

## **Time to act: The challenges of working during and after cancer, initiatives in research and practice**

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A diagnosis of cancer has a significant impact on work and employment. With improvements in cancer treatments more people are surviving longer, and it is estimated that there are approximately 700,000 people of working age with cancer in the UK (Maddams et al., 2009). This figure is increasing year on year (Maher and McConnell, 2009), not least because people are working later in life. While many people are able to remain in or return to work, a sizeable number experience problems: research shows that people with cancer are 1.37 times more likely to be unemployed than those without (de Boer et al., 2009). Patients experience a lack of well-timed and appropriate support, both in the acute phase and in the months and years following treatment. Health care professionals, in turn, report that they feel ill-equipped to respond adequately to patients' work-related difficulties (Amir et al., 2009).

For cancer survivors, the ability to work is important to maintaining social relationships, self-esteem and psychological well-being. A recent systematic review and meta-synthesis of the qualitative literature on employment and cancer (Wells et al., 2013) found consistent evidence that individuals' experiences of 'return to work' were strongly influenced by the degree to which cancer affected four key factors: self-identity, meaning and significance of work, family and financial context, and work environment. Work often helped people to re-establish normality and a sense of their former selves, but at the same time, self-identity was challenged by the physical and emotional consequences of cancer treatment, as well as others' reactions to changes in appearance, physical or cognitive ability. The meaning and significance that individuals had attached to work before cancer frequently shifted, as they re-evaluated their capabilities and priorities. The influence of financial pressures and family or friends towards maintaining or changing work consistently played a part, and the difficulties of negotiating sick pay, benefits and insurance were frequently mentioned. Finally, the organisational and interpersonal support received within the work environment played a particularly important role in enabling people to talk about and manage the

challenges they faced, negotiate different work patterns and responsibilities, and regain confidence at work.

The economic consequences of cancer-related lost productivity are significant. For survivors, being at work maintains financial stability, the loss of which can lead to financial distress and adverse psychological consequences (Sharp and Timmons, 2013). From a societal perspective, a recent cost-analysis across the European Union estimated that 60% of the economic burden of cancer was incurred in non-health-care areas, with almost V43 billion in lost productivity attributable to early death, and 83 million lost working days due to cancer related morbidity (Luengo-Fernandez et al., 2013). Welfare legislation in many western countries makes it the legal responsibility of the employer to make 'reasonable adjustments' to allow continuing participation in employment for people with disability including cancer. Yet a large proportion of those completing cancer treatment return to work only to leave within the year, reporting reintegration as too difficult.

Cancer survivors identify the role played by employers and co-workers as important in supporting and sustaining a successful return to work and in supporting career development (Wells et al., 2013). There is an increasing trend towards the devolution of human resource (HR) work to line managers. This devolvement means that line managers' role in the return to work process following illness is likely to be central. However, a UK study (Amir et al., 2010) of line managers' experiences suggests that employers/line-managers require training, support, and resources to help them facilitate employment and job retention of employees diagnosed with cancer. Furthermore, most respondents in a UK national survey of Occupational Health (OH) physicians (Amir et al., 2009) felt managers treated referral to OH differently for employees with cancer compared to management referral for employees with other diagnoses. Whether this also holds in other European countries is unknown.

Unfortunately, many small and medium sized enterprises (and some large enterprises) lack the necessary resources to adequately support the health and well-being of their employees. In response to this, practical tools have been developed in the UK to help support an employee diagnosed with cancer throughout their cancer journey in relation to work (Munir et al., 2011, Munir et al., 2012, 2013; Yarker et al., 2010). This includes support for an employee taking sick leave and returning to work, or an employee who chooses to continue to work during treatment. The Line Manager Behaviour Checklist (Yarker et al., 2010; Munir et al., 2012) was developed for use with a range of chronic conditions, including cancer, and can be accessed by line managers through the Chartered Institute of Personnel Development (CIPD). A specific resource for those diagnosed with cancer is the 'Work it Out' tool (Munir et al., 2011), part of a Toolkit for employees, employers and health

professionals, available from the UK Charity Macmillan Cancer Support. This tool allows the employee to feel in control of decision-making by requesting appropriate information and support not just from their line manager, but also from other relevant stakeholders such as human resources and their oncology nurse or consultant (Munir et al., 2011; 2013). However, although such tools are valuable in minimising some of the undesirable outcomes of work issues for those diagnosed with cancer, the current literature suggests that much more needs to be done to enable those affected by cancer to sustain employment.

Recognising the growing interest and activity in research focussed on cancer and work in the UK and Ireland, a multidisciplinary group of researchers met at the University of Dundee in May 2011 to share ideas and develop collaborations. The CanWork research network was subsequently established, aiming to drive forward a programme of research on cancer, employment and finance (CanWork, 2011). More recently, the European Cooperation in Science and Technology (COST) has funded CANWON - a network of expert scientists, clinicians, economists and patient support groups and other stakeholders on cancer and work (de Boer, 2013). COST is an intergovernmental framework allowing the coordination of nationally-funded research on European level; it does not fund research itself, but it provides support for networking activities and facilitates disseminating research knowledge and best practice worldwide. The CANWON network currently connects 28 researchers from 18 EU countries. The network operates through four work groups: (1) prognostic factors for workforce participation in cancer survivors including gender- and country-specific differences; (2) work-related costs of survivorship for both patients and society; (3) the role of employers; and (4) development and evaluation of innovative, interdisciplinary interventions which effectively support employment. The network will make earlier and quicker exchange of new information possible. It also aims to increase the impact of research on cancer and work among policymakers, regulatory bodies and national decision makers as well as the private sector.

These initiatives aim to raise awareness of how cancer affects working life, and to draw attention to the need for more research into neglected areas such as: the needs and experiences of particular groups e.g. the self-employed; the views and experiences of line-managers working in small and medium enterprises (SME); the nature of the advice and guidance required by line-managers and employers; potential ways to improve the communication between line-managers, their senior management and relevant occupational health advisers and the survivors' clinical team; and the development and evaluation of effective interventions to support the achievement of work-related goals in cancer survivors.

Nurses and other practitioners working in cancer care also need to recognise the importance of work and take opportunities to assess and consider how cancer and its treatment may interfere with a person's ability to maintain their working life, and as a result, their identity and financial security. Evidence (albeit limited) suggests that the clinician team managing the patient can have a key influence on the likelihood of subsequent return to work (Pryce et al., 2007). Implementing the provision of work-related information, advice and support into clinical practice is an important next step. Front line oncology staff need not be experts in this field but need to be prepared to open this dialogue from the outset, asking appropriate questions, advising on the most likely course of events and how these may impact on work. In order to manage expectations and help individuals plan for their future working life, written and verbal information and support should be provided throughout the cancer pathway, particularly around the time of diagnosis and at the end of treatment. Oncology nurses have a key role to play in signposting to further advice and support, for example to hospital based social workers (where they exist), vocational rehabilitation services, local cancer support and information centres. Perhaps most importantly, nurses are in a position to ensure that an understanding of the complexities of work-related decisions and experiences becomes integral to the care of people with cancer.

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