

MAKING THE SHIFT

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CANCER SUPPORT**

Providing specialist work
support to people with cancer

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Foreword

Over a third of the two million people living with cancer in the UK are of working age (18–64 years). Cancer is a life-changing illness and can affect people for a long time after treatment has ended.

Work is an integral part of helping people get back to normality after a cancer diagnosis and treatment. For many, it can also be a financial necessity.

Not everyone diagnosed with cancer will be able to work, although most people with cancer want to return to work when they feel well enough and ready. However, the reality is that those who want to return to work don't always receive the support they need to do so. In particular, the availability of and access to specialist return-to-work services is severely lacking.

With survival rates improving and people retiring later, there is a large and growing number of people living with cancer who, with the right support, can be of great benefit to employers and make a significant contribution to the UK economy. Given the current economic climate, it makes sense to help more people stay in their job and get back into employment.

I am encouraged that one of the priorities of the new NHS Commissioning Board in England is to support people with health conditions so they can remain in or find

work. I also welcome the focus on work and health in the government's response to the sickness absence review, which I hope will bring improvements across Great Britain.

Yet these positive moves are still not enough to address this issue. Governments across the UK must do much more to help support the employment of people with long-term conditions, including cancer.

This report focuses on the lack of specialist vocational rehabilitation services for people who develop complex problems as a result of their cancer or treatment. Macmillan intends to use this evidence to start a debate with government about the importance of work to people with cancer and the lack of vocational rehabilitation services available to them.

In this report, we call for the health and work departments in the UK's four nations to 'make a shift' in their thinking and take responsibility for improving access to vocational rehabilitation in the UK.

I look forward to working with government and partners on this.

Ciarán Devane
Chief Executive
Macmillan Cancer Support



Governments across the UK must do much more to help support the employment of people with long-term conditions, including cancer.

Executive summary

Macmillan wants everyone diagnosed with cancer to have appropriate support to remain in or return to work, and for specialist vocational rehabilitation to be provided to those who need it.

Work has many benefits for people with cancer, such as improving confidence and helping them regain a sense of normality. Importantly, supporting people back into work is also good for the economy.

Cancer is a debilitating disease, and the effects of cancer are felt long after treatment is over. Consequences of cancer and treatment such as fatigue, pain, reduced mobility and depression can make it difficult for people to return to work. However, with the right support, many of these issues can be successfully managed.

One key reason why people struggle to remain in or return to work is the lack of vocational rehabilitation services. Macmillan research has shown that less than 2% of people with cancer access specialist return-to-work services, and over three-quarters do not access any support service linked to work or employment, such as an occupational health professional or Jobcentre Plus.

As part of the National Cancer Survivorship Initiative (NCSI), Macmillan has developed a three-level model of work-related support and vocational rehabilitation. As we show in this report, the piloting of the model has revealed best practice for delivering specialist vocational rehabilitation interventions (including health and workplace interventions) for people with cancer who have complex problems.

There is now good evidence that interventions delivered by vocational rehabilitation services improve work and health outcomes, including those for people with cancer. They have also been shown to be cost effective.

However, there has been little progress at a national level in this area since the 2008 review of vocational rehabilitation, which was commissioned by a group of stakeholders including the UK government. In particular, there is still a lack of capacity to deliver effective vocational rehabilitation for people with long-term conditions in the UK.

The recent government response to the sickness absence review is promising but it does not consider the role of secondary healthcare, including NHS rehabilitation services. Crucially, it does not look at how the NHS could be incentivised to view the return to work of people with long-term conditions as a positive health outcome.

Our report highlights the untapped workforce potential of people affected by cancer and the impact a lack of action in this area is having on the economy. In turn, the report makes the following recommendations to government.

- **There needs to be strong leadership in government and a renewed cross-government approach towards vocational rehabilitation.** Effective vocational rehabilitation for people with long-term conditions, including cancer, requires a combination of healthcare and workplace interventions. Because of this, the health departments in the UK's four nations and the Department of Work and Pensions (the Department for Employment and Learning and Social Security Agency in Northern Ireland) need to take joint ownership of this issue.
- **Government must take responsibility for improving the availability of and access to specialist vocational rehabilitation services for people with complex health problems, including cancer.** Appropriate vocational rehabilitation support should be an essential component of return-to-work services, and the NHS should be better incentivised to promote work as a positive health outcome for people with long-term conditions.
- **The new state-funded health and work assessment and advisory service must work effectively with secondary healthcare,** including NHS rehabilitation services, as well as with GPs.

1 Benefits of work for people living with cancer and the economy

There are over 700,000 people of working age living with cancer across the UK¹ and over 100,000 people of working age are diagnosed with cancer every year.²

Helping people living with cancer remain in or return to work can significantly benefit these individuals. Importantly, it also has wider economic and social benefits for the UK.

Benefits for people living with cancer

Work is important. It can provide people with a sense of purpose in life and has a strong influence on identity, self-esteem and confidence.

Many people with cancer who were employed before their diagnosis emphasise the significance of work in regaining a sense of normality and control over their lives after, and sometimes during, treatment.³

Work also contributes to financial independence and material comfort. Many people living with cancer say that financial necessity is a major factor in remaining in or returning to work after a cancer diagnosis.

There is strong evidence to suggest that for people who experience ill health or disability, remaining in or returning to work can actually help promote recovery and rehabilitation, and lead to better health outcomes.⁴

Work also promotes independence and full participation in society, and improves quality of life and wellbeing. Recent evidence of this comes from a survey led by the Department of Health in England. Participants in full-time employment after a cancer diagnosis were revealed to be more positive on a range of issues compared to those who were unemployed.⁵

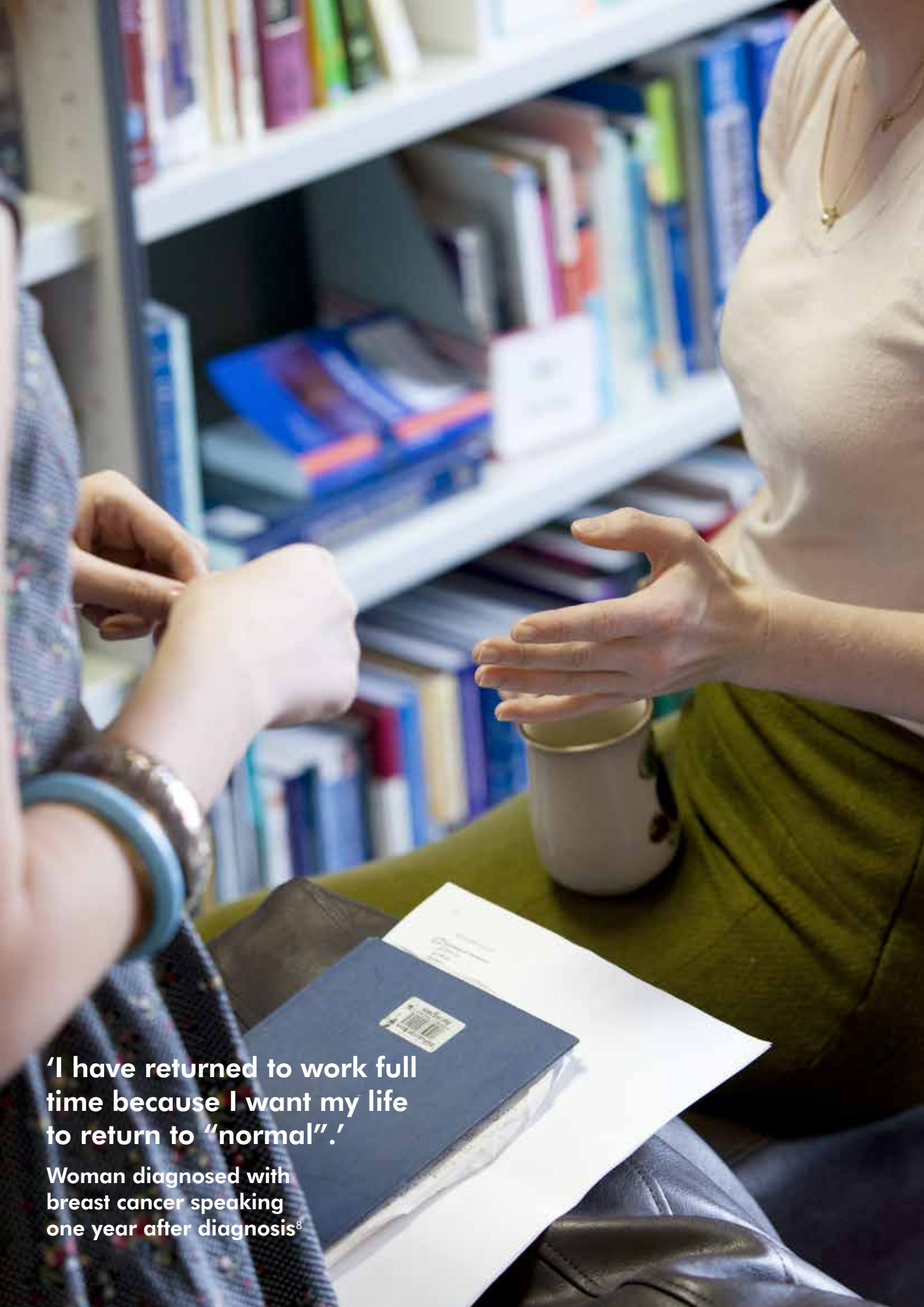
Benefits for the economy

Supporting more people with cancer back into work is also good for the UK economy. It would improve productivity in the UK, move people off sickness absence and reduce unemployment.

Currently, these potential economic benefits aren't being maximised. In 2008, a leading think tank estimated that £5.3 billion in productivity was lost in that year as a result of cancer survivors not returning to work.⁶

Over the next 20 years, this loss to the economy is likely to increase, with the number of people living with cancer in the UK set to double from two million to four million by 2030.⁷

Improving health and work outcomes for people with cancer could make a significant contribution towards economic recovery and future economic growth.



'I have returned to work full time because I want my life to return to "normal".'

Woman diagnosed with breast cancer speaking one year after diagnosis⁸

2 Why cancer survivors struggle to remain in or return to work

People respond to cancer and its treatment in many different ways. We recognise that not everyone will be able to or want to work after a cancer diagnosis.

But research does show the majority of people who are working when they are diagnosed with cancer want to return to work when they are ready and able, or they need to for financial reasons.⁹

However, many struggle on their own to get back to work, but later leave or change jobs due to problems that arise in the workplace, and others don't manage to go back at all.

Research also reveals that people who have had a cancer diagnosis are 1.4 times more likely to be unemployed than those who have not.¹⁰

We believe this is not surprising given how little support there is to help people with cancer return to work.

Many people give up work or change jobs because they struggle to manage the consequences of cancer and treatment. This includes physical symptoms such as fatigue and emotional consequences such as depression.

Most people with cancer will need some support to return to work, including information to help them self-manage their condition. In addition, there will be individuals with cancer who need more specialist vocational rehabilitation expertise (see chapter 3 for our definition) to help them with more complex issues. For example, people with neurological cancers may experience seizures, cognitive impairment, fatigue, visual problems, headaches and balance problems.

The problem is that not enough people with cancer are receiving general work-related support or more specialist help. This is despite over a quarter of people with cancer saying they would have found it helpful to access return-to-work support services.

From our own research, we know over three quarters of people living with cancer do not access any support service linked to work or employment, such as an occupational health professional or Jobcentre Plus. And less than 2% of people with cancer access specialist return-to-work services.¹²

Almost half of those who are working when diagnosed with cancer have to make changes to their working lives after cancer, with around 4 in 10 of these people changing jobs or leaving work altogether.¹¹

The main barriers which prevent people living with cancer remaining in or returning to work are as follows:

- **A lack of information and advice from health professionals** about how cancer is likely to impact on their working life, how they can manage this impact, and where they can go for advice and support. Macmillan has developed tools to help professionals direct people with cancer to appropriate work-related support.¹³
- **A lack of support from employers** – although most employers are supportive, there are still some gaps in their knowledge of how best to support an employee diagnosed with cancer. Macmillan has undertaken considerable work to improve employers’ knowledge and the support they provide.¹⁴
- **A lack of specialist vocational rehabilitation services** for people with more complex problems.

‘I was tired and drained from the treatment. I didn’t feel like myself, everything was foggy, and I was really emotional. I just didn’t feel confident about returning to work.’

Recipient of Glasgow vocational rehabilitation service

3 What should vocational rehabilitation look like for people with cancer?

To address the lack of specialist vocational rehabilitation services in the UK, Macmillan, as part of the National Cancer Survivorship Initiative (NCSI), piloted a new model of vocational rehabilitation services for people with cancer. This model was implemented and tested in seven pilot sites across England, with the overall aim of replicating the model nationally.¹⁵ Macmillan has also established a pilot vocational rehabilitation service in Glasgow.

NCSI vocational rehabilitation pilots

The Christie Hospital and Shaw Trust worked together to pilot a vocational rehabilitation service in Greater Manchester. The service adopted a case management approach to vocational rehabilitation and offered advice and guidance to patients. This involved helping people overcome return-to-work problems and legal and benefits issues, as well as liaising with employers and directing people to other support services.

In total, 260 patients received an intervention from the pilot service, with the average cost per patient being just under £385. Of these patients, 11% went from 'not working to working' and 32% went from 'sick leave to full work or modified work'.

The evaluation of the pilots in England recommended that specialist vocational rehabilitation for people with cancer should be provided as an essential component of return-to-work services.¹⁶

As part of the evaluation, we identified three different levels of work support necessary for people with cancer.

Level 1 – Open access to information and support

All service providers and health professionals should ask people living with cancer who are in work or have the potential to work about their employment situation. Following this conversation, they should then provide them with appropriate information and direct them to further support services.

Level 2 – Active support for self-management

Health professionals and other support staff with some specialist knowledge of work-related cancer issues should provide resources to help people self-manage so they can return to work.¹⁷

Level 3 – Specialist vocational rehabilitation

People who have complex needs should be referred to a vocational rehabilitation service for specialist case management support.

Our recommendation for specialist case management (level 3 in our model) is that it should feature vocational rehabilitation support used for other health conditions and more cancer-specific support (see box below for more detail).¹⁸

Our recommendations for specialist vocational rehabilitation services (level 3 support)

We believe specialist vocational rehabilitation services for people with cancer should incorporate the following types of interventions, which are applicable to other health conditions as well:

- assessment of an individual's capacity to work and workplace requirements
- rehabilitation to build physical, social and work skills
- negotiating a phased return to work
- liaison with employers
- modifications to the work environment
- psychological support, for example coaching or counselling
- careers advice and guidance.

In addition, specialist vocational rehabilitation services should also include more specific support relating to cancer and its treatment, such as:

- helping people self-manage cancer-specific symptoms and impairments in the workplace; in particular, fatigue, functional difficulties, cognitive problems and pain
- building confidence after a traumatic diagnosis and potentially a long absence from work
- helping patients to manage their employer's and colleagues' behaviour towards their cancer and return to work
- helping patients and employers to understand the consequences of cancer and treatment.

4 Why vocational rehabilitation matters

There is broad consensus on the need to improve the availability of and access to vocational rehabilitation in the UK. There are also issues around the capacity of NHS and private providers to deliver this support.

A large government-funded review of vocational rehabilitation in the UK found that structured vocational rehabilitation interventions can be both beneficial to individuals and cost effective.¹⁹

To date, the strongest evidence has been for conditions other than cancer, such as musculoskeletal conditions. However, people with cancer have many similar needs to those with other long-term conditions. Macmillan's work in this area has demonstrated that personalised and timely vocational rehabilitation interventions do result in better work and health outcomes for people with cancer and can be cost effective.²⁰

'I simply didn't have the confidence, knowledge, experience or energy to deal with this [issue of getting back to work].'

Recipient of Manchester vocational rehabilitation service

Our vocational rehabilitation pilots demonstrated a significant improvement in employment status between referral and discharge for many of those that received an intervention. In fact, almost half of those who received support from one of our pilot services had a positive work outcome, which meant they either remained in work or went from 'not working to working' or from 'sick leave to full work or modified work'.²¹

The pilots also found that the health-related quality of life of those who received a vocational rehabilitation intervention improved across all areas measured by a survey conducted six months after the start of the intervention.

The pilots showed that the average cost of a vocational rehabilitation intervention per patient was £850, with a range of £380 to £1,500. If an individual is supported back into work, the resulting tax returns will, on average, outweigh the cost of the intervention within the first three months of employment.²² This means if a person with cancer returns to work for 12 weeks that they otherwise might not have worked, the intervention could be argued to have paid for itself.

Internationally, vocational rehabilitation services in other countries such as Canada and Australia have been shown to be cost effective.²³

Building on the findings of the NCSI pilots, a three-year research study funded by the National Institute for Health Research will examine the clinical and cost effectiveness of vocational rehabilitation interventions. This work is due to be completed in December 2014 and will strengthen the evidence base further.

However, Macmillan believes existing evidence across a number of long-term conditions makes a strong business case for greater access to vocational rehabilitation now. We recommend the government does not wait for more evidence to be gathered before addressing the lack of vocational rehabilitation available in the UK.

'The service helped me gain control of my life again ... I felt confident enough to return to work.'

Recipient of Doncaster pilot vocational rehabilitation service

5 Why is there a lack of vocational rehabilitation provision in the UK?

There is a severe lack of appropriate vocational rehabilitation services in the UK to help people with cancer who have developed complex problems.

Our research in this area has highlighted three main reasons for this.²⁴

- **NHS rehabilitation services**, such as occupational therapists, are focused on hospital discharge and do not currently have the capacity to provide vocational rehabilitation. Other health professionals, such as cancer clinical nurse specialists and GPs, haven't the capacity or occupational health expertise to support people returning to work. This is also a reflection of the overall lack of access to wider rehabilitation services for people with cancer.
- **Government back-to-work programmes**, such as the Work Programme, are more focused on supporting people on long-term benefits than people on sickness absence looking to return to work. It's also not known how well these programmes/services meet the needs of people with cancer, or how easily people with cancer are able to access these services.

- **Occupational health (OH) services** and private healthcare providers usually only provide vocational rehabilitation services to people working in large organisations. In addition, not all OH professionals are trained to provide advice on cancer. A survey of OH doctors found that 48% were concerned their training did not provide them with enough knowledge to effectively support and advise employees with cancer.²⁵

The recent announcement by the government to introduce a new state-funded and independent health and work assessment and advisory service²⁶ is promising. It should help make occupational health support more widely available to employers and employees, particularly those working in small and micro businesses. However, we must make sure the service meets the needs of people with cancer, which will require the training of OH professionals to help them better understand the effects of cancer and its treatment.

It's not clear yet whether the new service will fill the gap in vocational rehabilitation provision. OH services are only one way of supporting people with cancer to return to work. It's also important that government considers how to improve NHS rehabilitation services, and how they will potentially work alongside the new health and work assessment and advisory service.

6 What does government need to do?

It's been five years since the UK's Vocational Rehabilitation Task Group, which included the UK government as a stakeholder, commissioned a report recommending that 'vocational rehabilitation should be a fundamental element of government strategy to improve the health of working-age people'.²⁷ This review was conducted to provide the evidence base for policy development in this area, but since then very little has happened at a national level.

The cross-government Health, Work and Wellbeing initiative to protect and improve the health and wellbeing of working age people across Britain has at times looked promising. And we recognise that some of its measures, such as the Fit for Work Service pilots,²⁸ did have a vocational rehabilitation focus and have helped to inform the recent government response to the sickness absence review.

However, the initiative appears to have lost some momentum, especially as the 'national director for health and work' role that led the initiative came to an end before any real progress on vocational rehabilitation was made. In addition, we also believe a major barrier to progress has been that improving access to vocational rehabilitation falls between the responsibilities of government departments.

Despite this, the government's recent commitment to a new health and work assessment and advisory service, which is part of their response to the sickness absence review, does appear to have potential. In particular, we welcome the service's case management component for people who have complex or ongoing problems.

However, overall, the government's response to the sickness absence review is disappointing in many ways in relation to vocational rehabilitation. It does not consider the role of secondary healthcare, so issues regarding NHS rehabilitation services are not addressed. Also, and crucially, the response does not look at how the NHS could be incentivised to view the return to work of people with long-term conditions as a positive health outcome.

To achieve real progress, we believe there needs to be a shift in thinking. Government needs to see it has a clear responsibility when it comes to vocational rehabilitation.

Our work demonstrates that effective vocational rehabilitation for people with long-term conditions, including cancer, requires a combination of healthcare and workplace interventions. This requires a collaborative approach involving government, employers, health professionals and charities.

In addition, the largest study on vocational rehabilitation in the UK recommends national coordination for these interventions.²⁹ We need government to put in place a comprehensive system that identifies those who would benefit from a vocational rehabilitation service and guarantees that they receive high-quality support.

For these reasons, we are asking for:

- **Strong leadership in government and a renewed cross-government approach to vocational rehabilitation.**
The health departments in the UK's four nations and the Department of Work and Pensions (the Department for Employment and Learning and Social Security Agency in Northern Ireland) need to take joint ownership of this issue.

- **Government to improve availability of and access to vocational rehabilitation support for people with complex health problems, including cancer.**
This includes ensuring that government return-to-work services include more effective vocational rehabilitation support to help people with long-term conditions stay in or return to work. Also, the government must better incentivise the NHS to promote work as a positive health outcome for people with long-term conditions.
- **The new state-funded health and work assessment and advisory service to work effectively with secondary healthcare, including NHS rehabilitation services, as well as with GPs.**

References

1. Maddams J et al. Cancer prevalence in the United Kingdom: estimates for 2008. *British Journal of Cancer*. 2009. 101: 541–547. This estimate is for 18 to 64-year-olds at the end of 2008.
2. Office for National Statistics. *Cancer Statistics Registration England*. 2009. Information Services Division Scotland. *Cancer Incidence Scotland*. 2009. Welsh Cancer Intelligence and Surveillance Unit. *Cancer Incidence Wales*. 2004–2008. Northern Ireland Cancer Registry. *Cancer Incidence Northern Ireland*. 2009.
3. Rasmussen DM, Elverdam B. The meaning of work and working life after cancer: an interview study. *Psycho-Oncology*. 2008. 17: 1232–1238; Kennedy F, Haslam C, Munir F, Pryce J. Returning to work following cancer: a qualitative exploratory study into the experience of returning to work following cancer. *European Journal of Cancer Care*. 2007. 16 (1): 17–25.
4. Waddell G, Burton AK. *Is Work Good for Your Health and Wellbeing?* 2006; Black C. *Working for a Healthier Tomorrow: Dame Carol Black's review of the health of Britain's working age population*. 2008.
5. Department of Health. *Quality of Life of Cancer Survivors in England: report on a pilot survey using Patient Reported Outcome Measures (PROMS)*. 2012. pp126–127.
6. Policy Exchange Research Note. *The Cost of Cancer*. February 2010.
7. Maddams J, Utley M, Møller H. Projections of cancer prevalence in the United Kingdom, 2010–2040. *British Journal of Cancer*. 2012. 107: 1195–1202. (Projections scenario 1 presented here).
8. Corner J, Wagland R. *National Cancer Survivorship Initiative: Text Analysis of Patients' Free Text Comments: Final Report*. University of Southampton. 2013. p50.
9. Macmillan Cancer Support/MORI. *Working with cancer – A survey of people with cancer*. 2001. 70% of respondents felt it was 'very important' to continue to work, with a further 13% thinking it was 'fairly important.'
10. de Boer AG, Taskila T, Ojajarvi A, van Dijk FJ, Verbeek JH. Cancer survivors and unemployment: a meta-analysis and meta-regression. *The Journal of the American Medical Association*. 2009. 301: 753–762.
11. Macmillan Cancer Support/YouGov online survey of 2,142 UK adults living with cancer. Fieldwork conducted 26 November to 14 December 2012. Survey results are unweighted. Figures presented in this report are based on 928 respondents who had completed treatment within the past five years.
12. Ibid.
13. For example, the *Work support route guide*, which is available at macmillan.org.uk/workandprofessionals
14. Such as *The essential work and cancer toolkit* and *Cancer in the workplace* DVD, which are available at macmillan.org.uk/employer
15. The National Cancer Survivorship Initiative is a partnership between the Department of Health and Macmillan Cancer Support, and is supported by NHS Improvement. The pilot sites were initially funded for 12 months (April 2010 to March 2011), with five receiving four-month extension funding to July 2011.

16. *Thinking positively about work: delivering work support and vocational rehabilitation for people with cancer – an evaluation of the NCSI Work and Finance Work-stream Vocational Rehabilitation Project*. July 2012.
17. These professionals include clinical nurse specialists, oncologists, GPs, vocational rehabilitation specialists, Jobcentre Plus staff, benefits advisers, and cancer information centre staff.
18. Full details of the content of specialised vocational rehabilitation interventions can be found on p46 of the NCSI vocational rehabilitation evaluation report. Supra note 16.
19. Waddell G, Burton AK, Kendall NAS. *Vocational Rehabilitation: What Works for Whom and When?* 2008.
20. Full details of the findings of the seven pilot sites can be found on pp24–37 of the NCSI vocational rehabilitation pilot report. Supra note 16.
21. Overall, 597 people received an intervention from the pilot sites. Positive work outcomes include: remaining in work or remaining in a modified role (no change); a move from modified work to full work; a move from not working to working; and a move from being on sick leave to full or modified work.
22. This is based on the estimate of income tax (£3,725) paid to HM Treasury for the median gross annual earnings for full-time employees in the UK.
23. Kenyon P. *Cost benefit analysis of rehabilitation services provided by CRS Australia*. 2003. The Institute for Research into International Competitiveness at Curtin University of Technology, Perth. As cited in the report on vocational rehabilitation commissioned by the Vocational Rehabilitation Task Group. Supra note 19.
24. *Returning to work: cancer and vocational rehabilitation. Report of a scoping study for Macmillan Cancer Support*. February 2008.
25. Amir Z. *Cancer Survivorship and Return to Work: UK Occupational Physician Experience*. 2008.
26. The commitment to this new service is outlined in *Fitness for work: the Government response to 'Health at work – an independent review of sickness absence'*. January 2013.
27. Supra note 19.
28. Between April and June 2010, Fit for Work Service pilots were launched in 11 areas throughout Great Britain. Pilots were formed by partnerships of health, employment and local community organisations, and offered biopsychosocial assessments of need and case-managed support to aid a quick return to work. From April 2011, seven of the pilots were funded for up to a further two years.
29. Supra note 19, p49.

Cancer is the toughest fight most of us will ever face. But no one should go through it alone. The Macmillan team is there every step of the way, from the nurses and therapists helping people through treatment, to the campaigners improving cancer care.

Together, we are all Macmillan Cancer Support.

For cancer support every step of the way call Macmillan on **0808 808 00 00** (Monday to Friday, 9am–8pm) or visit **[macmillan.org.uk](https://www.macmillan.org.uk)**

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