

March 2013



Returning to Work

Cancer survivors and the Health and Work
Assessment and Advisory Service

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‘First I prepared myself for dying....’

Compared with even a decade ago, returning to work is a realistic option for an increasing number of people with a diagnosis of cancer. Employment, however, is too often rarely sustained for long, and too many people with cancer withdraw from the labour market prematurely due to problems they face when returning to work:

“I would gladly have given my job to someone younger. It scares me to return to work, because I've been absent for over a year. What frightens me most is how my colleagues are going to take my return. I guess they never expected me to return to work. Too much has happened over the past year. Mentally I haven't been able to keep track of things. First I prepared myself for dying – now I have to re-orientate myself into work life.”

— 53-year old breast cancer survivor

Despite this there is growing evidence that with the right interventions it is possible for more people with a diagnosis of cancer to remain in the workplace for longer, if they want to. Despite a slow start, we are beginning to see signs that this is increasingly recognised by the health service, by employers and by the government. In this paper we focus on the recent development of return to work support services in the UK, and look at what issues need to be addressed to help people remain in work in for one disabling condition – cancer. However, many of the suggestions can be applied to other chronic conditions due to the similarities in problems that people with long-term conditions face in achieving sustainable and fulfilling employment.

Health of the workforce

Successful work retention for people with a diagnosis of cancer depends not only on the severity of one's condition but also on the individual's capacity to cope with crises or with fluctuations in health or functional capacity. The coping process nevertheless depends on several social aspects of work, such as the work environment and the amount of support one gets in the workplace. This process is also affected by the extent to which healthcare services prioritise work as a clinical outcome and a welfare system that supports job retention.

Early or premature departure from an active working life may be voluntary, involuntary, or involve self-imposed limitations. It may reflect a discriminatory event or the onset of a disability or a chronic illness. Large numbers of workers leave the EU labour market earlier than is desirable due to a disability resulting from chronic conditions. Work disability has therefore been recognised as a major economic and public health problem (Henderson, Glozier, & Elliott, 2005). In 2002, nearly 45 million people, aged between 16 and 64 years, were living with a long-standing health problem or a disability (Eurostat, 2002) and therefore struggle to remain in the labour market.

From an individual's perspective, work is often considered invaluable as it provides financial autonomy, self-respect, dignity, quality of life, and self-worth (Freedman & Fesko, 1996). From a societal perspective, work retention of people with chronic conditions is likely to become increasingly important over the next few decades as the cohort of baby boomers in Europe moves into the ranks of older adults and the retirement age continues to increase. Consequently, it was recently stated in a resolution on the EU employment guidelines that the target employment rate in the EU is to be increased to 75 per cent by 2020 (European Union, 2010).

In the last decade, increasing emphasis has been placed on the social and labour market inclusion of people with disabilities. This has been encouraged by a European-wide movement away from passive measures to more active ones, and has been achieved through the implementation of legislative instruments such as obligatory employment quota schemes, anti-discrimination legislation, job protection rights and targeted active labour market policies. These aim to support the participation of people with disabilities and make reasonable adjustments to enhance work participation (Shima, Zolyomi, & Zaidi, 2008). Despite these developments in legislation, including a call for a 10 per cent increase in employment of vulnerable groups (European Union, 2010), a group which includes people with disabilities, rates of employment of people with disabilities have fallen in several European countries (OECD, 2010). In the UK only around 53 per cent of people of working age with a long-term health problem or disability are in employment compared with 85 per cent of those without a disability.¹

As with people with other chronic conditions, cancer survivors are at a higher risk of unemployment or leaving the workforce early. Studies have indicated that only about 64 per cent of those who were employed at the time of diagnosis achieved a successful and sustained return to work 2-3 years after diagnosis, compared to a control group in which 76 per cent were employed (Taskila & Lindbohm, 2007). In addition, research combining the results of 36 studies showed that people have a 37 per cent higher risk of unemployment after cancer, and a threefold risk of disability compared to people without cancer (de Boer, Taskila, Ojajärvi, van Dijk, & Verbeek, 2009).

Despite the commitment of EU member states to increase work participation, the health services for people with disabilities do not currently reflect this. Services to support people with chronic conditions to return to work are limited, and rarely respond to the actual needs of people with these conditions. If the EU's Europe 2020 strategy is ever going to reach its goal of increasing employment more active policies enhancing work participation are urgently needed.

¹ Labour Market Statistic, Table A08: Labour Market Status of Disabled People, Office for National Statistics February 2013, <http://www.ons.gov.uk/ons/rel/lms/labour-market-statistics/february-2013/table-a08.xls>

Supporting people with cancer to stay in the labour market

Improving job retention rates for people with cancer will require a concerted effort from a number of different stakeholders, and will involve a varied mix of support services. However, the government is making one potentially very important step in integrating back to work support into the recovery process by introducing the Health and Work Assessment and Advisory Service (HWAAS).

Announced in January 2013, the Health and Work Assessment and Advisory Service will be introduced in 2014. The service is based on the recommendations outlined in the *'Health at work - an independent review of sickness absence'* (Black & Frost, 2011) and the experience of the government's Fit for Work Service pilots. It will provide occupational health advice to employers and employees, an important service for those who may otherwise not have been able to access this expert information. It will also instigate case management for complex cases which could have an important and positive influence for people with long-term conditions such as cancer.

An increasing body of research evidence suggests that it is beneficial for most people with cancer to start thinking about their return to work in the first few weeks of sick-leave. The majority of people with cancer will return to work, but without the right support they may experience difficulty in remaining in work (Taskila, 2007). Research has shown that 18 months after a diagnosis of cancer, a lack of workplace interventions was associated with high levels of fatigue, which in turn was correlated with higher levels of depression (Taskila, de Boer, van Dijk, & Verbeek, 2011). Helping employers make these interventions is vital to help this group remain in work. Whilst of course bringing important and positive effects for the individual, such a move would also create a positive economic impact. It has been estimated, for example, that employed cancer survivors are contributing over £16 billion to the UK economy every year, more than the UK house building industry (Oxford Economics, 2012).

The role of the healthcare professional is influential in the decision-making process for cancer survivors considering a move back to employment; their advice regarding the return to work is associated with a shorter duration of sick leave (Drolet et al., 2005; Pryce, Munir, & Haslam, 2007). We believe that HWAAS is potentially well placed to provide this kind of advice and support, and to be a major positive influence in helping individuals with cancer return to work.

HWAAS will fill a large and important gap in current support. A shockingly high 73 per cent of employers in the UK have no formal policy for managing employees diagnosed with cancer, while just one third of organisations ensured relevant staff had a good understanding of cancer and the impact of treatment on an individual's working role (Chartered Institute of Personnel and Development, Cancer backup, & Working with Cancer, 2006). There is currently little occupational health provision for people working in small and medium-sized enterprises (SMEs) who want to remain with their current employer (Staley, 2008). HWAAS, if implemented effectively, will help employers overcome these problems, providing the high

quality independent advice and support, and the access to occupational health and other professionals, that they are unable to provide themselves.

However, HWAAS has only been described in the broadest of terms in *'Fitness for work: the Government response to Health at work – an independent review of sickness absence'*, with many details yet to be confirmed. Until we have a clearer and more concrete understanding of how exactly the service will operate, it is difficult to say what kind of impact it will have for cancer survivors. This paper outlines our recommendations on how to improve the implementation and effectiveness of the service. The HWAAS could make a real difference to the lives of people with cancer, and this opportunity should not be missed.

HWAAS and cancer

Our most important, and most fundamental, recommendation is that we believe HWAAS should be accessible for people with a long-term, chronic or fluctuating illness, a category which includes people who have been diagnosed with cancer. The government response to Sickness Absence Review states that the 'vast majority' of people will be referred to HWAAS after four weeks of sickness absence. The only people who are exempt from referral will be those who are already close to returning to work or those with 'acute medical conditions who are undergoing treatment'. The paper does not mention how or if referrals for people with long-term or fluctuating conditions will work, a serious priority given that by 2030, approximately 21 million people of working-age will have at least one long-term health condition, meaning that half of the UK workforce might be affected (Vaughan-Jones & Barham, 2010). It is therefore vital that this important ambiguity be addressed, and that the service is both open to, and designed for, people with long-term conditions including cancer.

The government's response hints that the HWAAS would work with people who are not yet ready to return to work, helping them to create 'the likely timetable where more time is needed'. This is a welcome decision, as the government must ensure that this service is accessible to people who have been on sick leave for an extended period of time, or have a long-term condition. Referral routes to the service for people with cancer wishing to return to work should be clearly signposted and be considered a routine aspect of cancer follow-up care. Although the government response does mention the possibility of employers referring employees to the service, GPs will act as gatekeepers to HWAAS. It is vital then that the government learn from the evaluation of their Fit for Work Service pilot, which makes a number of suggestions as to how to engage GPs effectively (Hillage, 2012).

Despite the growing evidence that returning to work is a viable and healthy option for many people with cancer, employment is not an outcome in the Clinical Commissioning Group Outcomes Indicator Set (previously know as the Commissioning Outcomes Framework or COF) and GPs are given no incentive to ask whether a person is in employment, despite the employment of people with long-term conditions being an outcome in the NHS Outcomes Framework. Although employment is briefly mentioned in some NICE guidelines specific to

certain types of cancer, and alluded to in the NICE Guidelines for supportive and palliative care (NICE, 2004), this is not sufficient.

In order to facilitate and encourage referrals of people with long-term conditions to HWAAS we would recommend that GPs are incentivised as part of CCGOIS to ask patients whether they are employed. This will encourage GPs to consider employment as something within their sphere of influence, making it more likely that individuals will be referred to HWAAS. Given the difficulties that the Fit for Work service pilots (Hillage, 2012) had in contacting and getting referrals from GPs, without action cancer patients may not be consistently referred to HWAAS. Unless work is recognised and measured as a health-related outcome, it will remain too easy for employment to be an afterthought in cancer after-care.

Although GPs should remain the primary route by which the majority of people are referred to HWAAS, we believe that it should be possible for secondary health care services to refer as well, where appropriate. Although it is likely that this is only a small number of people, it would be another step in ensuring that HWAAS is open to all who could benefit from its services.

The assessment process

Although the Health and Work Assessment and Advisory Service will perform a number of functions, including on-going support and referral to other services such as vocational rehabilitation, its primary focus will be the assessment and the subsequent report its primary output. The information and advice in the HWAAS' report will guide the individual, the employer and relevant healthcare professional as to what kind of interventions are needed. It is therefore crucial to get the assessment right if the interventions that follow from it are to be effective.

Despite being a very different kind of assessment service, with a very different remit, there are lessons to be learned from the Work Capability Assessment (WCA). The heavy criticism that the WCA has received highlights some of the potential traps that any health-related assessment service can fall into. Perhaps the most notable of these is the importance of recognising the effects of co-morbidities, and the association between long-term and chronic illnesses, such as cancer, and common mental health conditions, such as depression.

Although cancer is a physical condition, it is often associated with common mental health problems, most notably with depression. Research indicates that between 4 per cent and 49 per cent of all cancer patients experience depression – a figure that changes depending on the stage of treatment and different ways of measuring the condition (Walker et al., 2012). Given the potential impact of depression and other mental health conditions, it is important that this is considered when designing the assessment process. HWAAS must also recognise the impact of fluctuating conditions and chronic pain, a category which includes cancer.

The importance of a holistic and individualised assessment should not be underestimated. In addition to developing appropriate measures on general work ability, there should be an assessment of the potential problems that might occur depending on the type of work, the kind of contract the patient has with their employer, and the patient's financial circumstances. The evaluation of the Fit For Work pilot scheme supports this, with interviewed case managers emphasising the importance of taking into account all aspects of health, work and domestic circumstances (Hillage, 2012). Many people with long-term conditions are the primary earners in the households. In our recent research into musculoskeletal disorders (MSDs) we found that two thirds of people living with MSDs are primary earners in their families (Zheloutkova, 2013).

Cancer and its impact on the individual will inevitably vary, requiring an individualised response from HWAAS. For example, a teacher with a permanent position and good health prior to their diagnosis of cancer is at less risk of running into financial problems than a brick layer with poor pre-diagnosis health, who is on a temporary contract. During the assessment, the following questions should be addressed:

1. How likely is it that there will be financial problems for an individual and their family if a patient is not at work? Should financial support be signposted?
2. Is the current job suitable for the patient or would it be necessary to consider another type of work?
3. How mentally and physically demanding is the job and is there a need for temporary or permanent workplace accommodations?
4. What is the relationship with the supervisor and is the patient able to talk confidently about his/her condition at the workplace, and with a reasonable expectation that such accommodations will be made?

It is also important to recognise that the answers to these questions may change during the course of the disease and treatment.

Finally, another lesson we can learn from our experience with the WCA, is the usefulness of regular evaluations of the assessment process. The Harrington reviews (2010 to 2012) have been important in shaping and reforming the Work Capability Assessment, and we believe a similar evaluation process may be useful when applied to HWAAS as well.

Implementing the advice

The success or failure of the HWAAS will rest on the quality and the practicality of the advice it gives, and the extent to which it can be applied within individual workplaces. As has already been discussed, making the service individualised will be essential in ensuring that it is

effective. Giving overly generalised, non-specific advice is a trap that could easily be fallen into. Involving different stakeholders in the return to work process will therefore be an important part of delivering the service, making sure that the advice, guidance and support is accurate, relevant, and able to be implemented.

'Fitness for work: the Government response to 'Health at work – an independent review of sickness absence' indicates that whilst support and advice will be available through HWAAS, an important part of the scheme will be signposting individuals to other services. However, for this signposting system to work, the support that they guide to must be available, accessible and effective. This is why we strongly suggest that the government consider the recommendations of the forthcoming Macmillan report *'Making the shift: Providing specialist work support to people with cancer'* regarding vocational rehabilitation (Macmillan, 2013). Ideally all services to which HWAAS signposts should dovetail with the assessment and advisory service, working in a mutually beneficial fashion.

The follow up and support that HWAAS will provide for patients with complex needs will be an important part of the service provided, and we welcome the decision to include these aspects. It is particularly important as evidence suggests that whilst the majority of cancer survivors are able to return to work, they are at higher risk of leaving the workforce early. The risk of disability is nearly three-fold in cancer survivors compared to people without cancer (De Boer et al 2009). The use of case management and follow up services for complex cases is therefore a welcome step, and one that will be particularly important for people with cancer. The government must make sure these services are easily accessible, with all stakeholders, including the individual, the employer, and relevant healthcare professionals, being able to return to the service for advice and support in implementing their initial advice.

Working today, working tomorrow – in spite of cancer

Returning to work and remaining in work can be difficult for many cancer survivors, who might have been away from the labour market for some time and may suffer from both the physical and mental impact of the illness. Current policy in the UK and other countries recognises the value of work for people's health, and increasing emphasis has been put on developing services that aim to help people with long-term conditions to remain in work.

The introduction of HWAAS has real potential to significantly improve employment outcomes for people with cancer, but the service should be carefully designed to ensure that it truly takes account of the needs of people with long-term or fluctuating conditions such as cancer. Specifically, we recommend that:

- Referral routes to the service of those who wish to return to work should be clearly signposted and be considered a routine aspect of cancer care.

- In order to facilitate this, employment should be made a clinical outcome in the Clinical Commissioning Group Outcomes Indicator Set, encouraging GPs to see employment as within their sphere of influence.
- The assessment process should be holistic, taking into account individual circumstances and avoid providing only over-generalised advice. We recommend that, as well as considering physical capacity, the assessment consider:
 1. Financial situation
 2. Suitability of current job
 3. Mental, physical and emotional demands of the job
 4. Relationship with the supervisor and colleagues to assess whether needed support is available at the workplace
- The government should work to include all key stakeholders in the service, including, GPs, employers, relevant healthcare professionals and occupational health services.

A carefully designed service that takes account of individual needs will surely have a positive economic impact through increasing the number of people able to work until the statutory retirement age, who would have otherwise left the workforce prematurely. The government has an important opportunity here, and we believe that this service has the potential to change the lives of the many cancer survivors who wish to work.

We look forward to learning more about the government's vision for this new service, and we hope to take an active part in its development.

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