

**The road  
to recovery:  
getting back  
to work**

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**WORKING  
THROUGH  
CANCER**



# Working Through Cancer

## The road to recovery: getting back to work

Getting back to work is a huge milestone for many people recovering from cancer. It represents a return to normality, financial security and a key point in reclaiming a daily routine. But it can be a difficult journey and one that people can feel they're doing on their own.

New research by Macmillan Cancer Support reveals that people who have had cancer treatment experience a range of problems when returning to work and that many are not getting the medical and rehabilitation advice and support they need.

### An emerging issue

Returning to work after a cancer diagnosis is an emerging issue. Around 90,000<sup>1</sup> people of working age are diagnosed with cancer every year and more people than ever before are surviving. Ten-year survival rates for all cancers combined have doubled over the last 30 years. Around 46% of those diagnosed are now surviving for ten years or more, and that number is still rising.

Financially, cancer hits working households hard. 71% experience a loss in household income, and that loss is on average 50%<sup>2</sup>.

The ability to return to work has a direct impact on individuals and their families, plus there are clear implications for employers and the economy, the health sector and the welfare system. It is in everyone's interests that we tackle this issue.

### Macmillan's research

As a first step to addressing these issues, the Macmillan Manchester Research Unit (MMRU) is undertaking a research programme into cancer and work. This is the first UK study to explore in detail the experiences of people returning to work after cancer treatment.

This report highlights key findings from the MMRU literature review and phases one and two of the research. It also sets out the next steps in providing the support people living with cancer need when trying to return to work.

<sup>1</sup> Office for National Statistics, 2003

<sup>2</sup> RDSi research, UK Patient Survey, commissioned by Macmillan Cancer Relief, 2006 (unpublished), sample 1137 people affected by cancer.

## Research objectives

The main objectives of the MMRU research were to:

- Gain a better understanding of the issues faced by people returning to work after cancer.
- Highlight where more support is needed.

## Research methods

The research by the Manchester Macmillan Research Unit (MMRU) consisted of:

- **Literature review**

While the research literature in this area is patchy, there are many findings that are potentially useful.

- **Phase 1**

A total of 284 people in North West England with a cancer diagnosis took part in a postal survey. Participants were aged between 18 and 55 and were working at time of diagnosis. To minimise distress to respondents and families, they were all approached via their GPs who, to secure ethical approval, had already excluded those too unwell to consider a return to work, or who did not meet our criteria. Women, particularly those with breast cancer, and white-collar employees were over-represented in the sample.

- **Phase 2**

In-depth phone interviews were carried out with 41 people from the original sample, to explore their cancer journey from their work history, through to diagnosis, treatment, time off work and their return to work. This study focuses on the experiences of those who returned to work.

## Key findings and conclusions

- **People with cancer have a strong attachment to the labour market.** As well as the financial necessity of earning, many desperately want to 'get back to normal' and returning to work is central to this. People do not need to be coerced or cajoled to go back to work, they simply need the right support at the right time.
- **Many people are unable to stay in work after cancer or else find their earning capacity is permanently affected.** This was true even amongst this 'best case scenario' sample whose GPs thought they had a reasonable chance of returning to work, and most of whom worked for larger employers. One in five did not return to the same employer, and one in ten had not returned to work at all as long as three years after their cancer diagnosis.
- **The evidence base on cancer survivorship and work is still relatively weak, particularly in the UK.** We still do not know enough about the barriers people face when returning to work or what interventions are most effective.
- **There is a lack of suitable medical advice.** Most receive little or no medical advice to help understand the impact cancer and its treatment will have on their working lives, and to help them return to work at the right time.
- **Employers have a key role to play.** A good relationship with the employer/line manager made a person much more likely to successfully return to work.
- **People who were able to have a phased return to work found this really helped.**
- **It isn't over once someone goes back to work.** Two in three of those who returned to work experienced difficulties including tiredness, loss of concentration and lack of confidence in their job. And almost one in five of this group reported their working life had deteriorated as a result of their cancer.

'I didn't feel quite ready physically and I still felt a bit wobbly mentally and emotionally, but I was coming to the end of my full pay and I just couldn't afford to go onto half pay.'

## Research findings

### The literature review

- The review highlights that little research has been carried out on cancer and the workplace, here and abroad. Given the growing number of people this affects in the UK, Macmillan believes that further research should be a priority.
- Many people are unable to stay in work after cancer or else find their earning capacity is permanently affected. A significant minority of people with cancer have permanent effects after treatment, these include disability or functional limitations like fatigue and loss of concentration. It is estimated that nearly four in ten people with cancer do not return to work.
- The lack of medical advice about work is a concern in a number of countries and it should be a priority to develop and test interventions in this area.
- The site of a cancer, age and type of treatment all appear to have an impact on people's decisions about work.
- Age is significant. Older workers are better equipped to deal with the emotional impact of a cancer diagnosis, but may need additional support to keep working until retirement. Younger workers need more psychological support.
- Many factors are involved when people make decisions about work after a cancer diagnosis. Economic need is a major factor. 'Getting back to normal' is also a powerful motivator, cited in several US and UK studies, and shows the important part work plays in people's lives. This suggests that providing effective support is more valuable than coercing people back to work.

'I wanted to get back to work as soon as possible... work was the normal life I had before and that's why I focused on it.'

## Quantitative survey of people diagnosed with cancer:

### How big is the problem?

- Even amongst this 'best case scenario' sample whose GPs thought they had a reasonable chance of returning to work, one in five did not return to the same employer. One in ten had not returned to work as long as three years after their cancer diagnosis.
- The type of treatment was a key influence in return to work rates. Of those who only received surgery, 90% returned to work. Those who received radiotherapy and/or chemotherapy or hormone therapy tended to take longer to return. Only 71% of those who received treatment other than surgery returned.
- Length of sick leave was found to be strongly associated with return to work rates – 90% of those who took less than 12 months' leave returned, compared to just 62% who took more than 12 months. 9.7% stopped working altogether.
- Men were more likely to take no sick leave at all, but were also more likely to take longer periods of absence. Women were nearly twice as likely to take 6-12 months as men.
- People on lower incomes were more likely to take longer sick leave. However, those on the lowest incomes were slightly more likely to take no sick leave at all, which might be explained by strong financial pressures to get back to paid work as soon as possible.



## In-depth interviews:

### What influences a return to work?

#### Better advice on when and how to return

- Half of those interviewed did not receive any medical advice when returning. 'Go back when you feel ready' was a typical response, particularly from GPs. However, once back at work around two-thirds experienced difficulties such as fatigue, loss of confidence and concentration.
- Nearly half the people returned to work after advice from an occupational health practitioner, but this was limited to people working in large organisations.

#### Easing back into work

- Where occupational advisers were involved, people were normally able to make a gradual return to work with a lighter workload and/or a shorter working week. This approach has valuable benefits and can influence people's longer-term employment prospects and well being.
- Several interviewees had to change their duties or job to cope with work demands.

#### Eagerness to return

- Getting back to work soon after treatment was seen as part of re-establishing a normal lifestyle for the majority of people in the study, and this was a strong incentive for them. However, this eagerness to return to work could create problems in going back too soon.
- Financial pressures were a strong factor in driving people back to work, which is especially important given the extra costs of treatment over a long period. This was more strongly felt by people who had less entitlement to sick pay from their employers, and who were off work for more than twelve months.

## Changing the work-life balance

- Having survived cancer and returned to work, most interviewees then changed their view of their work-life balance – attaching much less importance to work compared to their family life.
- A small minority changed their working lives with a new job or career. However, most returned to their previous job because they couldn't make significant changes in their work-life balance, even if they wanted to.
- In this context it is worth noting that working life deteriorates for a significant number of people after cancer. Of the two-thirds of people in the survey who said they experienced difficulties in returning to work, almost one in five said that this was the case.

## Importance of a good employer relationship

- A good relationship with the employer, together with longer service, were the major influences in people returning to work successfully. Support from work colleagues during sick leave was also highly valued.
- Nearly all the interviewees were able to sustain their return to work, and the support of their employer was important in this. Some people felt over-protected while a few felt they had excessive demands made of them.

'I was given lots of information about breast cancer and its effects but I wasn't given any information about what I should do about work.'



# Irene's story



'It was hard to even tell work – it all happened so quickly.' When Irene Soulsby was diagnosed with breast cancer in 2003 her life changed in an instant. Irene, then in her mid-forties, was working as a secretary in a large firm of accountants – a very busy job that suited her energetic personality.

Although Irene was in and out of hospital for a lumpectomy followed by radiotherapy within a week, it was months before she felt well enough to work. 'Some days it was difficult to get out of bed or even walk across the room', she says.

'Occupational health was very helpful, but I was still nervous about going back to work. I was very tired and it was hard to concentrate. You forget all the systems you have picked up over the years. By December I was shattered and slept through Christmas. It really took me a year to get back to normal.'

Financially, Irene feels she is fortunate in not having a mortgage to pay, having inherited her house. She used her savings plus a critical illness payment to settle mounting debts.

Irene says: 'When you start thinking about your life, you want to change it after cancer. I dived into reducing my hours to three days a week, even though it hit me financially. But there is always the thought that as you get older you are saving less for your pension.'

'I still go to a support group and I still get emotional about what happened. I was lucky in that the company has been very supportive, but I know others in the group who have been under pressure to return to work.'

## What is Macmillan doing?

Macmillan's national Working Through Cancer campaign is tackling this issue.

- We have already campaigned successfully to extend protection, under the Disability Discrimination Act 1995, to people with cancer from the point of diagnosis.
- The next phase of our MMRU research programme will explore the views and experiences of line managers and occupational health practitioners. Ultimately, we aim to develop and test an effective model for supporting people with cancer to return to work.
- An expert panel is being set up to provide strategic advice and support to the campaign.
- We are developing a range of tools, guides and information products to help rehabilitation, occupational health and Human Resources Professionals to support people in returning to work.



## What else is needed?

- It is unacceptable that many people returning to work after cancer treatment are getting no medical or rehabilitation advice. To make this transition smoother, people need to be given information about returning to work and referred to occupational health and rehabilitation services at key points in the care pathway.
- Employers should incorporate Macmillan's best practice guidance into their sickness and disability policies to ensure that their employees get the right support when returning to work after a cancer diagnosis.
- Macmillan urges the Department for Work and Pensions to work with us to ensure that Jobcentre Plus employment services are able to cater for the specific needs of people with cancer.
- There is an urgent need for more research to have a greater understanding of the issue and inform policy solutions. Macmillan wants the National Cancer Research Institute to make work and cancer a strategic research priority.

## Find out more

To find out more about Macmillan's Working Through Cancer campaign visit [www.macmillan.org.uk/work](http://www.macmillan.org.uk/work) or email [campaigns@macmillan.org.uk](mailto:campaigns@macmillan.org.uk)

## References

Amir Z., Moran T., Walshe L., Iddenden R. & Luker K., (2007), Return to paid work after cancer: A British experience, *Journal of Cancer Survivorship*, 1: 129-131