



# The EMPLOY Charter

Breast Cancer Care's guide to  
best practice in the workplace

Policy briefing



## Summary

In 2004 there were over 44,000 women and around 300 men diagnosed with breast cancer in the UK. A diagnosis of breast cancer can have a major impact on many areas of a person's life beyond their physical wellbeing, including their employment.

Breast Cancer Care has investigated the impact of a diagnosis of breast cancer on someone's employment. In 2006 we carried out a survey of breast cancer patients' experiences of employment. 417 people from around the UK responded. The survey explored how people managed work during and after treatment for primary and secondary breast cancer and what, if any, support they received from their employers. It also identified factors that influence individuals' decisions regarding whether to return to work. In February 2008 a focus group of people with secondary breast cancer was carried out to provide further information. An online poll on awareness of disability discrimination rights among people affected by breast cancer was conducted in early 2008.

The 2006 survey results demonstrate that people's experiences of work following a diagnosis of breast cancer are wide-ranging and individual. In particular, people have different treatment plans and different reactions to treatment which means their ability to work during or following treatment will vary.

On the whole, people found their employers to be supportive. However, only a few respondents reported good practice measures such as regular meetings, phased (gradual) return to work, or work adjustments made during and after treatment. This is despite the fact that some of these measures could often be regarded as legal duties under UK disability discrimination law.

It is very concerning that the majority of respondents were not aware of their rights as cancer patients under the Disability Discrimination Act in relation to employment.

## Key survey findings

### **Low awareness of rights for cancer patients under the Disability Discrimination Act (DDA)**

- 61 per cent of respondents were not aware of their rights under the DDA in relation to employment.

### **Wide range of individual experiences**

- The amount of time off work due to breast cancer taken by respondents ranged from one week to five years, with most of the respondents having taken between six months and one year off work overall.

### **Supportive employers**

- 62 per cent of respondents reported that their employer was supportive during their treatment.
- 57 per cent of respondents said their employer was supportive after their treatment.

### **Lack of regular employer-employee dialogue**

- 19 per cent of respondents reported they had regular meetings with their employer to discuss how to best manage their workload during their treatment.
- 23 per cent of respondents had such regular meetings with their employer after treatment.

# The EMPLOY Charter

The EMPLOY Charter uses each letter of the word EMPLOY to provide best practice guidance on how employers can support members of staff who have had a diagnosis of breast cancer. The charter also points out the legal employment rights of people with cancer and employers' corresponding responsibilities under disability discrimination law in the UK.

This charter is based on the results of our 2006 survey and outputs from the 2008 focus group of people with secondary breast cancer. It is also informed by the expertise of Breast Cancer Care staff, including the clinical team, and work with an advisory group of people with breast cancer, human resources (HR) experts, employment solicitors and a representative from the Employers' Forum on Disability.

**The EMPLOY Charter** and an accompanying booklet, **The EMPLOY Charter – Information for employers**, have been published and can be ordered from [www.breastcancercare.org.uk](http://www.breastcancercare.org.uk). These materials are supported by Employers' Forum on Disability. The booklet explains each of the charter points in more depth and indicates where these best practice measures might be considered legal requirements under disability discrimination law.

## Health professionals and Governments

To ensure that breast cancer patients have the information they need to make employment-related decisions, and to ensure that employers have the information they need to meet their legal duties towards an employee after a cancer diagnosis, Breast Cancer Care is also calling for the following:

- Breast cancer patients should be signposted to sources of employment-related and financial information and support, including the EMPLOY Charter, by breast care nurses or other health professionals involved in their care.
- UK Governments and Governmental Departments should work together to raise awareness of the DDA among employers and cancer patients.

See 'Our calls to action' on page 16 for more details.

# The EMPLOY Charter

## Breast Cancer Care's guide to best practice in the workplace

### Employer-employee dialogue

An employee with breast cancer should have the opportunity (but not the obligation) to have regular meetings with their employer to discuss the impact of their diagnosis on employment. Meetings should include discussion around reasonable work adjustments, time off needed, arrangements for transfer/effective management of the employee's work during sickness absence, phased return to work after time off and the possibility of flexible working.

### Money matters

The employer should provide clear information on an employee's financial entitlements including company and statutory sick pay and other relevant company benefits. The employee should be signposted to sources of specialist financial advice.

### Prejudice-free workplace

All employees affected by breast cancer have the right to work in a sympathetic environment, free from prejudice. An employee's privacy should be respected.

### Listening to the individual's experience

Everyone's experience of breast cancer is different and the medical treatments required will vary. An employer should take the time to listen to and understand the employee's individual treatment plan, experience of breast cancer and decisions about work, and accommodate the individual employee's needs where possible and reasonable.

### Off work time

An employee with breast cancer should not have to use annual leave for medical appointments, treatment and recovery from treatment, including breast reconstruction surgery. An employee should be able to attend prosthesis fittings and hair loss services where necessary, as well as emotional support services, through flexible working arrangements.

### Your responsibilities under disability discrimination law

People with cancer are covered by the Disability Discrimination Act. Their employer is required to make reasonable adjustments to help them at work. An employee should not be treated less favourably than colleagues because of their breast cancer or for a reason relating to their breast cancer, nor should they be subjected to harassment.

**Some of the information in this charter is of a legal nature. It is intended solely to provide an overview. No responsibility can be accepted for the completeness or accuracy of the legal information and professional legal advice should be sought in relation to any specific situation.**

# Background

The interaction of disability, health conditions and employment has become a significant area of public policy work in recent years, with an emphasis on supporting people into work as a strategy to achieve full employment in the UK.

A cross-Government programme was launched in 2005 called *Health Work Wellbeing*. This programme is sponsored by five Government partners: the Department for Work and Pensions, the Department of Health, the Health and Safety Executive, the Scottish Government and the Welsh Assembly Government. It aims to improve health and wellbeing among working age people by helping more people with health conditions find, and stay in, employment.

The Department for Work and Pensions commissioned an independent review into the evidence base on the health benefits of work. A report of the review's findings, *Is work good for your health and well-being?*, was published in 2006. It concluded that there is a strong evidence base demonstrating that work is generally good for physical and psychological wellbeing and that unemployment is associated with poorer physical and psychological health.

The Disability Discrimination Act (DDA) has been in force since 1996 and was amended in December 2005 to automatically give legal rights to everyone who has had a diagnosis of cancer. The Act stipulates that an employee should not be treated less favourably than colleagues because of his or her cancer, nor should they be subjected to harassment. Employers are required to make reasonable work adjustments to ensure that an employee with cancer does not experience any disadvantage. This includes adjustments to workplace policies, practices and premises. Examples of reasonable work adjustments might include arranging a phased (gradual) return to work for an employee after time off sick and allowing an employee extra breaks during work to cope with fatigue or menopausal symptoms caused by breast cancer treatment. In September 2007, the Department for Work and Pensions launched the *Employability* campaign, which aims to challenge employers not to make negative assumptions about the capabilities of disabled people and the talents they can bring to the workplace.

Cancerbackup, the Working with Cancer Group and the Chartered Institute of Personnel and Development (CIPD) published a survey report in 2006 based on the analysis of responses from 219 organisations. The survey found that more than one in five employers (22 per cent) was not aware that the DDA classes cancer as a disability. It also found that nearly three-quarters (73 per cent) of employers do not have a formal policy in place for managing employees affected by cancer.

The Cancer Reform Strategy, published by the Department of Health in December 2007, updates the NHS Cancer Plan of 2000 and sets out the direction for cancer services in England for the next five years. The Cancer Reform Strategy recognises that employers' awareness of the relevance of the DDA to cancer appears to be low. It cites a study that found that, while 80 per cent of employers are aware of the DDA, only 19 per cent know that cancer is classed as a disability (Simm *et al.*, 2007). The Simm study reports on a quantitative survey based on 2,001 telephone interviews with organisations with at least three employees.

The impact of breast cancer on employment from an employee/patient perspective remains a relatively unexplored area of research. Evidence from research in Canada and the USA

suggests the impact of breast cancer on working patterns is most severe in the first 6 months after diagnosis (Bradley *et al.*, 2007; Drolet *et al.*, 2005) and that most women return to work 12-18 months after diagnosis (Bradley *et al.* 2007). For some women this return to work is only for a short length of time perhaps due to later effects of treatment, breast cancer recurrence or arm-related difficulties, including movement limitations, swelling, and drainage problems (Bradley *et al.* 2007). The attitude of employers can be very important in the decision to return to work. There is evidence that an employer being accommodating of an employee's illness and treatment needs is an important predictor of return to work for people with breast cancer (Bradley *et al.*, 2007).

Some studies have categorised the difficulties employees have experienced in returning to work after cancer treatment into three main groups (Kennedy *et al.*, 2007, citing Spelten *et al.*, 2002). These are:

1. work-related difficulties, for example the pressures of work demands or financial pressures
2. disease-related difficulties, for example the side effects of treatment, the emotional impact of diagnosis and treatment, and the physical symptoms that may be caused by breast cancer treatment, lymphoedema (swelling of the arm, hand or breast area caused by damage to the lymph nodes in the armpit from surgery or radiotherapy) or secondary breast cancer
3. person-related difficulties, for example a shift in a person's priorities after a cancer diagnosis.

Kennedy *et al.*'s (2007) in-depth UK study into the experience of returning to work following cancer (predominantly breast cancer) found that financial concerns were an important consideration in the study participants' work decisions. The study also reports that a major motivation in returning to work for participants is a desire to return to 'normality' and to be able to concentrate on subjects other than cancer. Participants reported a variety of treatment side-effects, but the report identifies extreme fatigue as 'the most frequent symptom that was disruptive and difficult to manage at work' (p.24).

The Kennedy *et al.* study also found that participants had received little advice from health professionals about work issues. This is a gap in cancer care addressed by the Cancer Reform Strategy (Department of Health, 2007) which recommends that 'Commissioners should make sure that information for people who work and have cancer is made available to patients as soon as they are diagnosed. Advice on returning to work should be available for all patients of working age' (p.80).

The Minister for Public Health in the Scottish Government launched the Independent Advice and Support Service in September 2007. This initiative is funded by NHS Boards in a strategic partnership with various local Citizens Advice Bureaux. It aims to provide patients with information about a wide range of issues, including advice about access to benefits and support services (The Scottish Government, 2008).

The following pages give details from the analysis of Breast Cancer Care's 2006 survey into people's work experiences after a diagnosis of breast cancer.

The quotations throughout this document are from people sharing their experiences of employment after a diagnosis of breast cancer.

## Survey methodology

Between February and April 2006 a questionnaire was sent out to Breast Cancer Care's clients and volunteers. There were 337 responses. The same questionnaire was also administered in 2006 using an online survey tool on Breast Cancer Care's website, which obtained 153 respondents. However, 68 of these respondents lived outside the UK and were therefore excluded from the analysis.

## Respondents to the survey

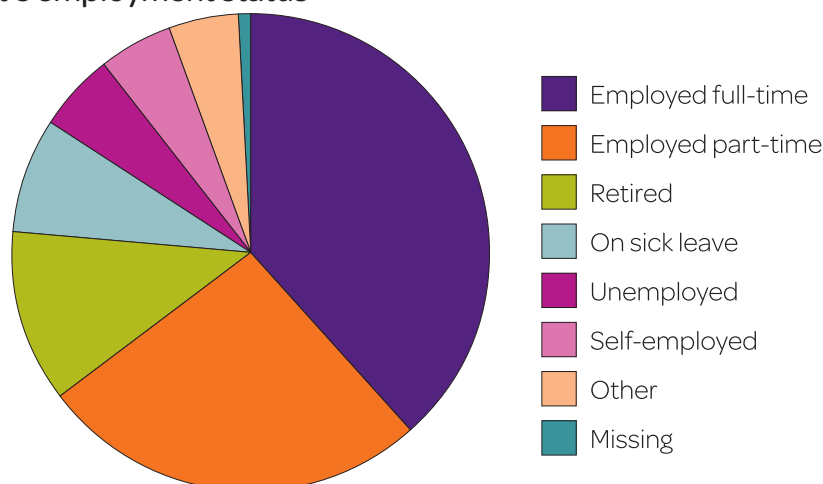
The final sample for this study (excluding respondents from outside the UK) was 417 respondents. 411 participants were female and five participants were male (one respondent did not state their gender). 83 per cent of respondents (346 respondents) indicated that they had had a primary breast cancer diagnosis, 3 per cent indicated that they had had a breast cancer recurrence (12 respondents) and 9 per cent indicated that they had had a secondary (metastatic) breast cancer diagnosis (37 respondents). The remaining respondents did not specify their type of breast cancer.

The majority of respondents (74 per cent; 310 respondents) were diagnosed with breast cancer between 2000 and 2006. 57 per cent of respondents lived in England (239 respondents), 26 per cent in Scotland (109 respondents), 16 per cent in Wales (67 respondents) and 2 responses came from Northern Ireland. Participants were aged between 20 and 69 when diagnosed with breast cancer, with the mean age being 45 years.

Some respondents were talking about their current employment while some were reflecting on previous experiences. At the time of the survey:

- 38 per cent were employed on a full-time basis (160 respondents)
- 26 per cent were employed on a part-time basis (110 respondents)
- 12 per cent had retired (49 respondents)
- 8 per cent were on sick leave (32 respondents)
- 5 per cent were unemployed (22 respondents)
- 5 per cent were self-employed (21 respondents)
- 5 per cent described their employment status as other (20 respondents)
- less than 1 per cent of people chose not to answer this question (3 respondents).

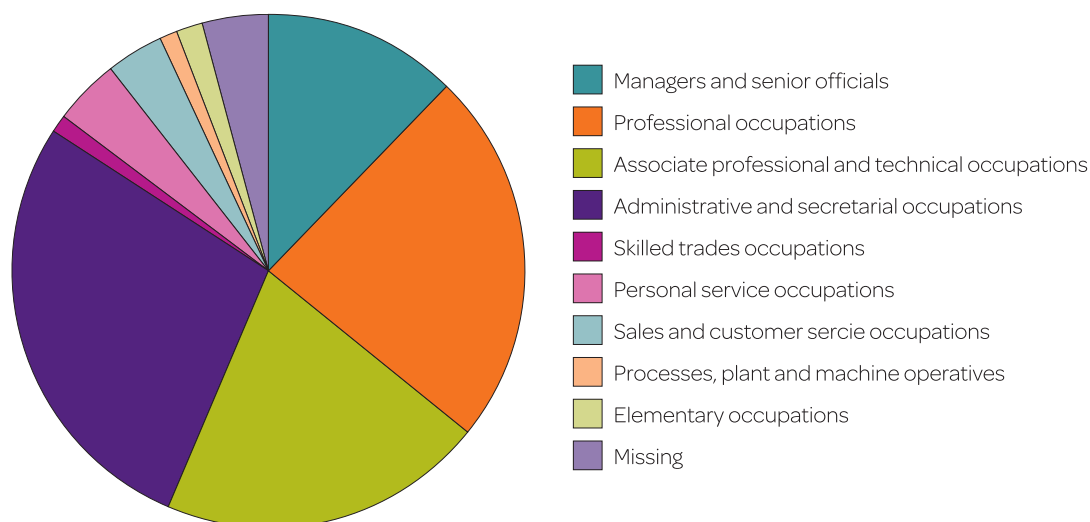
**Figure 1: Participant's employment status**



Respondents worked in a variety of occupations (codes are based on The National Statistics “Standard Occupational Classification 2000”, Appendix 1).

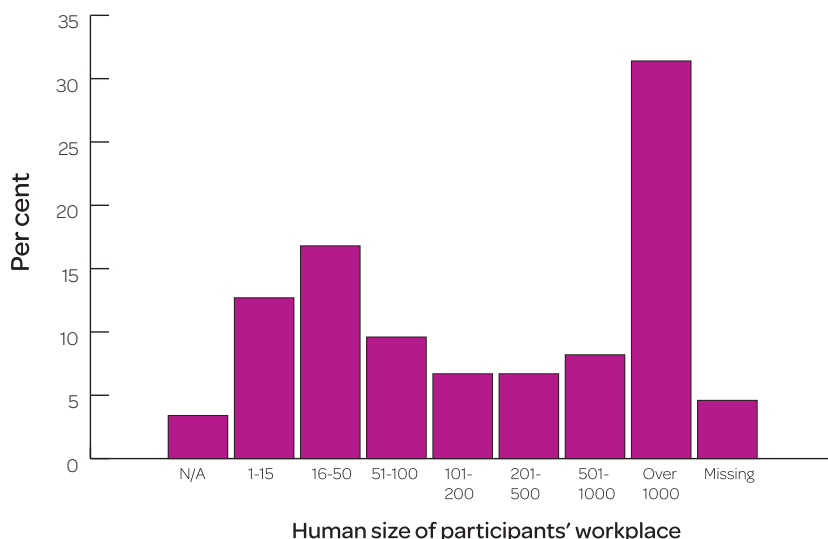
- 12 per cent worked as managers and senior officials (52 respondents)
- 24 per cent worked in professional occupations (98 respondents)
- 21 per cent worked in associate professional and technical occupations (86 respondents)
- 28 per cent worked in administrative and secretarial occupations (116 respondents)
- less than 1 per cent worked in skilled trades occupations (4 respondents)
- 4 per cent worked in personal service occupation (17 respondents)
- 4 per cent worked in sales and customer services (16 respondents)
- less than 1 per cent worked as processes, plant and machine operatives (4 respondents)
- 2 per cent worked in elementary occupations (7 respondents)
- 4 per cent did not indicate their occupation (17 respondents).

**Figure 2: Survey respondents’ occupational group**



Respondents’ workplaces ranged greatly in size, as measured by the number of employees, from the very small (16-50 employees) to large (over 1000 employees). See Figure 3 for more details.

**Figure 3: Human size of survey respondents’ workplaces**



# Breast cancer patients' experiences of employment

## The impact of breast cancer and treatment on employment

It is important to note that everyone's experience of breast cancer is different and the impact on employment will vary from individual to individual. Breast cancer is not just one single disease. There are several types of breast cancer. It can grow at different rates and be found at different stages of development. Breast cancer is also a complex disease, and it is difficult to predict what course it will take.

Different people will follow different treatment plans which are devised according to several factors including the individual's age, general health, the type of cancer, the extent of its spread, the size of the tumour and patient choice. Treatment for breast cancer may involve surgery, chemotherapy, radiotherapy, hormone therapy or targeted therapy – either alone or in different combinations. People will also vary in their emotional and physical reactions to breast cancer and breast cancer treatments.

Respondents gave the following information on the types of treatments they had received.

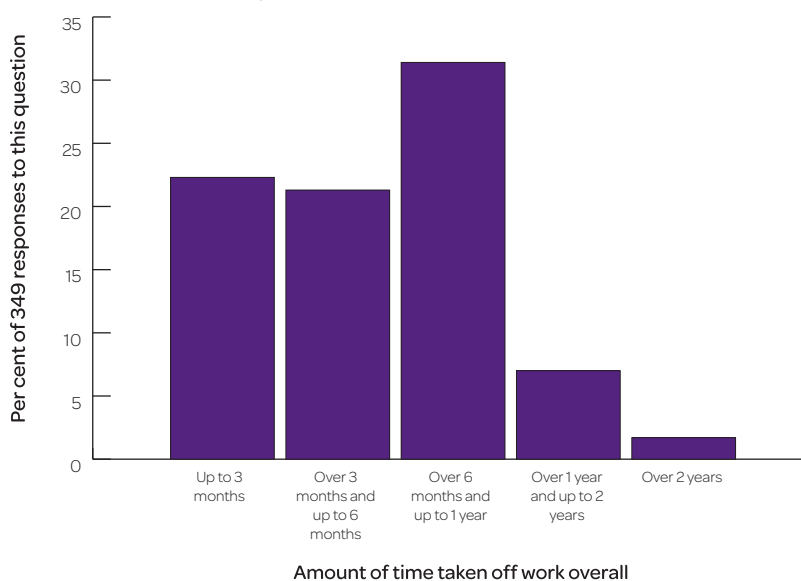
- 91 per cent had surgery (381 respondents)
- 73 per cent received hormone therapy (303 respondents)
- 70 per cent received radiotherapy (293 respondents)
- 66 per cent received chemotherapy (277 respondents)
- 3 per cent received Herceptin, a form of targeted therapy (13 respondents)
- 31 per cent of respondents had had breast reconstructive surgery (131 respondents).

The variety of individual experiences of breast cancer is reflected in variations in overall time taken off by respondents to our survey due to breast cancer. The time ranged from one week to

five years. Survey respondents were asked to approximate the amount of time they had taken off work. It is important to note that the times given may not represent one continuous period, but rather time off built up over different periods of treatment.

- 22 per cent took up to 3 months (93 respondents)
- 21 per cent took over 3 and up to 6 months (89 respondents)
- 31 per cent took over 6 months and up to 1 year (131 respondents)
- 7 per cent took over 1 year and up to 2 years (29 respondents)
- 2 per cent took over 2 years off (7 respondents)
- 16 per cent (68 respondents) chose not to answer this question.

Figure 4: How much time have you taken off work due to breast cancer



Given the variety of individual experiences of breast cancer, it is imperative that an employer takes the time to listen to, understand and accommodate an individual's situation. The following sections provide information from our survey on how different types of treatment may affect an individual's ability to work.

**'If I had to advise an employer about dealing with people going through cancer treatment I would say, "don't make assumptions". Everyone is different. Don't assume that the person will want to take six or nine months off work, but don't assume they won't, and don't assume that the issues will be the same throughout the period of treatment. The different parts of the treatment bring different challenges.'**

## Surgery

44 per cent of respondents (185 respondents) returned to work immediately after breast surgery. When asked to indicate their main reasons for returning to work, the most common reason chosen was 'I felt able and wanted to return to work' (163 respondents). This suggested that their return to work following surgery was a positive and individually-owned decision. A significant proportion of respondents (140 respondents) chose to add comments about their return to work after surgery. The three most common themes to emerge from these comments were:

- returning to work was phased-in or gradual after surgery or they were able to start back on part-time hours (31 respondents)
- returning to work was a welcome return to their normal routine (26 respondents)
- having a supportive employer was a key factor in making it easier to return to work following surgery (21 respondents).

**'I felt the need to normalise the situation. When you have a life threatening disease it can take over every aspect of your life and deny you who you are! Working kept me focused on who I was.'**

However, some respondents (18 respondents) indicated that they were exhausted when returning to work or that they had returned too soon.

28 per cent of survey respondents (117 respondents) indicated that they had not returned to work, as they were awaiting treatment. 19 per cent (80 respondents) chose option 'Other' and their comments included references to taking retirement, being made redundant or choosing to take some time off. 35 respondents (8 per cent) did not answer this question.

## Chemotherapy and radiotherapy

Responses to the survey highlighted how chemotherapy can affect people in different ways, with varying impact on their ability to work. Some people undergoing chemotherapy are unable to carry out their usual activities due to the severity of side effects they experience, while some people are able to do less than they would usually. Some people, however, experience very few side effects and feel able to carry on as before.

Reactions to radiotherapy also range greatly. Some patients may find fatigue caused by the treatment itself and the daily travel to the hospital overwhelming, while others may find that, apart from the time taken out for receiving treatment, it had minimal impact on their ability to carry out day-to-day activities.

**'I could not work during chemo as it put me into bed for a week each time... During radiotherapy I had to travel 45 mins to and from the hospital each day. I was tired so could not work.'**

**'I was working through my chemo and felt extremely well, I managed to hold down my 2 jobs...and also much to my surprise was back teaching my Aerobic classes.'**

169 survey respondents commented on the impact of chemotherapy or radiotherapy on their ability to work. Of those:

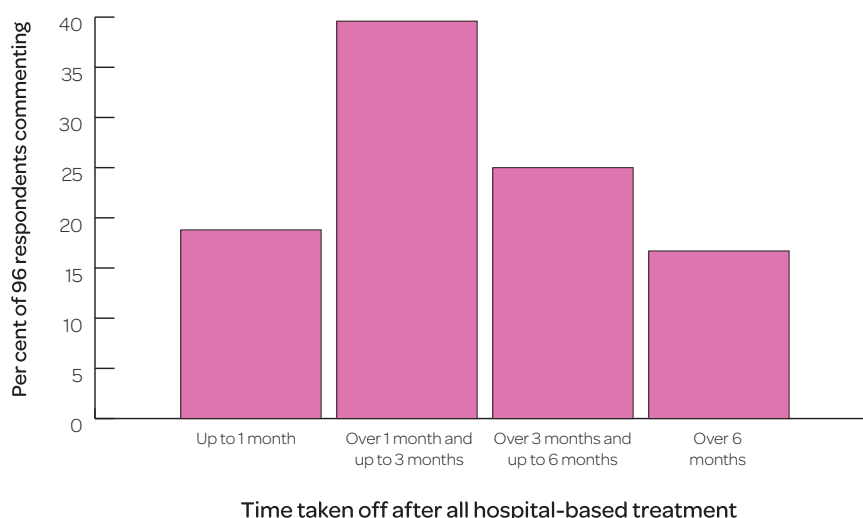
- the majority, 63 per cent, reported feeling too exhausted to be able to work during their treatment (106 respondents)
- 19.5 per cent were able to work on reduced hours or from home (33 respondents)
- 6.5 per cent were able to work as they only experienced minor side effects from treatment (11 respondents)
- 5 per cent of respondents were not able to work due to risk of infection (9 respondents)
- 4 per cent reported that they were able to work between treatments (7 respondents)
- 1 per cent claimed that were not able to work, as their employer did not want to offer any flexibility (2 respondents)
- 0.6 percent had to work for financial reasons (1 respondent).

**'The impact of chemotherapy and radiotherapy made me feel so tired I was physically and mentally unable to work. Without the financial support from my parents I dread to think that I may have had to return to work for financial reasons. I was very lucky. I don't know how I would have coped.'**

## On completion of all hospital based treatments for breast cancer

41 per cent of respondents (172 respondents) returned to work straight away after completing all hospital based treatment, for example surgery, chemotherapy, radiotherapy. 28 per cent of respondents (117 respondents) took time off and 96 of them provided us with their comments about the amount of time taken off after hospital treatment. The times given ranged between 10 days and 15 months (see Figure 5 for more details).

Figure 5: How much time did you take off after all hospital based treatment



A further 2 per cent of respondents (7 respondents) decided on a career change after the completion of hospital treatment. 16.5 per cent of respondents (69 respondents) chose option 'Other' and comments given here included references to retiring and being made redundant. 52 respondents (12.5 per cent) chose not to answer this question.

## The role of the employer

The role of the employer in supporting a staff member who has had a diagnosis of breast cancer is crucial in enabling them to continue working during treatment or to return to work following treatment. Getting this right is important for the individual employee to help them manage the pressures of work after a cancer diagnosis. Managing the employee appropriately is also important for an employer in order to retain valued staff and send out a positive internal message to other employees that they are working for a caring and responsible organisation.

**'The support from my employer was crucial for two reasons: firstly I could take time off without any financial loss and secondly I felt valued and this was a positive message so much needed at that time.'**

**'I was expected to work full-time and under a lot of stress/time pressures – I was also threatened with termination of employment if I did not return to work soon.'**

62 per cent of respondents (259 respondents) reported that their employer was supportive during their treatment and 57 per cent (239 respondents) indicated that their employer was supportive after treatment. Only 3 per cent of respondents said they had not been given appropriate time off by their employer/line manager for medical appointments (13 respondents). However, when asked about specific good practice measures, few respondents indicated that these were being put into action by their employer.

**'My employers were so supportive that I felt well sooner, because I was under no pressure to return to work [this] made a big difference. My manager stressed that my health was paramount and said to come back on a part time basis. My salary was not affected by this.'**

The survey asked questions on the following areas of good practice in the workplace: regular meetings between the employer and employee and easy access to an occupational health officer or Human Resources (HR) officer.

- Only 19 per cent of respondents had regular meetings with their employer during treatment to discuss how best to manage their workload during their treatment (81 respondents)
- Only 23 per cent of respondents had such regular meetings with their employer after treatment (97 respondents)
- Only 20 per cent of respondents reported that they had easy access to an occupational health officer or HR officer to discuss work-related issues during their treatment (85 respondents)
- Only 23 per cent of respondents said they had such access after their treatment (95 respondents).

## Financial pressures

A diagnosis of breast cancer can have a significant impact on the finances of an individual and their family. There are a number of issues that can contribute to this such as time off work, the cost of travel to treatment and the cost of prescriptions for long-term treatments such as hormone therapy. Research by Macmillan Cancer Support (2006) found that nine out of 10 cancer patients' households suffer loss of income and/or increased costs as a direct result of cancer.

In light of this, a particularly worrying survey finding was that 19 per cent of respondents (80 respondents) reported that their employer's attitude had a negative impact on their ability to cope financially, for example through a lack of extended paid sick leave or paid time off for medical appointments. The three most common themes emerging from comments were:

- that some employees had felt forced to work for financial reasons when they were unfit
- some employees had no paid sick leave and this put them into financial hardship
- some had their pay reduced while they were on sick leave and so they had to return to work earlier than they wished.

**'I am entitled to six months' full pay and six months' half pay whilst off sick. I did not really feel well enough to return after four months, but wanted to keep the option open for another two months' full pay in case I was ill again at a later date.'**

## Attitude of colleagues

Working in an environment where colleagues and managers are sympathetic and supportive, yet at the same time respectful of privacy, can contribute greatly to an employee's ability to cope with work following a diagnosis of breast cancer and while undergoing treatment. It is crucial that arrangements for the transfer of the employee's work during sickness absence or a period of reduced working hours are effectively managed so that colleagues do not themselves become unwell with stress and anxiety by taking on extra work.

The majority of respondents to our survey had chosen to tell their work colleagues about their breast cancer diagnosis. 50 per cent of respondents (210 respondents) had told all their colleagues at work about their cancer diagnosis and 25 per cent (104 respondents) indicated

that they had told their close colleagues only. Only 2 per cent (8 respondents) indicated that they had not told colleagues about their diagnosis. The remaining respondents (23 per cent; 95 respondents) did not reply to this question.

It is very encouraging that the majority of respondents to our survey had not found the reaction of their co-workers to their diagnosis problematic. 66 per cent of respondents (273 respondents) reported that their work colleagues had been very supportive when they disclosed their condition. However, others felt that colleagues did not understand what having breast cancer means (12 per cent; 50 respondents), that colleagues had been gossiping about them (4 per cent; 17 respondents), or that they were stigmatised at work because of their breast cancer diagnosis (1 per cent; 5 respondents). It is important to note that when it occurs, being the subject of workplace gossip or feeling stigmatised by co-workers is very distressing and can have a considerable impact on an employee's ability to continue in work or return to work after a diagnosis of breast cancer. 17 per cent of survey respondents (72 respondents) chose not to answer this question.

**'I found that my peers expected me to return to work at full pace not appreciating the difficulty of three hours travelling per day (on crowded commuter trains), catching up with the work and trying to work effectively, as well as the physical effects of radiotherapy.'**

## Discrimination at work and the law

The Disability Discrimination Act (DDA) has been in force since 1996. The Act was amended in December 2005 to give legal rights to people with cancer as soon as they have it. (See page 4 for more background to the DDA.) It seems likely that people affected by breast cancer who are aware of their legal rights in employment would be more confident in responding to incidents of discrimination and better informed to put forward constructive suggestions for reasonable work adjustments.

**'I do not think most people consider cancer as something that is covered by the Act [Disability Discrimination Act] so there is a need to raise awareness of this point. Leaflets and guidance seems to assume that you will be off work when you are having treatment so don't cover it. There is a need for specific guidance for people who want to work.'**

**'Because I knew about Disability Discrimination legislation I felt very confident about being very honest on an application form for my current part time work.'**

It was encouraging to find that only 0.5 per cent of respondents (2 respondents) to our survey reported that they were discriminated against at work during their breast cancer treatment and only 3 per cent (13 respondents) responded that they were discriminated against after their treatment. These low numbers, however, could be related to employees being unaware of their rights at work and what constitutes unlawful discrimination. It is very concerning to discover that the majority of respondents to our 2006 survey, 61 per cent (256 respondents), were not aware of their rights under the DDA in relation to employment. A short poll carried out via our website in early 2008 suggested that awareness remains low more than two years after the Act was amended. Out of 102 respondents to our 2008 online poll, 69 (68 per cent) were not aware of their employment rights under the DDA.

Our 2006 survey asked about specific examples of discrimination. The number of examples given was low but was higher than the number of respondents who replied that they had been discriminated against. This perhaps suggests that respondents did not regard or recognise these examples as discrimination.

- 5 per cent reported that their job role has been changed without consultation with them during their treatment (19 respondents)
- 4 per cent reported that their job role had been changed without consultation with them after their treatment (15 respondents)
- 3 per cent reported that their role within their organisation was undermined and they were treated as if they couldn't do the job during their treatment (12 respondents)
- 6 per cent reported that their role within their organisation was undermined and they were treated as if they couldn't do the job after their treatment (23 respondents)
- 2 per cent reported they have been excluded from promotion opportunities during their treatment (7 respondents)
- 4 per cent reported they have been excluded from promotion opportunities after their treatment (18 respondents).

## Reasonable work adjustments

Employers are required by law to make reasonable adjustments to ensure that people with cancer are not at a substantial disadvantage at work compared to other people. These adjustments can be to all aspects of the employee's work. Examples of reasonable adjustments for an employee affected by breast cancer could include the following.

- Phased (or gradual) return to work after time off sick.
- Allowing an employee time off to attend medical appointments in relation to breast cancer or lymphoedema.
- Introducing flexible working to allow an employee to attend a breast cancer emotional or practical support service, such as a support group, prosthesis fitting or hair loss service, during normal working hours.
- Allowing an employee extra breaks during work to cope with fatigue or menopausal symptoms caused by breast cancer treatment.
- Removing any manual handling tasks from an employee's job description if an employee's lymphoedema symptoms affect their ability to do these tasks, or supplying new equipment so an employee is able to continue with relevant tasks without lifting or stretching the affected arm. An employee's ability to do repetitive lifting and manual handling tasks may also be restricted for some time after breast reconstruction surgery.
- Exploring different adjustments to the immediate workstation, work premises or the employee's role if that employee has developed mobility impairments through their breast cancer (for example, caused by secondary breast cancer in the bone).

An employer is only required to make such work adjustments as are reasonable. In considering whether an adjustment should be deemed as 'reasonable' under the DDA, the Department for Work and Pensions (DWP) and the Equality and Human Rights Commission provides guidance on the factors that should be taken into account. See [www.dwp.gov.uk](http://www.dwp.gov.uk) or [www.equalityhumanrights.com](http://www.equalityhumanrights.com) for more information.

Only 24 per cent of survey respondents (101 respondents) reported having had work adjustments made during their treatment and only 32 per cent of respondents had had work adjustments made after treatment (132 respondents). This low number might be linked to low awareness of rights under the DDA meaning respondents were not aware of what adjustments they could reasonably request. Also some respondents might not have felt that they needed to have their work adjusted in any way.

**'I was diagnosed with secondary bone cancer [secondary breast cancer in the bone]. My office at work was on the second floor and no lift available. No effort was made by my employer to relocate me.'**

Only 50 per cent of respondents (208 respondents) indicated that they were offered a phased (gradual) return to work by their employer. This would usually be an example of a reasonable work adjustment that might be required by some employees after time off due to breast cancer.

**'My employer was very helpful and supportive. Along with occupational health, we agreed on a "getting back to work" programme which specified hours of work and which tasks should be undertaken on a gradual basis.'**

## Decisions about work after a diagnosis of secondary breast cancer

The term primary breast cancer describes breast cancer that is only found in the breast area. Secondary, or metastatic, breast cancer occurs when breast cancer cells spread to other parts of the body. A diagnosis of secondary breast cancer means that the cancer cannot be cured, although it can be treated and controlled, sometimes for years.

The emotional impact of a secondary breast cancer diagnosis, the side effects of treatment and the physical symptoms vary from person to person and can have a significant impact on employment, often being very different to that of primary breast cancer. For more information see our booklet **Secondary Breast Cancer**.

Out of the 37 respondents to our survey who indicated that they had had a diagnosis of secondary breast cancer, 10 did not continue to work. Of the 27 who continued to work, 10 did so with reduced working hours.

Results from the survey, and from the focus group carried out with people with secondary breast cancer, indicated that decisions about whether to continue working after a secondary breast cancer diagnosis vary from person to person. In general, responses fell into the following three main groups.

- Some employees are physically and emotionally able to return to work and wish to do so to regain a sense of normality in their lives.

**'Work has been a sanity saver for me.'**

- Some feel that the importance of work in their lives has diminished and it is more important to them to retire early on health grounds and spend more time with their family and friends.

**'I am still quite fit and healthy and really nothing has changed in terms of my ability. I don't want to change my life until I have to but I also feel uncertain about whether I should give up or reduce my hours on the basis that I may not have much time left to do things.'**

- Some are unable to continue to work due to the physical and/or emotional impact of the diagnosis and are compelled to retire for medical reasons.

**‘Alongside the physical aspect of my secondary diagnosis, the psychological and emotional side was enormous and I knew I couldn’t cope with the external stress of work alongside what was going on for me.’**

It is important to note that people with secondary breast cancer who choose to, and are able to, continue working are likely to require adjustments to their working patterns. For example, they may need to work reduced hours, work at home for part or all of their hours, or take on more flexible working arrangements. Employees affected by secondary breast cancer may also require physical adjustments to their immediate working area and adjustments to enable them to access workplace facilities, such as toilets, a canteen or meeting spaces.

## Our calls to action

Our calls to action for employers are encompassed in the publication of the EMPLOY Charter (see the charter text on page 3), Breast Cancer Care’s guide to best practice in the workplace.

In addition to the charter, Breast Cancer Care is calling for the following:

**Breast cancer patients should be signposted to sources of employment-related and financial information and support, including the EMPLOY Charter, by breast care nurses or other health professionals involved in their care.**

Health professionals play an important role in signposting patients to sources of practical and emotional support and information. It is important that the area of employment and finance is not overlooked and that patients are pointed towards sources of information in this area, for example from the Department for Work and Pensions, the Equality and Human Rights Commission and voluntary sector organisations.

Health professionals could also play an important role in raising awareness of the significance of the Disability Discrimination Act among cancer patients by letting them know at the point of diagnosis that they have rights under the disability discrimination law and signposting patients to sources of specialist advice and information.

**UK Governments and Governmental Departments should work together to raise awareness of the DDA among employers and cancer patients.**

The majority of employers and employees appear to be unaware of the relevance of the DDA to cancer. The Department for Work and Pensions, the Department of Health, the Scottish Government and the Welsh Assembly Government are currently successfully collaborating through the *Health Work Wellbeing* initiative to promote the health benefits of work. It is time for these Departments and Governments to work together to raise awareness of the DDA among employers and cancer patients.

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Breast Cancer Care is here for anyone affected by breast cancer. We bring people together, provide information and support, and campaign for improved standards of care. We use our understanding of people's experience of breast cancer and our professional expertise in everything we do. Visit [www.breastcancercare.org.uk](http://www.breastcancercare.org.uk) or call our free helpline on **0808 800 6000** (for Typetalk prefix **18001**).

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