

# OXFORD ECONOMICS

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## Can Work, Will Work

Valuing the contribution and understanding the needs of people living with cancer in the workforce

*maggie's*

**unum**  
Because everyone  
needs a back-up plan



OXFORD  
ECONOMICS

## 1 Executive Summary

There are more than 2 million people with cancer in the UK and over 300,000 new cases are being diagnosed each year. But although more people are being diagnosed, earlier screenings and life-saving medical treatments mean more and more are now living with it as a chronic condition – in fact, cancer survival rates have doubled in the last 40 years<sup>1</sup>.

But society hasn't kept pace with medical advances. Whilst there has been a positive shift in attitudes to support people in dealing with diagnosis, there is less understanding and support in place for life during and particularly beyond treatment, particularly in the workplace.

For the first time, this report shows there are more than 560,000 people with cancer in the workforce today, contributing over £16 billion to the UK economy every year – more than the UK house building industry. As prevalence and survival rates rise, this will grow to more than 1.1 million people by 2030, making a significant contribution of £29 billion every year.

Many people with cancer are not able or do not want to return to work after treatment. But this report shows there are 63,000 who do want to work but are currently being held back by a lack of support for both employees and employers. If overcome, work could play a vital role in their recovery – the people who took part in this research told us work gave them a sense of normality and purpose, rebuilt their self-esteem and provided a focus outside of cancer.

From talking to both people with cancer and with employers, we know the reasons behind these barriers are complex. People with cancer told us that, despite their employer's initial efforts to support them, an unintentional chasm opens up in their relationship due to a lack of regular and meaningful communication and shared understanding on both sides.

They described it as the triple whammy effect: diagnosis, followed by job loss or a negative experience at work, leading to a collapse in confidence and self-esteem. For many, this downward spiral ends with them dropping out of the workforce permanently.

Employers also feel they lose out. They feel the negative effect on staff morale, lose valuable talent and expertise, and see the costs of managing absence and replacing staff impact on their bottom lines.

People with cancer told us they need better support from their employer, particularly improved communication and understanding of the effects of cancer. But employers need support too. They told us they wanted to do the right thing for staff with cancer but were often stumbling in the dark without guidance or coming up against rigid work policies.

And the role of the line manager cannot be underestimated – our report shows they often have the biggest impact on someone's experience of working with cancer because they are often the main contact the employee has with their employer.

With the number of people living well with cancer increasing every year, this issue must be addressed now. It's in everyone's interests to build a shared knowledge and understanding between people with cancer and their employers.

For the first time we can show that with the right support an extra 63,000 people with cancer who choose to work could be helped back into the workplace, businesses could save money through reduced absence management costs and the economy could grow by £1.8 billion.

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<sup>1</sup> CRUK 'Cancer Stats Key Facts, August 2012'

And that's just today – by 2030, this would rise substantially to more than 136,000 people, contributing £3.5 billion every year.

Maggie's are experts in supporting people with cancer, providing emotional, practical and social support to people with cancer and their families and friends. Unum are specialists in working with businesses and employees on industry-leading rehabilitation for people with long term illnesses.

Together they have launched a new partnership to raise awareness and better understand these issues and commissioned this report to discover, for the first time, the valuable economic contribution of people with cancer, to explore the barriers preventing those who want to from returning to work, and the potential benefits if these are overcome.

Through tailored support and education, Maggie's and Unum aim to provide what people need and deserve to build a life beyond cancer. They will be launching Cancer in the Workplace workshops to provide employers with useful insights, information and management strategies to support them in approaching these situations with knowledge, empathy and understanding.

This report calls for a number of recommendations to help people living with cancer and employers to work together to realise this potential:

#### **Businesses need support to:**

- implement a comprehensive and staged return to work programme.
- maintain open, regular and meaningful communication whilst employees are off sick or undergoing treatment.
- provide education, guidance and training at all levels about what to expect from someone returning to work after cancer.
- provide line managers with the education, guidance and support to manage the return to work of someone with cancer.
- appoint a coach, mentor or third party to help facilitate communication and education between employer and employee.

#### **People living and working with cancer need support to:**

- acknowledge that their everyday needs and role in the workplace may change.
- be clear and ask their employer for the flexibility, guidance or management they want.
- seek advice, support and guidance from third parties to help them and their employer.

#### **Ann-Louise Ward, Programme Director at Maggie's**

“Last year Maggie's received 100,000 visits from people with cancer. This report reflects what we hear again and again in our Centres across the UK – the issues that many people face as a result of dealing with cancer in the workplace. Through facilitating focus groups at our Centres, we were able to explore the issues surrounding cancer in the workplace and give a voice to those who experience them. We are delighted to be working with Unum to raise awareness of the issues and provide support to both people with cancer in the workplace and their employers.”

## 1.1 Introduction

This report investigates how many people with cancer and returning from treatment are currently in employment and their contribution to the UK economy. It also looks at the people living with cancer who want to return to work but are encountering barriers, including those who are currently unemployed or have opted to leave work permanently, and the difficulties that they face in returning to or obtaining work. The report also explores these barriers from the perspective of those who work in Human Resources (HR) and line managers, the frontline staff handling cancer in the workplace. This was done through a combination of focus groups with people with cancer who have returned to the workplace, and interviews with HR and line managers. Finally, this report analyses how these barriers may be overcome and the benefits for people with cancer, for businesses and for society if this can be achieved. From this we have drawn recommendations for employers and employees to help support people with cancer who choose to return to the workplace. The recommendations build on those made by the National Cancer Survivorship Initiative and its strategic recommendations<sup>2</sup> and therefore complement and build on current Department of Health thinking.

## 1.2 The economic contribution of people living with cancer

Maddams, Utley and Møller (2012)<sup>3</sup> estimate there are **2.1 million** people in the UK who are currently living with or have had treatment for cancer. Of the **860,000** people with cancer who are of working age, some **560,000** of these are currently in employment, comprising **1.5%** of the total number of people employed in the UK.

For the first time, this research estimates that the **560,000** people in employment contributed **£16 billion** to UK GDP, using average hours worked<sup>4</sup> and 2011 pay rates for people who have previously suffered a long term illness. That's **1.1%** of the UK's total GDP – to give a sense of scale this is more than the housebuilding industry.<sup>5</sup>

With improved healthcare, cancer prevalence is set to increase as the number of people surviving cancer increases. Over the next twenty years prevalence rates are predicted to rise from **3.3%** to **5.7%**.<sup>6</sup> By 2030, it is estimated there will be four million people with cancer in the UK, twice the number today.

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2 Eva, G, (2012), 'Thinking positively about work: Delivering work support and vocational rehabilitation for people with cancer', Final report, July.

3 Maddam, J, Utley, M, and Møller, H, (2012), 'Projections of cancer prevalence in the United Kingdom, 2010-40', British Journal of Cancer, pages 1 to 8.

4 Using data from the Office for National Statistics (ONS) Labour Force Survey in 2011.

5 ONS, (2011), 'Annual Business Survey 2010'. Data for SIC35.1.

6 See Maddam, Utley, and Møller, (2012).

The increase in the number of people with cancer will have a profound impact on the UK labour market. This will be amplified by the increase in the state pension age. It is estimated by 2030 there will be 1.7 million people with cancer of working age or choosing to remain in the workforce beyond the state pension age.<sup>7</sup> Of these, 1.1 million will be in employment, almost double the number today. They are estimated to comprise 3.3% of the total number of people employed in the UK and to contribute £29 billion to the economy each year, at today's prices.

Many people aren't able or don't want to work after treatment, but those who choose to often face significant barriers in the form of a lack of understanding and communication with their employers. Many feel that their jobs are under threat and that they have become an 'inconvenience' to be 'managed out'.

If people with cancer do lose their jobs an analysis of some 36 academic studies suggests that returning to work may not always be easy for cancer patients: de Boer, Taslila, Ojajarvi, van Dijk and Verbeek (2009)<sup>8</sup> find that people who have had cancer are 1.37 times more likely to be unemployed than those who have not. In particular, people who survived breast cancer, gastrointestinal cancer and cancers of the female reproductive organs were found to be at increased risk of unemployment.

The study also suggests that a high unemployment rate is more likely to impact the probability of cancer patients being unemployed than that of those without cancer. Given that unemployment has historically been a lagging indicator of the state of the economy, this suggests that people with cancer may struggle to find employment for some years to come as the country experiences weak recovery.

These perceived barriers may discourage people with cancer who want to work from rejoining the workforce. This is bad for individuals who feel work provides a sense of purpose and self-esteem, bad for businesses who lose talented staff and are left with expensive replacement costs, and bad for the economy through a loss in productivity, wage payments and tax receipts.

### 1.3 The importance of work

Whilst the importance of work to business and the health of the UK economy is clear, work is also important to the psychological well-being and recovery of cancer patients. People with cancer or recovering from treatment who participated in our focus groups felt work was vital to them<sup>9</sup> because it provided a focus outside of cancer and helped to build a sense of normality, security, structure, purpose and self-esteem.

“I want to go back to work because I want to do something other than cancer. I want to get back my life.”

<sup>7</sup> The closure of defined benefit schemes, increases in longevity, increase in the old age dependency ratio and poor state of government finances all suggest that people will need to work for longer.

<sup>8</sup> de Boer, A, Taslila, T, Ojajarvi, A, van Dijk, F, and Verbeek, J, (2009), 'Cancer survivors and unemployment: a meta-analysis and meta-regression', *Journal of the American Medical Association*, Volume 301, pages 753-762.

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As well as providing financial security and independence, work has a huge impact on mental well-being. Our participants said that work was an important distraction from medical treatment and helped them to regain control or normality, making them feel a step closer to recovery. Having a structure or a daily routine was valued by individuals but was also felt to help the wider family to live through and beyond cancer.

Most importantly, focus group participants felt that continuing to work or returning to work was vital to their self-esteem. Some spoke of a sense of failure if they were unable to return to work or perform the same role as before. Others said that work helped to prevent them from falling into a downward spiral, where a lack of purpose and structure resulted in a loss of confidence, self-belief and, in some cases, depression.

These findings are consistent with previous research. Boelman's (2011)<sup>10</sup> analysis of the experience of health and social care professionals suggests that the importance of work varies between individuals and significantly for the same individual over time depending on where they are in their path from diagnosis to treatment and beyond. Her study and that of Eva (2012)<sup>11</sup> suggest work can bring very similar benefits to people with cancer.

### 1.4 Perceived barriers for people with cancer

There are many people with cancer who are not able to continue to work or return, often due to medical reasons; however many choose to<sup>12</sup> but are encountering non-medical barriers that could be overcome.

A number of academic studies have put forward reasons as to why people recovering from cancer have higher unemployment rates. Nachreiner, Dagher, McGovern, Baker, Alexander and Gerberich (2007)<sup>13</sup> point to the difficulty of combining treatment with full-time work. Park, Park, Park, Kim and Lee (2008)<sup>14</sup> suggest physical and mental limitations may be a major cause of unemployment. Verbeek, Spelten and Work (2007)<sup>15</sup> and Main, Nowels, Cavender, Etschmaier and Steiner (2005)<sup>16</sup> suggests it may be discrimination.

“Work makes you feel normal, as though you haven't got cancer; it's the mental stimulation and the routine.”

“It's part of your routine. It's like morning coffee. It makes you feel normal.”

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9 Twenty two people with cancer participated in focus groups in Dundee and London hosted by Maggie's Cancer Care Centres held during October 2012. Of these, 19 were in paid employment at time of diagnosis. At the time of the focus groups, 3 had no change in their work situation, 3 had intermittent time off for treatment and recovery, 5 have had changes made to their work arrangements, 1 is self employed, 7 were unemployed and 3 have left the workforce.

10 Boelman, V, (2011), 'Can we talk about work? Encouraging health and social care professionals to talk positively about work to people affected by cancer', RS Consulting.

11 Eva, G, (2012), 'Thinking positively about work, Delivering work support and vocational rehabilitation for people with cancer', July.

12 See Eva, G, (2012), 'Thinking positively about work; Delivering work support and vocational rehabilitation for people with cancer', July. She argues "Many people who have had cancer want to go back to work when they feel ready and able". Page 5.

13 Nachreiner, N, Dagher, R, McGovern, P, Baker, B, Alexander, B and Gerberich, S, (2007), 'Successful return to work for cancer survivors', AAOHJ, Volume 55(7), pages 290-295.

14 Park, J, Park, E, Park, J, Kim, S, and Lee, S, (2008), 'Job loss and re-employment of cancer patients in Korean employees', Journal of Clinical Oncology, Volume 26(8), pages 1302 to 1309.

15 Verbeek, J, Spelten, E, (2007), 'Work', in Feuerstein, M, ed, 'Handbook of cancer survivorship', New York, NY: Springer Science and Business Media.

16 Main, D, Nowels, C, Cavender, T, Etschmaier, M and Steiner, J, (2005), 'A qualitative study of work and work return in cancer survivors', Psychooncology, Volume 14(11), pages 992-1004.

Our focus groups explored what people living with cancer themselves perceive to be the barriers to continuing in employment or returning to work after treatment. The overriding image from the focus groups was of a widening divide in the relationship between employee and employer after initial support. This divergence was thought to be driven by:

■ **Lack of knowledge on the part of both employee and employer**

Many participants pointed to a lack of knowledge amongst both people with cancer and employers as to what physical and emotional changes to expect during and after treatment. Many of the respondents did not know how their capacity to do their jobs would change and several did not want to admit they could no longer do everything they formerly could, both to themselves and to their employer.

■ **Difficulty in communicating changing needs**

The majority of the focus group participants found it difficult to communicate with their employer about their prognosis and changing needs and most looked to their employer to provide the lead. It was recognised by most that for the employer to be able to help, employees with cancer must be able to express their needs, but many lacked the confidence to do so or were worried about how their employer might react.

■ **Lack of regular, meaningful communication**

Employers were seen to be embarrassed about talking about cancer and many participants felt as though the subject were a taboo. This was sometimes interpreted as disinterest. Whilst on sick leave, most had received little or no communication from their employer and on returning many had no regular communication with their line manager or HR about their illness.

■ **Line manager lottery**

The majority of employee and employer communication was undertaken though line managers and employees with cancer have very different experiences, largely driven by the reaction and personality of their line manager<sup>17</sup>. One participant said despite working for the same organisation, he and his wife had ‘black and white’ experiences.

“My manager was supportive at first but changed the moment she found out I wouldn’t be back within a three month period. I felt like I was an inconvenience to her.”

“I want to say what is happening with me but I don’t think I can.”

“It changes when you become a commercial liability to them. They want productivity out of us. They’ll have done some numbers and decided it’s better to get rid of you than do this.”

“You are stumbling around in the dark hoping for a little guidance.”

<sup>17</sup> CBI/Pfizer, (2011), ‘Healthy returns? Absence and workplace health survey 2011’ finds that 57% of employers surveyed regard “line managers taking primary responsibility for managing absence” as the top five means for managing absence across all illness types. See page 24.

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## ■ Fear of inflexibility

Some of the focus group participants had found their employer unwilling to accommodate flexible working and duties, and that their employer did not recognise the need for flexibility post-treatment. As a result, several were concerned about admitting they couldn't do everything they did before.

## ■ 'Tick box' HR culture

The 'tick-box' approach of many HR departments was perceived to be a major barrier to a successful return to work. This recourse to HR and the rule-book is perceived to be a key driver of the divergence between employee and employer and is often believed to be a route to severing employment for people with cancer.

## ■ Lack of trusted third parties

HR and Occupational Health are often perceived to be on the side of employers and motivated by commercial pressures. Focus group participants thought there was a need for an independent third party to facilitate education and interaction on both sides.

## ■ Empathy deficit

Many participants were suspicious that their illness was felt to damage the bottom line and that their interests were very different from those of the employer. They often felt that line managers failed to understand or empathise and considered them an inconvenience.

## 1.5 Consequences for people with cancer

It is vital to bridge the perceived communication gap between people with cancer who choose to return to work and their employers, and to overcome the unnecessary or unwitting barriers that many encounter.

The consequences of these unnecessary barriers can be devastating. Several of the participants in our focus groups said they had suffered a 'triple whammy' as their cancer diagnosis was swiftly followed by either job loss or a very negative work experience which in turn led to a collapse in self-esteem and, in some cases, depression.

Many told us they had been made redundant or forced to leave, whilst others continued in work but were unhappy or felt as though they were not being used to their full potential.<sup>18</sup> As a result, just over a third were now unemployed and another tenth had permanently withdrawn from the workforce.

“It severely knocked me back. In hindsight, if I'd known that's how I would be treated, I wouldn't go back. I felt so battered, so worthless, my coping mechanisms are at rock bottom. I'm applying for other jobs but my self-confidence is gone.”

“They didn't understand the stages you go through. They didn't understand what was going on inside.”

“If we expect employers to support us, we have to give something of ourselves.”

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<sup>18</sup> A fifth of people returning to work after cancer treatment reported a deterioration in job satisfaction and career prospects in one study. See Amir, V, et al (2007), 'Return to paid work after cancer: A British experience', *Journal of Cancer Survivorship*, Volume 1, pages 129-136.

The participants felt the psychological consequences of the adverse experience at work and job loss were huge. Not least because it compounded the emotional shock of cancer diagnosis and for some the impact of treatment (such as fatigue or loss of the ability to concentrate). This caused a fall in self-confidence and feelings of anxiety and depression. Some spoke about feeling a sense of guilt or failure.

For many of those who had left work, their negative experience had left them with little confidence in their ability to regain employment. It also made them reluctant to be open with any potential future employer about having been diagnosed with cancer and made some feel unwilling to seek employment again in future

## 1.6 Perceived barriers to employing people with cancer

In our employer interviews, people from HR departments and line managers were asked about the barriers people with cancer who choose to return to work are encountering.<sup>19</sup> Virtually all the HR and line managers perceived their firm to be a benevolent employer and a number cited cases where they felt the firm had done all it could for employees with cancer or returning from treatment.

### The barriers identified were:

#### ■ Emphasis on physical capability

Most of the employers focused on an employee's physical ability to do the job and their medical needs. They did not focus at all on the emotional and psychological aspects of returning to work which, as our focus groups show, are a particular concern to people with cancer. The employers we interviewed felt that there may be barriers relating to the capability of an employee with cancer to fulfil their job role when it involved physical work, the speed at which they could work and their mental clarity when undertaking research. Others focused on constraints relating to the need for medical care. Jobs which involved lots of foreign travel were perceived to be potentially problematic.

#### ■ Lack of guidance from employee

There was a strong belief that every employee with cancer should be treated on an individual basis, because each cancer-type is different and will require different support. As a result, most employers look to employees with cancer to communicate their needs. The focus group findings, however, show that employees are looking for the employers to take the lead, leaving a gap in communication and support.

“It depends on where they work, it depends on the type of cancer, the type of person they are.”

“My mental health completely collapsed when I stopped working. In the structure of society a job is important.”

“I'm a very open person, but I don't know whether I should tell future employers.”

<sup>19</sup> Staff in Human Resources or line managers with previous experience of staff with cancer in 11 firms and government departments or other parts of the public sector were interviewed during October 2012. The interviews were conducted by telephone.

### ■ Difficulties in arranging cover for senior staff and contingency planning

There was an acknowledgement that people with cancer would require time off for treatment, but how problematic that would be for the firm was perceived to depend on the role the person fulfilled. A number of interviewees thought that it was easier to arrange cover for junior staff. The hierarchical structure of most large organisations meant they were more numerous, so there were more of them to pick up the work of the person with cancer in their absence. Lower skill requirements also made it easier to get replacement temporary staff or people on fixed short-term contracts. It was perceived to be far more difficult to arrange cover for senior staff.

### ■ Absences more problematic for SMEs

Staff absences (planned or ad hoc) due to ill health were perceived to be more difficult or costly to cope with for small and medium-sized enterprises (SMEs). This was felt to be the case as they have less staff to cover any time off, and the cost of managing absence and recruiting and training replacements would take a large share of their profitability. Likewise they would have fewer, if any, HR resource to organise the person's return to work.

### ■ Uncertainty for employers and colleagues

Interviewees felt that having a staff member with cancer (or any other long-term illness) created uncertainty for the business. This focused on whether they would return from treatment, over what timescale and whether they would be fully able to resume their duties. Furthermore, because cancer is covered by the Disability Act, a job cannot be re-advertised until they know the employee's medical prognosis. Ad hoc absences were perceived to be problematic. One line manager mentioned that one employee with cancer had told them they were worried about having ad hoc time off on days when they were required to produce a piece of work.

### ■ Need for training on cancer

Virtually all the interviewees felt their firm would benefit from having greater knowledge of cancer and best practice relating to the employment of people with cancer. At present, the vast majority of HR and line managers interviewed felt their company's understanding of the impact of chemotherapy on cognitive abilities and of fatigue and cancer on staff's psychological wellbeing could be improved.

### ■ Fear of dealing with emotional impact of cancer

Very few of the HR and line managers interviewed felt the emotional or psychological effects of cancer were a focus. After prompting, some interviewees mentioned a fear of having to deal with an emotionally damaged person, regardless of whether this was a reality. Others mentioned social awkwardness, especially as colleagues feel unsure whether to ask how someone with cancer is and whether they want to talk about their illness. This was not felt to be specific to cancer, the same awkwardness surrounded most serious physical and mental health problems.

“It is difficult for both sides.”

“Not knowing how long the person will be off for, so not being able to put in place any contingency plan, whether or not someone is replaced. It is the uncertainty of it and how long it is going to go on.”

■ **Rigid return to work policies**

One employer interviewed thought their return to work scheme may cause problems for staff with cancer. Each person returning on a full-time basis could start on a short hours or part-time basis, but had to be working full time within eight weeks. This was thought to delay possible return dates, until the individual knew they could work full time within eight weeks.

“The possibility, even if it is not a reality, of frequent absences either for physical weakness or having to go for treatment, that for me is the biggest barrier from an employer’s perspective.”

1.7 Consequences for employers

Cancer treatment and recovery can involve long-term absence (sometimes defined as 20 continuous working days off)<sup>20</sup> from employment. A couple of studies have investigated the cost of absence on employers. CBI/Pfizer (2011) estimates the cost of long-term absence to be nearly £6 billion a year to UK employers. One interpretation of this figure is it reflects the productivity foregone while staff are away from work. CEBR (2012) estimates managing long-term absence to be £6.5 billion for the whole economy a year.<sup>[1]</sup>

**These costs include:**

- the salaries of replacement staff
- the recruitment and training costs associated with these replacement staff
- a loss in productivity
- absence management, and the compliance and red tape associated with this
- Occupational Sick Pay (OSP) paid to the absent employee

It is impossible to calculate what proportion of each of these estimates of the costs of illness is due to cancer. But one indication can come from Unum’s payment of Income Protection cases, almost a fifth of these relate to cancer. Assuming this holds for the whole economy, cancer is currently costing firms £1.1 billion in lost productivity<sup>21</sup> and £1.2 billion in hard costs, including the costs of absence management, recruitment and training replacement staff. These figures will increase in size with the predicted growth in the number of people with cancer in employment from 560,000 today to an estimate of 1.1 million in 2030.

There can be a number of damaging consequences for employers who lose staff because they feel unable to return to the workplace, not least the loss of skills and expertise.

There are a number of costs associated with managing absence or, in a minority of cases, managing cancer patients out of the workplace. These include the costs of severance pay and potential litigation costs, the costs of advertising the post, screening costs, the loss in productivity while a replacement can be found and the costs of formal and informal training to get the new employee up to speed.

<sup>20</sup> See CBI/Pfizer, (2011), ‘Healthy returns? Absence and workplace health survey 2011’, May.

[1] CEBR, (2012), ‘The benefits of private sector employers from the adoption of group income protection as an employee non-salary benefit’ finds that statutory and occupational sick pay for all illnesses costs private and public sector employers £6.47 billion a year.

<sup>21</sup> Calculated on the basis of the CBI/Pfizer (2011) estimate of the cost of long-term absence.

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Several studies have attempted to quantify the costs of staff turnover. Estimates suggest it costs a firm 30-50% of the annual salary of entry level employees, 150% of middle level employees and up to 400% for specialized, high level employees. So, managing a staff member with cancer out of the business and replacing them is likely to be costly.

Managing people with cancer out of the business may also impact the behaviour of other staff. It may have a negative impact on morale and hence productivity, particularly that of the individual's close colleagues.

## 1.8 Crossing the chasm

Combining data collected from the ONS and based on population and employment surveys conducted during 2011/12, it is possible to estimate there are currently 260,000 people of working age with cancer who are outside the workforce. This number is predicted to increase to 570,000 people by 2030. A proportion of these will be unable to work due to ill health. Likewise, some will be prevented from working as they are parents or carers. A proportion of the remainder choose to work, but are prevented from doing so by the barriers discussed above.

If it was possible to overcome these barriers, the individuals would realise all the psychological and financial benefits from employment, businesses would save on the costs of absence management and recruitment and society would benefit from their economic contribution. It is in everyone's interest to build a shared knowledge and understanding between people with cancer and their employers and ensure that everyone has access to the right support.

“An amazing commitment to work and to carrying on.”

### The dividend

To estimate the potential benefits of helping people with cancer who choose to work to do so it is necessary to know two pieces of information:

- What proportion of the people with cancer outside of the workforce are physically able to work
- Of these, what proportion want to work but are being prevented by a lack of support.

Sadly, there is an absence of cancer-specific data on both questions.

Instead, the analysis draws on research on claimants of Incapacity Benefit for multiple health reasons. Kemp and Davidson (2007) find just over a quarter of respondents were permanently off work due to their illness or disability. Of the remainder, who were physically able to work, around a third did not participate in the workforce due to social attitudes.<sup>22</sup> If these figures hold for cancer, it is these people who are held back due to real and perceived barriers.

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<sup>22</sup> Kemp, P, and Davidson, J, (2007), 'Routes onto Incapacity Benefit: Findings from a survey of recent claimants', Department for Work and Pensions, Research Report No 469.

This forgotten third today represents around 63,000 people who have cancer or are returning from treatment and want to work but who feel for one reason or other excluded from the world of work. Using detailed data on the pattern of employment, pay, and productivity, it is possible to estimate that today if they gained employment they would contribute £1.8 billion to UK GDP.

As the number of people with cancer and those returning from treatment increase, so will the forgotten workforce, unless action is taken to address this issue. On the present course, the participation gap will rise to over 136,000 people by 2030. These people could contribute £3.5 billion (in today's prices) to UK GDP in eighteen years time.

## 1.9 How to realise the dividend (policy recommendations)

### For businesses

#### **Employers need to respond to the growing number of people with cancer in the workplace and both recognise and celebrate their valuable contribution to business.**

The sheer number of people living and working through cancer means this is now too big and important an issue for employers to ignore; yet the approach taken by many businesses is outdated and simply doesn't account for these rapid changes. Meanwhile, the minority of businesses that manage cancer patients out of the workplace need to recognise that this is no longer sustainable or responsible – as this report has shown, cancer patients are not a burden on business, but valuable and active members of the workforce whose talent and expertise impacts directly on the bottom line.

#### **Businesses must respond by taking a bigger and more active role in helping employees with cancer to return to work when they are ready.**

The first step for UK businesses is to review their approach and policies for managing cancer in the workplace, and to create the right framework to support those employees who are affected – from employees with cancer, to line managers, to HR managers. Nor is this an issue for these alone – change needs to start at board level with senior managers recognising their duty of care and communicating the valuable contribution of people living and working with cancer.

#### **There are simple steps that businesses can take to support employees with cancer and empower them to take an active and productive role in the workplace:**

- **Businesses need to take a more rounded and long-term approach to managing employees with cancer.** This report has shown that many employers take a short-term approach to cancer with a primary focus on the period when employees are off work for treatment; yet some employees feel the emotional and physical effects of their cancer for years and need continued support even after they are back at work. Employers must address this by developing a more long-term approach to cancer which deals not only with the medical aspects and treatment, but also considers emotional and psychological needs.

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- **All businesses should implement a comprehensive and staged return to work programme.** People living and working with cancer feel that employer support ends once they come back after treatment and want their return to work to be more structured; yet many are unwilling to ask for modifications to their role, either because they assume their employer will not be flexible about their duties and hours or because they are unwilling to admit they can no longer do the same things as before. Businesses, meanwhile, are often unaware if employees are struggling and do not realise that modifications or checks would be welcome. A phased return to work programme would help both employer and employee to work together to manage a successful return to the workplace.
- **Businesses need to maintain open, regular and meaningful communication whilst employees are off sick or undergoing treatment.** This will help to make employees with cancer feel that they are a valued member of the business and make it easier to open up communication when they return to the workforce.
- **Businesses need to provide education, guidance and training at all levels about what to expect from someone returning to work after cancer.** Both employees with cancer and their line managers feel they are stumbling in the dark and would benefit from guidance; yet misunderstanding and lack of knowledge can create a damaging chasm between them. Better education would help both to recognise the needs of employees with cancer.
- **Businesses need to return HR to its frontline role as response to employee needs and remove the impersonal, tick-box culture.** Employees often distrust HR departments and feel that they don't prioritise their needs. HR departments can address this by ensuring a consistent, gold-standard approach to handling cancer and providing line managers and employees with access to information, tools and support, bringing in independent third parties where necessary to provide expertise.
- **Businesses should appoint a coach, mentor or third party to help facilitate communication and education between employer and employee.** As this report has shown, there is a perceived chasm between employer and employee and in many cases the interests of each are seen to be very different. Employers must recognise that in many cases an independent third party can help to overcome this barrier and provide guidance for both parties.

### For people living and working with cancer

Whilst the onus is on businesses to provide better training and a clear return to work programme, people living and working with cancer can also help to improve their experience at work.

A cancer diagnosis can be devastating. At an already difficult and emotional time, possibly during treatment, a cancer patient will often not be able to look ahead to practicalities like their return to work. Even when they do, they may not know what to expect or what support they need. Many want their employer to take responsibility for their return to work; yet employers, usually well-versed in the legal and medical aspects of cancer, often know little about what to expect when their employee returns to work and find it difficult to know what they need.

There are simple steps that people with cancer can take to help their employers give them the right support.

- People living and working with cancer need to acknowledge that cancer will have both a physical and psychological effect on their day-to-day life – and that their needs and participation in the workplace may change.
- They must also recognise that their employer is looking for their guidance on how to manage and approach their return to work. To get the tailored support they need they must ask their employer for the flexibility, guidance or management they want.
- Cancer patients planning to return to work should seek advice, support and guidance from third parties. Although employers expect them to ask for the support and flexibility they need, often cancer patients will not know what this is. It is important that people living and working with cancer seek out information and guidance from healthcare professionals and third parties about what to expect physically and psychologically, their rights in the workplace and what they need from their employer.

## 1.10 Maggie's and Unum

Maggie's are experts in the area of supporting people with cancer, empowering them to live with and beyond cancer with emotional and psychological support.

Unum offers industry leading rehabilitation as part of its Income Protection services. We help employees to return to work and get back to normal, and in particular we have a deep expertise in helping people with cancer and their employers, to find the best outcome for them.

Working together, we have commissioned this report to understand this issue and how it can be best addressed.

We recognise that addressing this problem will take time and everyone needs support and guidance.

That's why we are working to provide support and to educate both employees and employers to overcome these unnecessary barriers. These will include:

- Cancer in the Workplace lectures for HR professionals to be held at the nine UK Maggie's Centres in 2013
- Online and printed information and educational resources for employers
- An enhanced Where Now? course – providing the tools and support for life beyond cancer - with information on returning to work
- Cancer in the Workplace workshops for line managers to be delivered by Maggie's internally in companies.

We want both employees and employers to receive the support they need and deserve to live well with cancer.

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