

Working Through Cancer

Employer Support Research: Summary Report

June 2011



The Changing Cancer Story

The story of cancer is changing; more people in the UK will have a cancer diagnosis at some point in their life or a family member's life and more people are living with or have survived beyond a cancer diagnosis. There are already two million people in the UK living with cancer and the number is expected to rise by around 3% a year¹ to four million by 2030 if current trends continue².

Cancer is now a significant issue in the workplace. Greater numbers of people who have had a cancer diagnosis are at work or returning to work – with return to work rates of up to 84% reported for some cancers³. And there is now substantial evidence about the importance of work in the cancer journey and the costs – to individuals, business and the economy – of barriers to work for people affected by

cancer. Research on the provision of support in the workplace for people living with or beyond cancer tells a compelling story about the likely positive impact of support on individuals – promoting recovery, reducing depression, improving personal relationships, preventing cancer poverty – and on potential gains for business through reducing absence and increasing human capital through retaining expertise.

Government and employers are acknowledging this link and placing greater emphasis on the importance of workplace health and return to work initiatives. The coalition government has stressed the role of employers in health promotion and in their communities as part of the 'Big Society'.

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INTRODUCTION

Working Through Cancer

Macmillan Cancer Support has led development of workplace support for those living with and beyond cancer in the UK. The Working Through Cancer Programme (WTC) has added to these resources. Motivated employers can access a substantial selection of well constructed resources through a range of media (e.g. online, at the Learn Zone, on the phone or in print form). The EMPLOY Framework supported by Breastcancer Care is another addition.

However, evidence about the availability and effectiveness of this type of workplace support

for people affected by cancer is limited. Macmillan Cancer Support identified a need for research to provide evidence about what works best to support people living with and beyond cancer to return to and remain in work more specifically.

The findings from this research on Working Through Cancer Employer Support is being used by Macmillan Cancer Support in developing a package of support for employers on work and cancer and also to inform policy makers concerned with employer support for people living with cancer and other long term health conditions.

The research

The research, carried out by Shared Intelligence for Macmillan Cancer Support, investigated current policies and practice in workplace cancer support and assessed the need for an additional package of support from Macmillan and the forms that this might take. The key research considerations were:

- Employer need and interest in a Macmillan package of WTC resources;
- The types of resources that should be included in any package (and how this might vary for different types of organisations);
- The best channels/methods for Macmillan delivering these resources, and the WTC package overall;
- The possible impact on Macmillan resources and infrastructure in developing

and disseminating a WTC package;

The research included an evidence review to generate a better understanding of the cancer support issues to be explored with employers. Interviews took place with senior managers and/or Human Resources (HR) professionals in 37 large private and public sector employers⁴, and an on-line survey of 190 line managers on their experiences of managing employees with cancer and the support resources that they would like.

The employers covered retail, manufacturing, construction, utilities and service sectors across the UK and had a variety of Human Resources (HR) and Occupational Health (OH) arrangements in place, which fell into 3 broad categories:

- very large organisations (1000 employees +) with correspondingly sized HR departments and an in-house OH team/resource
- organisations with a central HR function within their head office (in some cases with OH support) with area based HR teams or local HR advisors
- organisations with a central HR team supported by line management arrangements – most likely organisations with around 500 employees.

There were also a few examples of organisations with externally commissioned OH support from healthcare organisations e.g. BUPA, Santia.



EMPLOYERS' VIEWS AND EXPERIENCE

The interviews with senior managers (most often HR or OH managers) from the 37 employers, including 13 Macmillan corporate partners, produced valuable insights into attitudes towards cancer and work as well as an understanding of current support for employees living with and beyond cancer.

Views around cancer and cancer in the workplace

All employers were clear that cancer is an issue that provokes a very personal reaction and feeling, although there was a difference in views, linked to personal experience of cancer. Those managers who had first or second hand experience of the illness were generally comfortable with the issue and could discuss cancer in the workplace in an open and exploratory way. This compared to those who had a lack of direct knowledge and so tended to follow established support guidelines in relation to, for example, managing long term health conditions.

General workplace health and wellbeing

When asked an open question about workplace health and wellbeing generally, no employers specifically mentioned cancer as an issue or challenge and there were no examples given of cancer specific policies. The most common health and wellbeing challenges identified

by employers were mental health and muscular skeletal conditions. Others mentioned dealing with an aging workforce, the impacts of shift work and heart disease. There were some examples of where high prevalence rates for mental health and muscular skeletal conditions had led to specific policies being developed and introduced by employers.

Employers were clear that concerns and associated responses around workplace health and wellbeing were dictated by high prevalence and thus absence rates associated with the particular condition.

“Cancer is not a big issue at the moment – that is in terms of numbers”

Some employers recognised that prevalence rates may increase thus making cancer more of an issue and should this be the case, it would provoke the development of specific policies. Also, there was an indication that family members of someone who is living with cancer may be an overlooked group as they may not communicate this role and there is little understanding of an appropriate response to their needs. Where these issues were raised employers indicated an interest in finding out further information about this in terms of numbers and issues.

Employers also highlighted the challenge of tackling long-term absence in a supportive way while paying due reference to what the organisation can afford.

“It’s difficult to strike the right balance between the desire to be supportive and the constraints of what we can support financially”

Current experience with cancer or long-term conditions

The majority of employers had some experience of supporting an employee living with and/or beyond cancer. Generally the approach taken is supportive, flexible and adapted to the needs of the individual within guidelines of standard company absence management and rehabilitation policies, although this can vary due to the type of employment undertaken.

There is a clear sense that employers are now doing more to support individuals to remain in/return to work while experiencing/recovering from illness. Line managers tend to be the first point of call for employees with long term conditions, but in cancer cases they tend to be supported by HR and/or Occupational Health (OH) managers as when this illness becomes long-term (over four weeks for most organisations) HR and OH will be notified and become directly involved in the with case.

Several employers recognised that it is helpful for individuals to have more than one point of call as someone other than their line manager can be seen as more neutral or easier to relate to about health especially where gender or age is an issue.

Working Through Cancer

There is evidence that some conflicts can arise between the needs of the individual and business when supporting an employee living with or beyond cancer.

“Sometimes you can’t do the right thing for doing the wrong thing”

Most employers thought that support given to those who are affected by cancer tends to be similar to other long-term conditions in terms of formal policy - but different in practice. Reasons for this were based on the unpredictability of how the diagnosis and treatment of cancer will affect each individual, which means it can be more difficult to plan a meaningful workload and schedule than for those with other long-term conditions and requires a more personalised response to individual needs.

“Cancer has huge physical and emotional/psychological effects which need to be managed over a long-term period”

The research suggests that organisations that have a corporate partnership with Macmillan had found that this had helped to increase knowledge of cancer within organisations

“We have always helped with cancer, but the relationship with Macmillan has made

people more aware (of the issue)”

However, a number of corporate partner organisations stated that OH/HR managers do not have any direct contact with Macmillan and it would be good to have a closer relationship with Macmillan from a HR/OH perspective to inform employee support’

Current support provided

Most employers had some form of health and wellbeing policy or programme in place. Generally focus is on prevention and promotion of general health and wellbeing. The extent of health and wellbeing support is related to the size of organisation and level of HR/OH resource.

“There has been a gradual improvement in terms of wellbeing aspects and support of the (Occupational Health) service – rather than it being perceived as a stick to beat people with – now there is more of a focus on an educative/preventative approach”

There are some examples of organisations working in partnership with charities, local authorities and the NHS to deliver health information and campaigns. These were more common in the larger companies and tended to focus on prevention and

promotion of general health and wellbeing through, for example, encouraging smoking cessation or physical activity, or in one case, mobile screening units on site.

Although information on promoting and managing health comes from a range of government, charity, OH and partnership sources, employers said that they often struggled to find information on local support services, including on financial support available, for people living with cancer.

A range of media are used to communicate information on health and wellbeing, the most common being leaflets, e-bulletins and/or the organisation’s intranet. Advice tends to be distributed in the format in which it was originally produced and so passed on at little cost to the employer.

The amount of awareness raising and training for line managers on workplace health and wellbeing differs across organisations. Although HR and OH managers recognise the importance of the line manager in supporting someone living with or beyond cancer, the capacity of line managers to give this support in practice varied in relation to age, experience and general attitude.

“The word (cancer) can frighten line managers, especially newer, less experienced ones – this is less so with other long-term illnesses”

Most employers via HR and/or OH, felt they did what they could to support line managers as far as practical, given logistical issues and time constraints. This included distributing information on workplace health and wellbeing to line managers; liaison between line managers and HR/OH and in some organisations, specific coaching and training for line managers on dealing with long-term absence.

Beyond some corporate partners, there was little knowledge of Macmillan's resources for employers and line managers. And even within these corporate partners, there was scope for more promotion of the resources across the organisation. Some employers felt that current Macmillan resources had too much focus on compliance with legal obligations rather than offering them support.

Need for and interest in Working Through Cancer (WTC)

The majority of employers were interested in additional supports (including the majority of corporate partners consulted). For some organisations, however, a stronger business case would be required to spur action in this regard. Such a case would need to include not only increasing cancer prevalence, but also the effects on mental health which combine to increase the impact of cancer on employers as well as individuals. The impact is still greater if carers are included,

both through the direct impact on potential absenteeism and the need for flexible working as well as because of the additional caring responsibilities causing stress and anxiety.

The most common supports requested were: coaching/support for line managers; an advice helpline; and information about local supports and financial support/advice.

"Most helpful would be information for line managers"

"We need to have information on the counselling and support that is out there to allow us to guide employees towards this"

The research showed that a range of media are important for support to employers – electronic, hard-copy and access to a specialist advisor – at different levels, for different staff and for different types of organisation. There is also a need for more face-to-face and targeted marketing of WTC supports to overcome barriers of time and lack of awareness from employers.

"It would be good if Macmillan could visit HR/OH teams and deliver briefing or training to them"

Employers were unwilling to pay for generic support especially in the current economic climate

and given relatively low cancer prevalence rates within most organisations. However, some managers said they would be willing to pay for bespoke services/supports for their organisation.

"It (justifying the cost for support) always comes down to making a business case"

Overall, employers were keen to be seen to be working with Macmillan to improve support for employees affected by cancer. A number of corporate partners said that they see WTC as part of the partnership role and are willing to develop their existing relationship beyond fundraising. While organisations would welcome the opportunity to promote any relationship with Macmillan and use Macmillan branding where relevant, there was no real interest in or perceived need for specific kite marks or accreditations, especially if effort was required by the organisation to go through the process to get such recognition.

"The Macmillan brand is already strong so [we] just need the association"

Reflecting their greater provision of health and wellbeing support generally, there is slightly more willingness from organisations with larger HR/OH functions to develop closer working relationships with Macmillan staff.

SURVEY OF LINE MANAGERS

Six organisations (from different sectors and including three corporate partners) that took part in the employer interviews issued the on-line survey to a sample of their line managers resulting in 190 responses.

Thoughts on Cancer

The survey found that the majority of line managers feel comfortable talking about cancer to some degree (64% or 119). However, only 23% (42) were very comfortable in talking about cancer with nearly a fifth saying they felt either quite uncomfortable or very uncomfortable.

The majority of line managers have had some experience of cancer in the workplace, with 69% (128) having worked with or managed colleagues who had had a cancer diagnosis. There was less experience (or maybe less

awareness) of having worked with carers of people with cancer.

There was a relatively weak understanding of cancer as an illness and its effects in the workplace. Less than half (44% or 79) of line managers thought that they had either a good or very good understanding.

Cancer and Work

Few line managers considered themselves very well equipped in dealing with any aspect of supporting an employee/colleague living with or recovering from cancer. Generally line managers felt best equipped in talking about cancer and in managing time off/change in working hours or workload. They are less well equipped in dealing with the physiological and physical challenges associated with cancer.

However, responses suggested that line managers are not less well equipped to deal with cancer than they are other long-term conditions and that level of experience in dealing with a particular health issue – including cancer - does not necessarily correspond to competence in that regard.

The research also suggests some lack of ability from line managers in dealing with the impact on and/or attitudes of other employees and stress and emotional challenges associated with cancer in the workplace. This supports the widely held view from the employer interviews that line managers need support

in understanding cancer and the journey someone affected by it will go through.

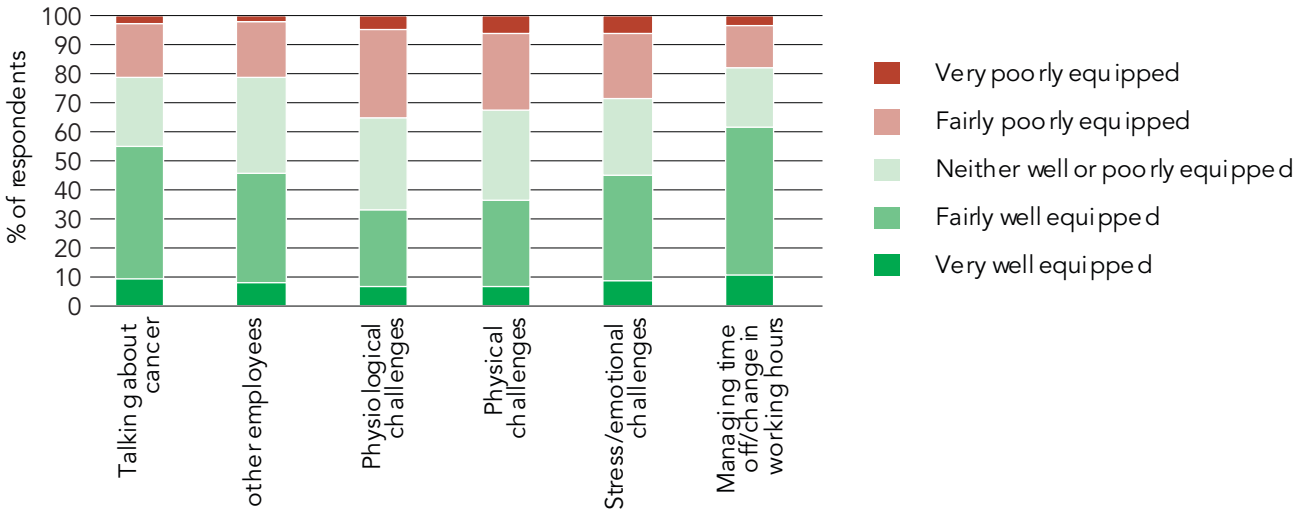
Support Resources – Current and Future

Over three quarters of line managers surveyed (78% or 140) thought that support was available from their employer to assist them in supporting an employee or colleague living with or recovering from cancer. However, only a small number of respondents had actually made use of these services. There was most awareness and use of face-to-face discussion and advice from HR/OH, and of written company policies – and less knowledge or take up of written advice, signposting to other sources of support and of training or awareness raising.

The survey showed that that HR/OH services were seen as the most popular means by which to access information about cancer (68% of respondents) with less merit given to more informal methods such as through colleagues or family and friends, which has important implications for how best to reach line managers. A relatively high value was also placed on cancer charities as a source of support with 41% (72) respondents indicating that they would access information from this source. Despite this, only 16% (27) of respondents were aware that Macmillan offers support to employers and line managers and of these, few had actually used them. This reinforces other findings from both the



HOW WELL EQUIPPED DO YOU FEEL IN DEALING WITH THE FOLLOWING ASPECTS OF CANCER IN THE WORKPLACE (184 RESPONSES)

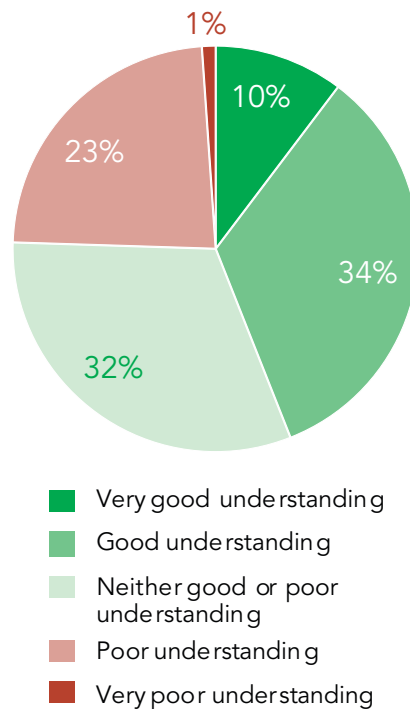


line managers' survey and the employer interviews that while cancer support resources may be known about, their use is not actively promoted or widely taken up.

Almost all line managers (90% or 154) felt that they would benefit from additional resources to assist them to support employees or colleagues recovering from cancer. These included general information/guidance for line managers, information on support available for employees living with or beyond cancer including local supports and financial assistance, advice on how line managers can talk about cancer and access to a helpline for professional advice.

Most line managers said they would prefer online routes of accessing this information, with 87% (150) indicating this as useful or very useful. This was closely followed by a telephone

LEVEL OF UNDERSTANDING OF THE IMPACT OF CANCER AS AN ILLNESS AND ITS EFFECTS IN THE WORKPLACE (184 RESPONSES)



helpline (74%, 128) and face-to-face training/briefing (69%, 120). However, time is clearly the biggest barrier to accessing assistance in supporting an employee or colleague living with or recovering from cancer, identified by over half the line managers. Not enough knowledge about cancer in the company was identified by 39% (58) of participants.

Working with Macmillan

81% (141) of line managers felt it would be beneficial if their organisation was to be seen to be working with Macmillan around cancer in the workplace, but there was little interest in a formal award scheme. Instead, 79% (138) thought being part of some form of employer membership scheme to receive expert advice on the development of cancer friendly policy and practices would be useful.

CONCLUSIONS

At a time when the number of people living with a cancer diagnosis is increasing, there is evidence of the benefits to individuals, businesses and the economy of supporting employees affected by cancer, and the Government is urging employers to take greater responsibility for health promotion as part of the Big Society, this research has shown that:

- Employers feel that cancer is an issue that provokes a very personal reaction and feelings but supporting employees living with and recovering from cancer, or caring for people with cancer, is not currently considered as a key challenge by most employers;
- However, a large number of employers are aware that cancer is an issue of growing concern and do recognise the importance of supporting individuals living with or beyond cancer in the workplace and have indicated a clear demand for resources to assist them with this;
- Although levels of experience in dealing with cancer cases

in the workplace varies across employers, the research highlights a general lack of clear guidelines for employers and a low awareness of readily available support;

- This is reinforced by line managers, who tend to be the first port of call for employees who have received a cancer diagnosis but do not necessarily feel equipped to support the employee within the policies of the employing organisation and would welcome appropriate guidance and support resources.

The following have emerged as the most commonly identified areas for support:

- A need for awareness raising of work and cancer issues generally and presentation of a business case or rationale for action in a format that will capture employers' interest e.g. how it impacts on absences, productivity etc;
- Dedicated support for line managers to assist them in managing and supporting

employees living with and beyond cancer - not just with regard to talking about cancer but to help them understand the physical and physiological impacts, treatment plans etc in order that work can be effectively planned and adapted to the abilities and limitations of individuals;

- Increased awareness within organisations of where they can signpost employees living with and beyond cancer to for further support, particularly in terms of local support groups and networks, and financial advice;
- Access to a helpline to provide personalised professional advice for HR/OH professionals and line managers in order to back up more general guidance. This is identified as being best delivered via access to some sort of helpline.

Overall, employers and line managers were keen to be seen to be working with Macmillan to improve support for employees affected by cancer.

Endnotes:

¹ Maddams J, et al. Cancer prevalence in the United Kingdom: estimates for 2008. British Journal of Cancer. 2009. 101: 541-547

² Internal analysis by Intelligence & Research, Corporate Development Directorate, Macmillan Cancer Support

³ Grunfield E A, Low E and Cooper Cancer Survivors' and employers' perceptions of work following cancer treatment, Occupational Medicine 2010;60:611-617

⁴ The research focused on employers with 500+ employees to reflect the size of Macmillan's corporate partners and employers that were likely to have a dedicated HR function and policies on cancer.