 15.03.12 | Richard |

1503   **CP:** Yeah. And then the *last* thing we did

1504   we talked about *suggestions*

1505   that might help other people

1506   with their friends and with their friendships.

1507   Yeah?

1508   [writing - see artefact 7]

1509

1510   R: Hmm.

1511

1512   **CP:** And some of the things

1513   [papers moved – finds and shows flipchart suggestions]

1514   let me just remember what people say.

1515   So some of the suggestions

1516   that we had was (…)

1517   [writes ]

1518   it's important to give people *time*.

1519

1520   R: *Yes, yes.*

1521

1522   **CP:** Erm, respect.

1523

1524   R: *Yes.* Yes. Yes. [laughs]

1525

1526   **CP:** Yeah?

1527

1528   R: *Yes.*

1529

1530   **CP:** That was something that came up

*[handwritten margin note, left: Using day 2 Flipchart]*

*[handwritten margin note, right: Time – very definite response.]*

51

499

Interview 11              15.03.12     Richard

| | |
|---|---|
| 1531 | and things like loyalty. |
| 1532 | |
| 1533 | R: **Yes.** *Yes! Yes.* [laughs] |
| 1534 | |
| 1535 | **CP:** Those were things, |
| 1536 | *all* things that you mentioned as well. |
| 1537 | |
| 1538 | R: Yeah. |
| 1539 | |
| 1540 | **CP:** Then things, well, hmm. |
| 1541 | Obviously kind of with the communication (…) |
| 1542 | |
| 1543 | R: Yeah. |
| 1544 | Yes. |
| 1545 | |
| 1546 | **CP:** People have to try and communicate differently. |
| 1547 | |
| 1548 | R:    [*Yeah. Yeah.* [laughs] |
| 1549 | |
| 1550 | **CP:** That's easier said than done! |
| 1551 | |
| 1552 | R: *Yes, yes, yes.* |
| 1553 | |
| 1554 | **CP:** Both sides again have to |
| 1555 | do a bit of *hard work*, |
| 1556 | a bit of *effort*. |
| 1557 | |
| 1558 | R: Yes. |

*Handwritten margin notes:*

Again very **strong** response

Suggested list helpful way of summarising + confirming with R.

Hard work ?not so strong for him [but feels maybe hard work for friends?]

52

Interview 11        15.03.12    Richard

1559

1560    **CP:** On both sides

1561    [draws- artefact 7]

1562    for all of these things.

1563    Erm, and then yeah,

1564    one of the other things was the,

1565    so the thing about *emotion* was,

1566    you know, don't take it too personally.

1567

1568    R: Yeah. Yeah. Yes. Yeah.

1569

1570    **CP:** Are there any *other* suggestions

1571    you can think of, Richard,

1572    that would be helpful for other people

1573    if you were giving advice?

1574

1575    R: Erm. Yes. [points to photo of RG members]

1576

1577    **CP:** That lady, Melanie?

1578

1579    R: **Yeah**. Erm Ah!

1580    Shu shuh!

1581    Erm. )...) Yeah.

1582

1583    **CP:** You liked (...)

1584

1585    R: Erm, *yeah!*

1586

[He strikes me as pretty chilled despite massive difficulties with comm^n !]

[Unlikely match but they really seemed to 'click' on day]

53

Interview 11          15.03.12     Richard

1587    **CP:** Yeah?

1588

1589    R: Yeah.

1590

1591    **CP:** So she had some good ideas?

1592

1593    R: *Yeah. Yes.*

1594

1595    **CP:** I'm trying to think (…)

1596    I think she was the one

1597    who was saying about the emotions, wasn't she.

1598

1599    R: Yeah.

1600

1601    **CP:** Don't personalise it, give us a break.

1602

1603    R: *Yeah. Yes. Yeah.*       [Again v. defnte]

1604

1605    **CP:** So you liked, you liked her suggestions.

1606

1607    R: *Yes.*

1608

1609    **CP:** Yes, because those were from her experience,

1610    weren't they?

1611

1612    R: *Yes. Yeah.*

1613

1614    **CP:** Yes. Something else she said

54

502

Artefact 7. Related.
15.3.12.

Dance
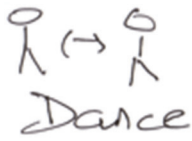
Pub music

relationship

bumpy ←→ flowing

memory?
history

Old?
Young?

1 year 2 3 4 →

time

respect

Suggestions
friends —

Communicate differently

hard work

loyalty

??

# Appendix Q

## Transcript extracts: Sam and Martin

## Transcript extract – Sam (Phase 1)

Interview 10 – 7.12.10   Sam-M- 51- Jan 07

| | | |
|---|---|---|
| Some people say as Info giving | 1627 | or you're doing stuff |
| | 1628 | you have quite a lot of friends, |
| | 1629 | and then a lot of people say |
| | 1630 | that when they have a stroke, |
| | 1631 | when their speech is affected, |
| | 1632 | they tend to lose their friends which, |
| | 1633 | you know, can understand. |
| | 1634 | [Mum: Hmm. [agrees]] |
| jumping gun friendship actions | 1635 | Erm, so what *this project* |
| | 1636 | is about is trying to think |
| | 1637 | is there any, anything we can do |
| | 1638 | to make that situation a bit better. |
| Friendship withdrawal | 1639 | So if I, thinking about your friends, Sam, |
| | 1640 | did they stop coming to see you? |
| | 1641 | Or did you (...) |
| | 1642 | [draws 2 figures and arrows] |
| | 1643 | Who stopped it? |
| | 1644 | Was it you? Or was it them? |
| | 1645 | [indicating Sam and 'others'] ] |
| | 1646 | |
| | 1647 | **SAM:** [stares at page 8 secs] |
| | 1648 | |
| | 1649 | [looks up at CP ] (2 secs) |
| | 1650 | |
| | 1651 | **CP:** So let's try and draw this. |
| | 1652 | Okay. So this is you. Sam. |
| | 1653 | And then you've got your friends. ( 10 secs) |
| | 1654 | [draws stick figures – |

Handwritten annotations:
- About the project aims
- Comment [c72]: I think Im emphasising potential outcomes not the exploring f experiences
- Technique – diagrams /mnd
- Comment [CP73]: Direction of rejection
- NB Dont forget to write about comp.
- Reaction – S. lack of comp
- Comment [CP74]: I think no idea what I was asking
- Technique – draw question

59

Interview 10 – 7.12.10   Sam-M- 51- Jan 07

| | |
|---|---|
| 1711 | Erm, okay. Well, we're getting, |
| 1712 | we're getting to the end. Is there, |
| 1713 | Ernm is there any *advice* |
| 1714 | that you would give to people |
| 1715 | who have aphasia |
| 1716 | from your experience? (4 secs) |
| 1717 | Either about, either about (..) friends |
| 1718 | [writes advice – friends, life] |
| 1719 | or about kind of just getting on with life in general. |
| 1720 | ( 9 secs) [S looks at CP neutral expression] |
| 1721 | About life. |
| 1722 | Any advice or any tips that you would give? |
| 1723 | (11 secs) |
| 1724 | |
| 1725 | SAM: [sound] |
| 1726 | |
| 1727 | CP: Any thoughts on (...) |
| 1728 | (4 secs) |
| 1729 | Or are there any erm, |
| 1730 | any ways that you would like |
| 1731 | for things to be different? |
| 1732 | ( 7 secs) [ S looks down at page] |
| 1733 | Apart from probably going back to |
| 1734 | not having, [hhm] not having the stroke. |
| 1735 | But given that that's happened, |
| 1736 | are there any, (..) any things |
| 1737 | that you think are *important*. |
| 1738 | [pause of 7 seconds] |

*(Handwritten margin notes:)*
Marker – ending
Question – advice about friends
Question – life advice
Why did I broaden this?
Wittering! – ? CP reaction to discomfort
Question – what's important.

62

506

Transcript extract – Martin (Phase 2)

*[handwritten: In response to DVD of S+S.]*

1921    CP: Because I suppose with the music group

1922    that's, you know,

1923    in a way that's being together

1924    and using music as a way to have opinions and …

1925

*[handwritten: Yes indeed but acquiesced?]*

1926    M:       [Yes, indeed.

1927

1928    CP: (…) Erm, one of the other things

1929    that came up on the day was that people said erm,

1930    when you have a stroke erm,

1931    there's a lot more emotion

1932    [sound of writing- artefact 6]

1933    flying around.

1934

1935    M: Oh really.                                          Comment [c51]: Said with slight surprise?

1936

1937    CP: And I remember some of the ones they mentioned

1938    is that people get a bit more angry or frustrated

1939    [sound of writing] or some people said

1940    that they (…) they cry a lot,

1941    when they're watching a film or listening to music.

1942    Erm, is that something that's an issue for you

1943    or not, not particularly?

1944

*[handwritten: ?Acquiesced.]*

1945    M: I think so.

1946    But erm, (…) yeah.

1947

1948    CP: You're pulling a face like you're not quite sure.

1949

1950    M: Yeah, I don't, don't know.

Interview 13 17-03-2012      Martin -M – 48 – 10/2010

1951    I don't, we ...

1952

1953    CP: Would you say you're more emotional?

1954

1955    M: I think, I think so.

1956

1957    CP: You are.

1958

1959    M: Yes, indeed, indeed.

1960

1961    CP: And your friends do they find that a bit strange or (...)

1962

1963    M: Don't know. I don't know.

1964    Yeah, I don't think so.

1965

1966    CP: Looks like they just carry on the same.

1967

1968    M: Yeah. Yes, indeed.

1969

1970    CP: They carry on the same.

1971    Yeah, yeah.

1972

1973    M: Yes, indeed.

1974

1975    CP: So for you

1976    the advice to erm,

1977    yeah, for you this isn't such a big, such a big one.

1978

1979    M: I think so, yeah.

1980

66

# Appendix R

## Technology and Friendship

**Technology and Friendship**

| Type of technology/ communication | Ways used within friendship | Examples |
|---|---|---|
| Mobile Phone | • Record of friends in phone address book | Joan strimmed out all her pre-stroke contacts just leaving close friends and family as contacts with photos. She described these as people she knew she could trust<br>J: But if you look at everybody else it's Kate, Teresa, Mary, erm, Emma, the group and everybody else is my family.<br>CP: Right. So you've kind of, I remember you saying you've kind of done a strimming out, you cut out all of the contacts<br>J: All the shits out, yes.<br>CP: Yes, so you've just got the people who are your friends and your family.<br>J: And that's it. (Joan, line 1988) |
| Text | • Planning meetings, confirming times and places<br>• Exchange of frequent affectionate texts | Karen's sister/friend sends multiple 'love you' daily messages alongside the details of carers visiting times. |
| Smart phone photos | • Humour, non-verbal joke telling, expressing personality<br>• Spelling out words via keyboard in conversation with friends where speech is distorted | Gary shows photos of incongruous signs on his phone |
| Smart phone games | • To and fro exchanges between friends within a game | Sarah and her friend make up to three scrabble exchanges daily as meeting up is more difficult now. They describe this as a way of having fun and knowing each other is okay |
| IPad | • Use of images to support | David uses Google maps to show where he works, demonstrate |

|  |  | music likes, demonstrate his competence to friends |
|---|---|---|
| | conversation<br>• Use of text to speech facility to share news with friend in current affairs conversation | |
| Skype | • Regular calls to maintain contact with friends living abroad or further away | Grant and his wife have weekly Skype call with Grant's oldest friend and ex-work colleague living in Africa |
| Facebook | • Re-connecting with old friends from work and school<br>• Demonstrating identity through thumbs up/down likes and dislikes<br>• Using Facebook to share jokes with friends<br>• Using a Facebook group to organise a holiday<br>• Using Facebook 'online now' icon to stay in touch with friends abroad | David's friend in America used Facebook to organise a holiday abroad. David found the shared photos and conversation made it feel as if there was something 'more more human sort of thing about it ' (David line 1840)<br>Frank shares jokes via Facebook<br>F: Some of the time, yeah, yeah. I just send stupid pictures and things like that, you know. Because it's like the things that you can (...)<br>CP: Yeah, so that's something you quite like doing?<br>F: Yeah, yeah. I've always been a joker. That's not changed, that's not changed, so.<br>(Frank, line 424)<br>Shana looked out for her friends in Greece coming online<br>S: But I know the, erm, the *dot* like Facebook online now so you can see the (...) list erm, (...)Yes, 'online now'. So yeah.<br>CP: Oh right, okay.<br>S: *Hello!* You know.<br>CP: So you do a quick message to them.<br>S: And that's it. *Hello* dot dot dot.<br>(Shana, line 2125) |
| Internet and email | • Using email to accommodate the greater time it takes to write | David described email and the internet as a 'life saver'<br>D: Yes I would say it's almost a *life saver* actually, I think. |

| | messages to friends <br> • Using the internet to find out and share information about stroke and aphasia | CP: Really? <br> D: Well if I had my stroke in er th- thirty years ago my life would be, (..) erm well … …. it would have been horrible. Couldn't have done much. (….) And people won't understand *what* the problem is, yeah, you know. (David, line 1817) |
|---|---|---|
| Digital photos | • Sheets with photos of friends to initiate conversations about friends | Chris and Tina use laminated sheets of photos of friends to plan and organise social events |

# Appendix S

## Update to study participants

## Aphasia, Friends and Friendships Research Project

## Update – June 2012

### A reminder about the project

The **Aphasia, Friends and Friendships Research Project** is looking at how people with aphasia experience **friendship** after a **stroke**. The project is focusing on **younger people** who have had a stroke – mainly people under 65.

The project is a **Participatory Action Research Project** – a group of people with aphasia are actively involved in making the decisions about what we do and how we do it. The project is co-ordinated by Carole Pound and based at Brunel University.

We want to know:

- **Who** people think of as their friends

- **Any changes** in friendships after a stroke

- **What's important** about friendships when you have aphasia

- What things **get in the way**

- **What helps** develop and maintain friendships

We hope the findings from the project will be useful to:

- **People** who have **aphasia**

- **Friends and family** members

- **Rehabilitation services**

- **Policy makers**

**Stage 1 – Interviews with people with aphasia**

Summer 2010- Spring 2011

We **interviewed 12 people** with aphasia about their friends and friendships.  Everyone was different:

✓ Some people were in their 20s and 30s. Some were older

✓ Some people had regained a lot of speech and language, some people had more trouble talking and communicating

✓ Some people had their stroke a long time ago, some people had their stroke quite recently and were newer to the experience of aphasia.

✓ Some people had lost friends, some people had kept their friends or gained new friends. Some friendships were different now.


People talked about many **different types of friends:**

• Old friends from the past, from school or college

• Friends from work and interests: ex-colleagues, football friends, drinking friends, bridge friends

• neighbours and friends living nearby ; friends living abroad or further away

• virtual friends – on Facebook or email

• family friends and friends through their children's lives.

• Family members and partners who were also counted as friends. And pets were too!

• Some people had made 'fast friends' (new friends who also had aphasia) at local support groups.

Carole and the advisory group **analysed** the interviews. We looked for some **common themes** and also the **differences** between people. We developed a **model of friendship**.

---

**Stage 2 – Friendship and Aphasia Research Days**   Spring 2012

We wanted to test out this **model of friendship** with more people with aphasia. So the Project Team developed **a day** about **Friendship and Aphasia**. We produced some **video stories**. We commissioned some **art and poetry** from people who have aphasia. We thought about different ways people could **tell stories** about their own experiences of **friends and friendships.**

We ran one day in **Northampton** and one day in **London**. About 20 new people with aphasia came to the events. They shared their ideas and experiences about friendship with aphasia. They came up with some great ideas about **what was important** and **suggestions** to develop and maintain friendships.

You can see more about these events on the **website** –

www.friendshipandaphasia.weebly.com

After the Research Days Carole **interviewed** most of the participants. She asked them what they thought of the days. And we gathered **more information** for our model of friendship and aphasia.

**Next steps**

We are reaching the **final stages** of the project now.  In the next 6 months we plan to:

- ✓ **Write up** what we found out from all the interviews
- ✓ Start **sharing the findings** with people working in stroke rehabilitation
- ✓ Think about **best ways** to **tell people with aphasia and their friends** about the project

If you have any **suggestions** please do get in touch. You can contact:

**Carole**: carole.pound@brunel.ac.uk

Brunel University, School of Health Sciences & Social Care

Mary Seacole Building, Kingston Lane

Uxbridge UB8 3PH

**XXXX**: at Different Strokes, Northampton

Or email address

**XXXX** : at Connect, London

Or email address

**Thanks again** for your help with the project.

We will contact you with a **final summary** in **2013**.

# Appendix T

# Recommendations for others

**Recommendations for others**

These recommendations are a summary of ideas shared by people with aphasia at the Friendship and Aphasia Events in Northampton and London, and people with aphasia who have attended dissemination events at stroke support groups.

**Recommendations for people with aphasia**

| Key messages | Suggestions and ideas |
|---|---|
| ✓ Friendship is really important<br>✓ Be more aware of friends and friendship<br>✓ Don't forget your friends | Talk to other people with aphasia – what has helped them stay in touch with friends? |
| | Make an effort to stay in touch with friends |
| | Join a peer support group – it's a good way to get to grips with aphasia and make new friends |
| | Keep a sense of humour. Laugh a lot. |
| | Tell your friends you love them |
| | Get out of the house |
| | Do new things with your friends – that don't need too much speech |
| | Poetry, art or music might be helpful to move beyond words |
| | Think of communication props to help conversations with friends |
| | Get in touch with old friends from your past e.g through social networking. Send a card early on |
| | Take time out from rehabilitation. |
| | Have a go. Keep trying |
| | Pets can helpful – they treat you the same; they help you relax |

**Recommendations for friends and family**

| Key messages | Suggestions and ideas |
|---|---|
| ✓ Friendship is really important<br>✓ Be more aware of friends and friendship<br>✓ People with aphasia value their friends in the longer term not just in hospital<br>✓ Family are very important and friends can be too | Don't abandon your friends when they have a stroke |
| | Don't exclude friends by just focusing on family |
| | Don't judge people too soon. Give friendship time |
| | Stay in touch with your own friends – they will be good for you and for the person with aphasia |
| | Ask for help if you are unsure what to do, or how to communicate. Plan ahead, think what might help communication |
| | Read 'Better Conversations' for communication advice; Slow down; Learn to be comfortable with silence; Learn to listen better |
| | Be prepared to make an effort e.g. the effort to make contact. Remember friendship is often hard work |
| | Try visiting the person with aphasia in pairs at first |

| | |
|---|---|
| | Have faith in your friends – treat them as competent |
| | If people with aphasia get upset don't take it personally; 'lighten up' |
| | Be flexible. Try new ways to do things and new ways to hang out with your friends |
| | Don't patronise or over-protect your friends. |

## Recommendations for Health and Social Care Staff

| Key messages | Suggestions and ideas |
|---|---|
| ✓ Friendship is really important | Don't ignore friends. Remember family and friends are 'not all one lump' |
| ✓ Be more aware of friends and friendship | Think about how to include friends in goal setting, therapy tasks, finding out more about a person |
| ✓ Don't just focus on family | Help people with aphasia access peer support groups and peer befriending as soon as possible – persevere if people aren't keen early on |
| ✓ Friendship is not a tick-box exercise | Ask about friends in initial interviews and follow-ups |
| ✓ Don't medicalise friendship | Help people with aphasia access different stories of friendship to see what is possible |
| | Don't make assumptions, remember everyone is different. |
| | Give friends information too |
| | Remember how important the emotional and social side of aphasia are. Offer more education and information about relationships |

# Appendix U

## Dissemination Events

**Slide 1**

'Friendship is like a painting that is never finished': co-constructing knowledge about friendship and communication disability

INVOLVE Conference 2012
Carole Pound & Cressida Laywood

**Slide 2**

## Introduction

About us

About the talk
- Our **methods** of involving people with communication disability as research participants and co-researchers
- a **brief overview** of the key research findings
- reflect on **how involvement** has influenced our research

**Slide 3**

### I want to be more involved but with aphasia....

I like reading but its difficult...academic papers!!!!

Talking & understanding ...too fast, too complicated taking in the subtlety

Mobility: I can't drive now, I live alone, I have to organize to get places

Numbers : I live on my own, appointments, dates, telephone messages

Status: I lost my job, my desires, my ambitions. You get out of the loop!

Memory: its very difficult to think what did we did last meeting

Effort : Everything takes so long ...its exhausting

Emotions: frustration and control...I feel very raw now, no veneer

Remember also – Everyone is different

**Slide 4**

## About our project

How do younger people with aphasia experience and understand friendship?

How does the involvement of people with language impairment influence friendship & aphasia research?

Participatory action research

**Slide 5**

Exploratory
12 interviews

Innovation
2 Friendship events

Evaluation
16 interviews

22 Advisory Group meetings + contact by Skype & Facetime

**Slide 6**

### Some strategies for involving people with aphasia (as interview participants)

Supported conversation

Conversation ramps e.g. diagrams, photos, key word writing and drawing

Stones

Checking, verifying, key words

Extra time

Stories/ideas from others with aphasia

INVOLVE , Nottingham
November 2012

1

INVOLVE Conference November 2012

**How has being involved in the project made a difference to you?**

- Learnt about my friendships
- Cycling – better mobility & wellbeing, more energy, getting out
- Giving and learning from others in the project
- Double-edged sword Can be emotional – understanding more about my impairments
- Made me stronger, coping better through meeting up with friends
- Using my skills and having them acknowledged

**What other co-researchers said**

Tom: when it begun we didn't know what it was ...its like could be anything really ... .. I quite like the idea of the unknown you know and it was like , like ...Star Trek! Jeff: Beyond I [laughter] Tom: yes , boundaries ...the frontiers ...

Its one person ...its ...the group ...committee ...it's the ...stimulating its erm 11 o clock and ...i don't know the agenda and its surprise...its ...'oh' back of the head ...and another word and a little ...thing and , but it's a group not one person

'I think change for me is like I know what ...participation research is and now I very ...critical other research like you know you have research and they say 'ooh you know we have to do focus group' to erm like like ...'consult' people ...I don't like that ...lots of research its just guinea pig, guinea pig aren't they '

Its been hard but I wouldn't have it any other way ...but coming out of that it makes you positive and you can cope better'

**Conclusions/ key messages**

About friendship and aphasia

- Friendship is complex, and dynamic – it doesn't fit neatly into boxes!
- Friendship is very important when you acquire aphasia
- 'Friends and family are not all one lump'
- Friendship is very important in rehab and beyond – do healthcare professionals think about it enough?

About involvement and participation

- People with (severe) aphasia can be involved in conversations and interviews & developing theory
- Participatory research lends itself to more creative, flexible methods

**Acknowledgements**

- Co-researchers with aphasia
- Supervisors
- Interviewees & artists
- Support organisations

connect
the communication disability network

*different* **Strokes**

**Thanks for listening**

- More about the project
- www.friendshipandaphasia.weebly.com

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**Questions**

?

INVOLVE , Nottingham
November 2012

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Talk at Different Strokes     November 2012

## Our research – General patterns

**Friends are very important !**
- In hospital
- Going home
- In the long term

**Patterns of friendship**
- Lose friends
- Keep the same friends
- Make new friends

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The Friendship tree

Trees and roots

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## What people said – Overview

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## Friendship is really , really hard work

- Getting out and about
- Busy friends
- Talking ! e.g. making arrangements
- Poor understanding of stroke & aphasia
- Confidence, anxiety etc
- Reactions of friends
- Driving & transport
- Money
- Other difficulties e.g. epilepsy

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Dawn: Friends don't put in the (...) effort to try sometimes.
CP: So they need to maybe, they could maybe (..) work a little bit harder at it?
Jack: Yes. Yeah.

"I find that aphasia and I think you know, erm, my physical disabilities and everything, you know, and it means that everything, you know and because I can't drive and everything [..] it's, it's just such a struggle' Melanie

Why do some friends drop away?
Dawn: I think because people feel a bit awkward, don't they?
Jack: Yes. Erm, erm, erm. [mimes puzzled face]
CP: They're not quite sure what to say?
Jack: Yes, yes. Yeah, yeah. Okay

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## More than me - Friendship is 2 way

Defining friendship & aphasia

ONE WAY

'more than me': friendship is 2 way

reciprocity

making a contribution

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'well a person is only a friend if they can open up everything to you. When I first had the stroke nobody was allowed to tell me anything'

'Some people ...me , me , me...very early the stroke ... ..., the meeting. It's obviously the friendship. At home it's the me, me, me.'

Families are great ...but sometimes they 'smother' you – 'my family have been so protective, they've kind of tended to push my friends to the side'



## Humour and Hanging Out

Defining friendship & aphasia

humour & hanging out

just being

role of humour

Acts

'more than met...'



Telling jokes to friends differently ... on Facebook , or with photos on the phone

I use humour to get out of my aphasia muddles ...I feel more confident if I make a joke of it

I come out with words that are laughable...amusing ...all my friends without aphasia we scream with laughter at words that sound the same...that for me is an important aspect of relationship ...humour



## Advice & Suggestions about friendship for ...

Friends

Family

People with aphasia/ stroke

Medical staff/ Healthcare workers



## Thanks for taking part

Huge thanks to people with aphasia who helped the project in :
- Northampton
- London

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More about the project
www.friendshipandaphasia.weebly.com

# Appendix V

## Publications and presentations

**Publications**

Pound,C. (2011) 'Reciprocity, resources and relationships: New discourses in healthcare, personal and social relationships'. *International Journal of Speech Language Pathology* ,13(3), pp.197-206.

Pound, C. and Laywood, C. (2012) 'Involving people with communication disability in participatory research: the Friendship and Aphasia project', *INVOLVE*, NHS National Institute for Health Research, November.

Hewitt, A. and Pound, C. (in press) 'Communication barriers: creating access and inclusive relationships.' In Swain, J., French,S., Barnes, C. & Thomas,C (eds.) *Disabling Barriers: Enabling environments* 3ʳᵈ edn. London: Sage Publications.

**Conference Presentations**

Pound, C. (2010) 'Revisiting the social model of disability: Promoting access to participation, relationships and inclusion.' Keynote presentation Speech Pathology Australia. Melbourne, May.

Pound,C., Gryzbowska, B. and Reynolds, F. (2011) 'My friends are my anchors'; Friendship and aphasia. International Human Sciences Conference. Oxford, July.

Pound,C. and Mehta,B. (2011) 'Friendship and aphasia.' British Aphasiology Society Conference. Reading, September.

Pound,C. (2011) 'Revisiting relationships in therapy and beyond.' Keynote presentation, Irish Association of Speech and Language Therapists Biennial Conference, Dublin, November.

Laywood, C. and Pound,C. (2012) 'Friendship is like a painting that is never finished': Co-constructing knowledge about friendship and aphasia. INVOLVE Conference, Nottingham, November.

Khosa, J. and Pound, C. (2012) Hanging onto and hanging out with friends: Experiences of friendship after stroke and aphasia. Invited presentation, UK Stroke Forum, Harrogate, December.

**Other Presentations and Talks**

Pound, C. (2010) 'Absent Friends – including people with aphasia in friendship research'. London: Social Perspectives Colloquium, University College London (poster).

Pound, C. (2010) 'Absent Friends: Including people with aphasia in friendship Research'. Brunel University PhD Student Conference, Uxbridge, July (poster).

Pound, C. (2010) 'Relationships and aphasia'. Aphasia Alliance meeting. London, October.

Pound, C. (2010) 'Involving people with aphasia in research'. University of Queensland/ University of Christchurch/ Auckland University – Communication Disability Research Centre Round Table, May.

Barrow, R. and Pound, C. (2010) Revealing reciprocity – How do people with aphasia talk about give and take? International Society for the Analysis of Clinical Discourse, Round Table meeting, Dublin, April.

Pound, C. (2012) The Forest of Friendship: Exploring experiences of exile and friendship after aphasia. Brunel University PhD Student Conference, Uxbridge, July.

Grzybowska, B. and Pound, C. (2013) Friendship and Aphasia. Different Strokes group meeting, Northampton, May.

Grzybowska, B. and Pound, C. (2013) Friendship and Aphasia. The Stroke Association, Kettering Stroke Group, May.

Khosa, J. and Pound, C. (2013) Friends, friendship and aphasia. Northampton Different Stroke Symposium, Northampton, May.

Pound, C. et al (2013) Connect for a day – Friends and Friendship, Connect, London, August.
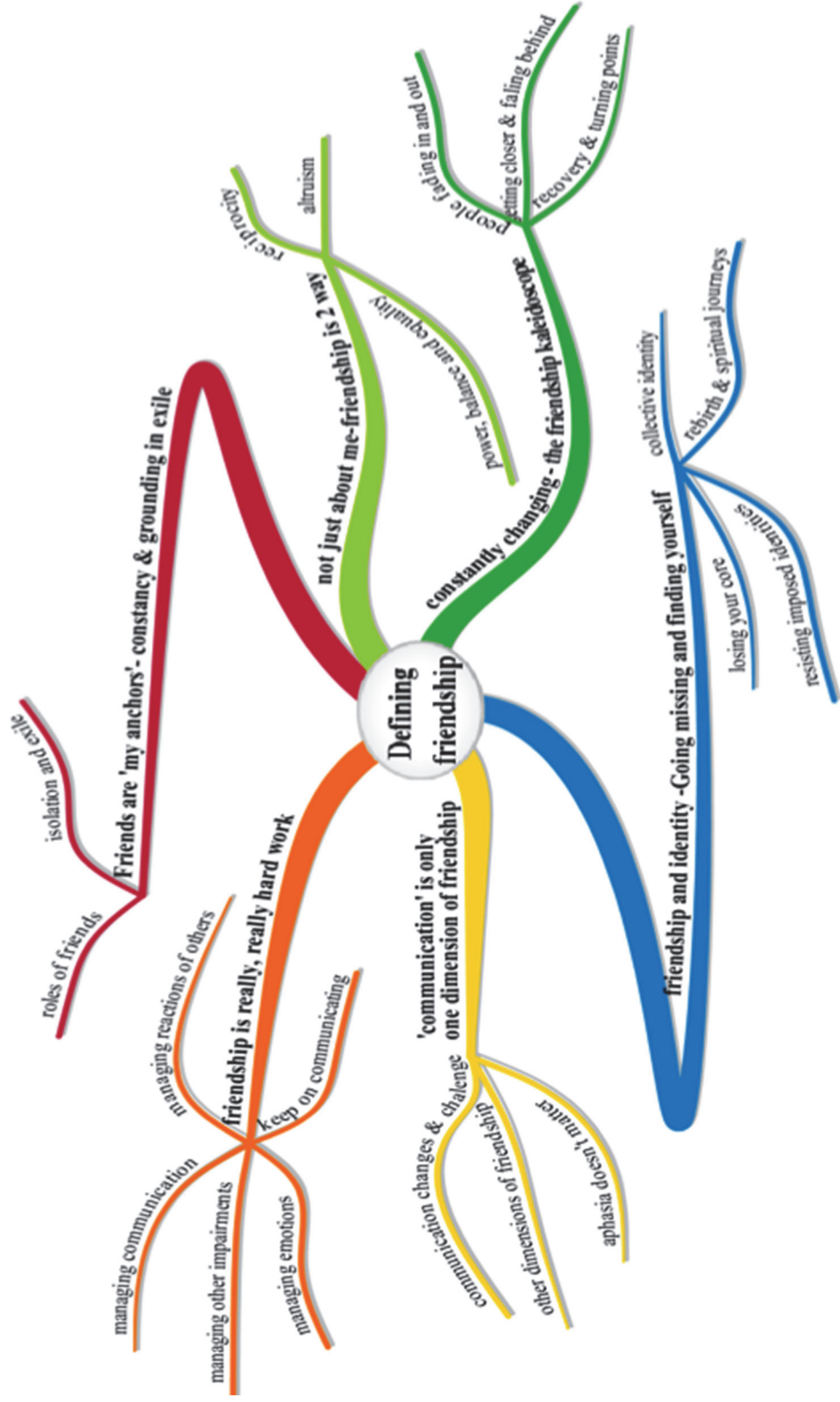
# Appendix W

## Forest of Friendship diagrams

Figure 7.2
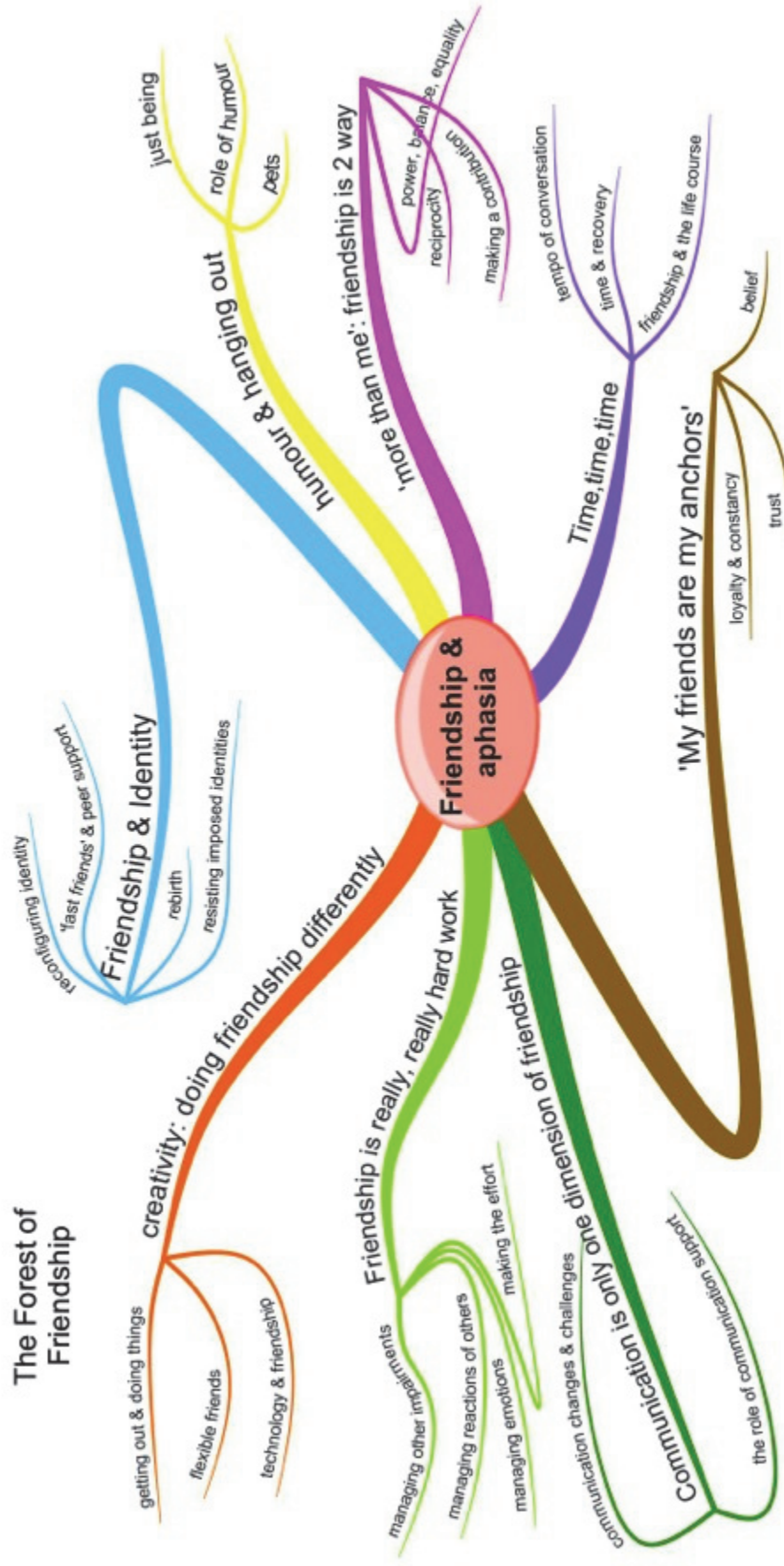Forest of Friendship diagram (Phase 1)

The Forest of Friendship



Figure 9.1
Forest of Friendship diagram – Final version

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