

Work and cancer

How cancer affects working lives

February 2005

cancerBACUP
helping people live with cancer



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Foreword

Every year approximately 90,000 people of working age in the UK receive a new cancer diagnosis. The potential impact on the working life of our country is substantial – more than 500,000 people in the UK under the age of 65 have been diagnosed with cancer at some point in their lives. These figures are expected to rise, largely as a result of our ageing population: our risk of cancer increases with age.

Current projections suggest that by 2006, 45–59 year olds will form the largest group in the labour force. For Government and employers, this means an increased need to maintain the employability of older workers and a need to maintain the relevance of their skills – the experiences of older workers will become relatively more important to workforce performance as a whole. For many, those experiences will be affected by cancer.

Thankfully, as cancer treatments improve, more people are surviving the disease and continuing or resuming their everyday lives, including their working lives. In my own experience I have met very few employees with cancer who do not want to resume as normal a working life for as long as possible. Very few hide their heads under the metaphorical bedcovers and hope that it will all simply go away. In fact, research shows that people who have had treatment for cancer are as productive as people who have not had cancer, they take less time off work than other employees and, in general, they perform well in the workplace. Most employees with cancer also believe that continuing to work is important to them and vital to their self-esteem.

As this report shows, the world of work is broadly sympathetic to employees who develop cancer. People feel able to discuss cancer in the workplace; baseline practices are in place; and colleagues and line managers are greatly supportive of employees diagnosed with and treated for cancer.

Sadly, however, this report also shows that too many employees drop out of the labour market following cancer treatment. While for some this is necessarily related to the severity of the cancer and its symptoms, for others it is due to isolation, loss of self-esteem and lack of confidence in their ability to work effectively.

This report increases our understanding of why this happens. According to its findings, too few organisations are offering flexible working and return to work policies to support employees with cancer; too few are making sure employees are aware of such policies or that they are implemented. Information on statutory rights, organisational benefits and other important forms of support is sadly lacking.

Even the language we use, however well-meaning, can be unhelpful for employees with cancer who are trying to resume their working lives. People affected by cancer are not 'sufferers' and they are not 'battling' or 'fighting' the disease, any more than someone with

diabetes is. For example, when a prominent person dies, the press often characterises this as 'losing the battle' against cancer. This is very unhelpful, since it implies that the patient is to blame if the disease prevails. A good attitude will certainly help everyone, the patient, family and friends, to live with the illness, and going to work is part of that.

Without these shifts in attitude and working practices, employees with cancer will not feel valued or assisted by their organisation as a whole in managing their cancer in the workplace and in returning to work after treatment. Good employers who recognise the importance of retaining increasingly valuable members of their workforce will want to improve their own performance in this area. They will also be encouraged to do so by the amended Disability Discrimination Act due in October this year which is likely to cover almost all cancer patients from the point of diagnosis.

This report recommends practical measures to ensure employees with cancer are supported in the workplace and assisted in returning to employment should they so wish, as so many do. I would encourage employers to take note of its findings and implement its recommendations without delay.



Alastair Ross Goobey, CBE

Governor of the Wellcome Trust and Deputy Chairman of GWR Group plc

CancerBACUP Trustee

Executive summary

1. This report presents the findings of new research into how cancer affects working lives. It outlines previous research into the subject; the background to this report; and discusses the methods and results of a CancerBACUP survey of employees currently or previously affected by cancer. The report draws conclusions from the research and ends with a series of recommendations for policymakers, health professionals and employers, together with tips on good practice for employers and advice for employees. Research was undertaken by CancerBACUP working in association with researchers at Goldsmiths College, University of London and at the University of Nottingham.
2. Each year approximately 90,000 people of working age receive a new cancer diagnosis. More than half a million people in the UK under the age of 65 have been diagnosed with cancer at some point in their lives¹. With continuing progress in diagnosis and treatment, more people are surviving the disease, continuing or resuming their everyday lives, including their working lives, during or following treatment. For cancer patients of working age, the survival rates are generally higher than for the elderly².
3. Current projections suggest that by 2006, 45–59 year olds will form the largest group in the labour force³. This means that the experiences of this age group will become relatively more important for the workforce as a whole. As cancer risk increases with age⁴, a greater proportion of the future workforce will therefore be affected by the disease. Cancer is, therefore, an issue for the employer and the workplace.
4. Previous research has shown that people who have treatment for cancer are as productive as people who have not had cancer⁵, that they take less time off work than other employees⁶ and that, in general, they perform well in the workplace⁷.
5. Many people with cancer are already covered by disability discrimination legislation and from October 2005 it is likely that almost all cancer patients will be protected from discrimination in the workplace and in other parts of everyday life from the point of diagnosis under the amended Disability Discrimination Act. However, the Government currently plans to exempt certain cancers from extended protection.
6. Recent research, however, indicates that a third of employers are not aware that employees with cancer may be protected under the current Disability Discrimination Act⁸. In addition, only 15% of respondents to CancerBACUP's survey were aware that more cancer patients are likely to receive protection under the amended Act. If employers and employees are unaware of the provisions of the amended legislation, it is unlikely to be implemented.
7. Anecdotal evidence gathered on CancerBACUP's helpline suggests that common

issues raised by employees affected by cancer include: anxiety about whether to disclose their illness to their employer; a fear of being victimised; a lack of confidence in talking to colleagues about cancer; guilt at taking time off; a lack of awareness about legal rights and entitlements; financial hardship; difficulty getting time off for treatment and coping with side effects after treatment has ended.

8. CancerBACUP's survey on Cancer and Work attempted to test this anecdotal evidence by gathering data from employees on their experiences of managing cancer and work and on the adequacy of information and support provided to them regarding work-related issues.
9. Survey results show that over half (58%) of employees with cancer are keen to continue working. 51% say it is important to their self-esteem; and 45% are glad to have an area of their life (ie work) that is relatively normal. The majority of employees with cancer (over 70%) feel well supported by their line managers and colleagues, reveal that they have cancer to their line managers and feel able to talk about it at work.
10. In addition, baseline support for employees with cancer is in place, with a large majority being offered paid time off to attend all medical appointments and extended sick leave.
11. Despite this, survey results show that cancer has a negative effect on employment patterns and on an individual's financial stability. Nearly a third of respondents (31%) do not return to work following treatment and nearly two thirds (61%) experience financial difficulties. While this withdrawal from the labour market can, for some, be related to the severity of the cancer and its symptoms, for others it is due to a loss of self-esteem and confidence.
12. More than a third of employees (41%) say that their working life has deteriorated as a result of their cancer. More than a third (37%) say that their career prospects have deteriorated and 40% say they felt out of touch with work during their treatment. More than a quarter (29%) say their job satisfaction has deteriorated; approximately the same number (30%) say that they have lost confidence in their ability to do their job, and feel guilty when taking time off for medical appointments and treatment. A quarter of all respondents (25%) say they fear disclosing their cancer to a new employer. The reasons for these findings can be found in the rest of the survey results.
13. A large majority of respondents (84%) find the side effects of cancer treatment difficult to manage in the workplace. More than two thirds (67%) find fatigue alone most difficult to manage during treatment followed by loss of concentration and nausea/sickness; fatigue, stress and emotional distress are difficult to manage at work *following* treatment. Yet more than half of respondents (56%) have not been advised by their cancer doctor about how their treatment will affect their ability to work.

Those left in the dark are less able to talk about their cancer at work and, as a result, may have unrealistic expectations about what they can do, and are less able to ask for reasonable adjustments to their work. Further and regular guidance and support is needed from health professions to employees with cancer on this matter during and following treatment. These issues need to be better understood by employers to inform their management of employees with cancer. (See Recommendations page 28)

- 14.** Less than a fifth (18%) of employees with cancer are offered information by their employer about managing work issues associated with their cancer, yet those who do not receive it are nearly four times more likely to report that their working life has deteriorated than those who do receive it. Respondents who have been offered this information are over three times more likely to feel able to talk about their cancer at work. The provision of information in the workplace about managing work issues associated with cancer is crucial.
- 15.** Information is also lacking and/or of poor quality in a number of other areas: only half (51%) of respondents are offered information about their statutory rights or about any extra organisational benefits offered by their employer (50%). Only 14% are offered information about how to talk about cancer to their colleagues. Just under half of respondents (46%) judge that the information they are given by their employer is either poor, or very poor. Despite this, less than a third (30%) are directed towards other sources of information and support.
- 16.** Flexible working practices and practical support on managing work issues are crucial for employees with cancer and are also in need of improvement. Only half (51%) of respondents are offered regular consultations about managing their workload during treatment; only a quarter (28%) are offered support in managing work issues associated with their cancer. Less than half (42%) are offered work adjustment policies or alternative working arrangements (46%); more than a third (40%) are not offered a return to work meeting with their employer. Just under a quarter (24%) are offered support in discussing their cancer with their colleagues; less than a third (30%) are offered counselling.
- 17.** This type of support is pivotal: those respondents reporting that their working life has deteriorated as a result of their cancer are less likely to have received the above means of support; those who were not offered flexible/alternative working arrangements were fifteen times more likely to experience significant financial difficulties as a result of their cancer.
- 18.** In addition, some respondents report very poor organisational practices: 2% say they have experienced direct discrimination; 6% report they have been overlooked for promotion; and 2% have felt pressure to resign. However, many employees are not aware of their entitlements under the law at present or under the expected

amendments of the Disability Discrimination Act.

19. Many organisations are struggling to provide the information, support and flexibility employees with cancer need if they wish to continue or return to work during or following treatment. Line managers and colleagues provide good support to employees with cancer but there is a lack of support for all concerned from organisational policies, practices and information provision. Support therefore seems to be dependent on individual relationships between line managers and colleagues.
20. Flexible working, return to work policies and the provision of comprehensive, high-quality information and support for employees with cancer need to be enshrined in organisational policy, championed by senior managers and made part of the culture of an organisation if they are to be accessible and fair, and if employees with cancer are to feel more confident about managing their cancer in the workplace and returning to work following treatment. Improved information and support is also needed for line managers and colleagues working alongside employees with cancer. (See Recommendations page 28)
21. In addition, all cancer patients should be protected from discrimination from the point of diagnosis under the amended Disability Discrimination Act. Policymakers should ensure that a targeted education campaign raises awareness of the provisions of the new amended Act in the workplace and in healthcare settings. (See Recommendations page 28)
22. Employees should check the occupational sick pay and any medical benefits offered by prospective employers. They should ask for information about flexible work policies and return to work policies on offer.

Background

1

Introduction

Each year approximately 90,000 people of working age receive a new cancer diagnosis. More than half a million people in the UK under the age of 65 have been diagnosed with cancer at some point in their lives⁹. With continuing progress in diagnosis and treatment, more people are surviving the disease, continuing or resuming their everyday lives, including their working lives, during or following treatment. Cancer is, therefore, an issue for the employer and the workplace.

1.1

Legislation and cancer

Many people with cancer are already covered by disability discrimination legislation and from October 2005 it is likely that almost all cancer patients will be automatically protected from discrimination in the workplace and in other parts of everyday life under the amended Disability Discrimination Act (DDA).

1.2

Under the current (as at February 2005) definition, cancer patients only count as disabled once their cancer starts to have a substantial and long-term adverse effect on their day-to-day activities (although the rules for progressive diseases generally are slightly more flexible). The Disability Discrimination Act will change this so that almost all cancer patients are covered by the DDA from the point at which they are diagnosed. More information on this can be found in section 8.1 of this report.

However, the Government is currently proposing to reserve the right (by regulations) to exempt certain types of cancer from protection from the point of diagnosis. The Government intends to exclude the following cancers as they feel these are the most common cancers which are considered not to normally require substantial treatment:

- basal cell carcinomas (Rodent Ulcers)
- most squamous cell carcinomas of the skin
- Bowen's Disease
- in-situ skin cancers (ones which do not affect the full skin thickness and can be treated easily and simply)
- in-situ cancer of the cervix uteri which it is likely can be treated successfully and fully by cone biopsy.

The Government estimates that an additional 145,000 people with cancer will gain protection each year from the new clause. However approximately 83,000 people newly diagnosed with cancer each year will not have protection from the point of diagnosis because their type of cancer does not require substantial treatment.

1.3

Business and cancer

Effective management strategies to support employees with chronic illnesses have been found to reduce long-term sickness absence and staff turnover, improve productivity and staff morale, and minimise the loss of experienced and highly skilled workers¹⁰. Furthermore, placing a focus on retention – through providing work adjustments and flexible working opportunities – has been found to reduce rehabilitation costs.

Labour markets are becoming more competitive and projections indicate that in ten years time there will be two million more jobs in the economy¹¹. Current projections suggest that by 2006, 45–59 year olds will form the largest group in the labour force¹². This means that the experiences of this age group will become relatively more important for the workforce as a whole. As cancer risk increases with age, a greater proportion of the future workforce will therefore be affected by the disease¹³. At the same time, survival rates for cancer patients of working age are generally higher than for the elderly¹⁴.

Before diagnosis many cancer patients make effective contributions to the workforce and, as treatments continue to develop, they are increasingly able to contribute during and following treatment. By supporting people through and after their treatment, employers are less likely to lose valuable employees.

Research has shown that people who have had treatment for cancer are as productive as people who have not had cancer¹⁵, that they take less time off work than other employees¹⁶, and that, in general, they perform well in the workplace¹⁷. Recent figures suggest that approximately 67% of cancer patients in the US return to work following treatment¹⁸ with similar patterns found across European countries.

The incentive for employers to improve their support for employees with cancer could not be greater.

1.4

Cancer in the workplace – anecdotal evidence

Callers to CancerBACUP's helpline regularly raise concerns about how their cancer is affecting their employment. Anecdotal evidence gathered by the helpline nurses suggests that common issues raised by employees affected by cancer include: anxiety about whether to disclose their illness to their employer; a fear of being victimised; a lack of confidence in talking to colleagues about cancer; guilt at taking time off; a lack of awareness about legal rights and entitlements; financial hardship; difficulty getting time off for treatment; and coping with side effects after treatment has ended.

Cancer in the workplace – formal research

1.5

Little is known about the specific work-related needs of cancer patients and those working along side them (e.g. employers, line managers, co-workers and occupational health professionals).

Research within the area of rehabilitation and chronic illness has identified that where patients are provided with effective support – emotional support and tangible adjustments to the way in which their work is designed, organised and managed – they are better positioned to continue to work and manage their illness at work. Little is known, however, about how these experiences compare to those with cancer.

Two studies have indicated that many symptoms associated with cancer and its treatment can represent barriers to continued employment. The first refers to physical factors related to the disease¹⁹; the second identifies the following as work limitations associated with cancer and its treatment: memory loss; fatigue; difficulties concentrating for long periods of time; analysing data, learning new things; and keeping pace with others²⁰.

Recent research also suggests that the ways in which cancer affects an individual's ability to work can be accommodated by a range of adjustments to the design and management of their work. These adjustments fall into three categories – modified physical load, flexibility of hours worked and flexibility of job tasks²¹. These studies, however, rely on small-scale case study research or large-scale studies confined to specific US states.

The role of disclosure in obtaining support during the acceptance of cancer and its treatment is well documented²². Research into the disclosure of stigmatised conditions at work shows that support is contingent on disclosure²³, yet disclosure is contingent on perceived organisational support²⁴. Disclosure has also been found to be encouraged where colleagues already know about the illness and its implications. It has also been found that people are likely to disclose where clear benefits can be gained irrespective of stigmatisation and work culture. There is a need to identify when and how cancer patients tell their employers and their colleagues, and the effect that this has for them in managing their illness.

In the light of CancerBACUP's anecdotal evidence and the need for further research into this area, CancerBACUP decided to carry out its own research. This work was undertaken in partnership with Dr Joanna Pryce and a team of researchers at Goldsmiths College, University of London and Dr Fehmidah Munir, Institute of Work, Health and Organisations, University of Nottingham.

2

Project aims

The overall aims of the research were to:

- provide a better understanding of how cancer affects working lives
- gather data from employees on their experiences of managing cancer and work
- gather data on the adequacy of information provision and support to employees with cancer regarding work-related issues
- provide a research base for recommended improvements
- inform the development of targeted information and supportive work policies.

3

Project methods and demographics of sample

3.1

Participants

1200 paper questionnaires were distributed by CancerBACUP to a random sample of users on the CancerBACUP telephone-support line between August 2004 and January 2005. The survey was also made available online on the CancerBACUP website.

328 responses were received: 210 were on paper, 118 were online.

3.1.1

Gender/ethnicity

The respondents were predominantly female (77%) and the age range of respondents was 18–68 years, with the average (middle) age within the group being 50 years. 84.6% of respondents were White British, White Irish or Other White, while 2.9% were from black and minority ethnic communities. (The remaining percentage did not complete this category.)

Men were under represented in the sample as women make up 46% of the labour market²⁵. Minority ethnic communities were also under represented as they make up 7.9 per cent of the UK population²⁶.

3.1.2

Cancer type and treatment

A wide range of cancers were represented within the respondent sample (102 different types). The most common form of cancer reported amongst our sample was breast cancer (44%), followed by non-Hodgkins Lymphoma (4%), prostate cancer (3%) and cancer of the bowel (2.75%). 58% of respondents were undergoing cancer treatment, 35% had completed treatment.

However, within the UK population generally, breast cancer accounts for 15% of all cancers; lung cancer 14%; large bowel 13%; and prostate 11%. The majority of respondents to our survey were women, which explains why breast cancer was well reported in our study. Other common cancers such as lung, bowel and prostate cancer were not.

The most common form of treatment was surgery (65%: 54% men, 72% women), whilst 59% had received chemotherapy and 52% received radiotherapy. Only 37% of respondents had received oral medication. In total, 24% of respondents had received only one form of treatment, 28% two forms, 28% three forms and 15% all four forms of treatment.

Occupation

The respondents came from diverse industry sectors (incorporating 199 job categories). They were classified as follows:

Professional	12%
Managerial/Technical	19%
Skilled/Operational – non-manual	54%
Skilled/Operational – manual	7%
Part-skilled	7%
Unskilled	Less than 1%

Whilst our sample draws from a wide range of job types, lower skilled jobs are under represented.

In terms of sizes of organisations represented, 6% of respondents were self-employed, 24% worked in small organisations (between 2 and 49 employees), 29% worked in medium-sized organisations (between 50 and 1000 employees) and 34% worked in large organisations (more than 1000 employees) at the time of their diagnosis.

Those working in medium-size companies were slightly over represented in our sample. According to current statistics²⁷, 40% of the UK's organisations are small, 10% are medium, and 50% are large.

Private health insurance

24% of our sample said they were offered private health insurance by their employer. However, this group is over represented in our sample as only 7.85% (4.68 million people) of the population are covered by private health insurance in company schemes²⁸.

3.1.3

3.1.4

3.2

Measures

The survey incorporated cancer-specific, occupation-specific, and demographic items, the issue of revealing a cancer diagnosis to line manager and colleagues, and questions relating to policies and practices at work.

3.3

Analysis

The findings are reported in percentages throughout the report and considered in light of a comprehensive literature review drawing from cancer, chronic health and rehabilitation domains.

While these percentages provide good baseline information and help us to build a picture of the current workplace experiences of cancer patients, the links between workplace supports and key health and employment outcomes are also discussed within this report. These links are calculated using odds ratios.

For example: those who did not receive information about managing work issues associated with cancer were nearly four times more likely to report that their working life had deteriorated as a result of cancer than those who had been given information.

Summary of survey results

4

Key messages

4.1

1. Over half of employees with cancer are keen to continue working

Over half of respondents (58%) said that continuing to work was important to them. 51% said it was important to their self-esteem; 49% said that it was important to have an area of their life (ie work) that was normal.

2. A majority of employers provide paid time off to attend all medical appointments and a majority of employees receive sick leave for longer than the period in which the employee is entitled to receive Statutory Sick Pay

A large majority of respondents (84%) had received paid time off to attend all medical appointments. 89% of large organisations offered this, as did 85% of medium-sized organisations and 76% of small organisations. A majority of respondents (74%) had received sick leave for longer than the period in which the employee is entitled to receive Statutory Sick Pay. Over half (58%) have easy access to occupational health or human resources departments. Most (70%) had been offered fewer or flexible contracted hours.

3. Most employees with cancer feel well-supported by colleagues and immediate line managers

One of the most positive results of the survey was that a large majority of respondents felt they had received good support from their colleagues (77%) and immediate line manager (74%) during cancer treatment.

4. Most employees with cancer are able to reveal and talk about their cancer in the workplace

A large majority of respondents had revealed the fact that they had cancer to their line manager (88%) and to their colleagues (86%). A higher proportion of women (92%) than men (78%) said this. Most had told their line managers because they needed time off for appointments; most had told their colleagues because they believed they could offer emotional support. A majority of respondents (72%) said they felt able to talk about their cancer at work. Most employees experienced anxiety before revealing their cancer to their line manager and colleagues (63% and 61% respectively).

5. Despite this, cancer has a negative impact on employment patterns. There is a significant drop in the number of employees with cancer returning to work following cancer treatment

Despite the above findings, there was a significant drop in the number of people returning

to work – overall 31% did not go back to work following treatment. The percentage of those working full-time fell from 59% before treatment to 35% after treatment.

6. A significant proportion of employees with cancer find that their working life has deteriorated as a result of their cancer. Many, particularly women, lose confidence, feel out of touch, and feel guilty at taking time off

More than a third of respondents (41%) said their overall working life had deteriorated as a result of their cancer and more than a third (37%) said their career prospects had deteriorated. More than a quarter (29%) said their job satisfaction had deteriorated. 25% of cancer patients said they feared disclosing their cancer to a new employer.

In addition, more than a third (40%) of respondents said that they felt out of touch with work during their cancer treatment. 43% of women said this compared to 32% of men. Just under a third (30%) of respondents felt guilty about taking time off for medical appointments and treatment. 33% of women said this, compared to 21% of men. Just under a third (30%) felt they had lost confidence in their ability to do their job during cancer treatment. More than twice as many women said this (35%) as men (15%).

7. Many employees with cancer experience significant financial difficulties as a result of their cancer

Nearly two thirds of respondents (61%) had experienced financial difficulties as a result of the impact of cancer on their work. More than a third (36%) had experienced significant financial difficulties. The findings reflect those of a survey carried out by cancer charity Macmillan Cancer Relief in 2003, which reported that 77% of cancer patients said their cancer had led to financial difficulties²⁹.

8. A large proportion of employees with cancer are not being advised by their cancer doctor about how their treatment will affect their ability to work and are struggling to manage side effects in the workplace during and following treatment

More than half of respondents (54%) had not been advised by their cancer doctor about how their cancer treatment would affect their ability to work.

A huge majority (84%) found it difficult to manage the side effects at work during treatment and more than half (54%) found it difficult to manage the side effects at work *following* treatment. Of those side effects, most people found fatigue difficult to manage during (67%) and following (41%) treatment.

Many also found loss of concentration (41%) and nausea/sickness (40%) difficult to manage during treatment; stress (27%) and emotional distress (24%) were commonly reported following treatment.

Those respondents who have been offered information of this kind by their cancer doctor were twice as likely to be able to talk about their cancer in the workplace.

9. Most employees with cancer are not being offered work adjustment policies or flexible/alternative working arrangements to help them manage their cancer in the workplace. Return to work policies are also lacking

Less than half (46%) had been offered flexible or alternative working arrangements or work adjustment policies (42%). Only half (51%) were offered regular consultation about managing their workload during their cancer treatment. More than a third (40%) had not been offered a return to work meeting with their employer. Only 10% of respondents had received physical adjustments to their work environment.

Such policies are crucial to respondents' experiences of working life. Those who reported that their working life and career prospects had deteriorated as a result of their cancer were significantly less likely to have received regular consultations about managing their workload; alternative working arrangements; adjustments to their working hours; or return to work interviews.

Those respondents who were not offered alternative working arrangements during and following their treatment were up to fifteen times more likely to experience significant financial difficulties.

10. Half of employees with cancer are not being offered information about their statutory rights or about extra organisational services

Only half (51%) of respondents had been offered information about their statutory rights or about any extra organisational services offered by their employer (50%).

11. Most employees with cancer are not offered information and support to manage their cancer in the workplace; the information that is offered is of poor quality

Less than a fifth (18%) of respondents had been offered information about managing work issues associated with their cancer. Only 14% had been offered information on how to talk about cancer to their colleagues; only a quarter (25%) had been offered support in doing so. Just under half (46%) thought that the information they were given was either poor or very poor. Less than a third (30%) had been offered counselling. Yet despite this lack of advice and support offered by employers, less than a third (30%) had been directed towards other sources of information and support.

Those who did not receive information about managing work issues associated with their cancer were nearly four times more likely to report that their working life had deteriorated as a result of their cancer.

Those who had been offered information about managing work issues associated with cancer were over three times more likely to feel able to talk about their cancer at work

12. Nearly a quarter of employees with cancer have access to private health insurance through their employer

24% of respondents said they had been offered private health insurance by their employer. 20% of large organisations had offered this, compared to 30% of medium-sized organisations and 17% of small organisations.

13. Some employees with cancer experience direct discrimination in the workplace

Some respondents reported very poor organisational practices: 2% said they had experienced direct discrimination; 6% reported they had been overlooked for promotion; 7% had received changes to their job without their agreement; and 2% had felt pressure to resign.

14. Most employees with cancer are not aware that most cancer patients are likely to be protected under the amended Disability Discrimination Act

Only 15% of respondents were aware that more cancer patients are likely to receive protection from discrimination under the new Disability Discrimination Act.

5

Detailed results of survey

5.1

The impact of cancer on employment patterns

- 59% of respondents were working full-time before their cancer treatment. Only 15% continued to work full-time during treatment and 35% worked full-time afterwards.
- 27% of respondents were working part-time before their cancer treatment. 19% worked part-time during their cancer treatment and 29% worked part-time work afterwards.
- 43% of respondents took sick leave during treatment; 12% of whom remained on sick leave following treatment.
- 12.5% took retirement during their cancer treatment; 5% retired following their treatment.
- In total, 31% of respondents did not go back to work following cancer treatment.

Results by gender

- More men than women were working full-time before their cancer treatment; more than twice as many men than women continued to work full-time during treatment; and more men than women took full-time work afterwards. (62% of men worked full-time before treatment; 28% continued to work full-time during treatment; and 42% took full-time work afterwards. 58% of women worked full-time before their treatment, with 11% working full-time during treatment and 33% taking full-time work afterwards.)
- Nearly three times more women than men were working part-time before their cancer treatment; nearly twice as many women than men worked part-time during their cancer treatment; and more women than men worked part-time afterwards. (32% of women worked part-time before treatment; 20% worked part-time during treatment; and 32% of women worked part-time following treatment. 12% of men were working

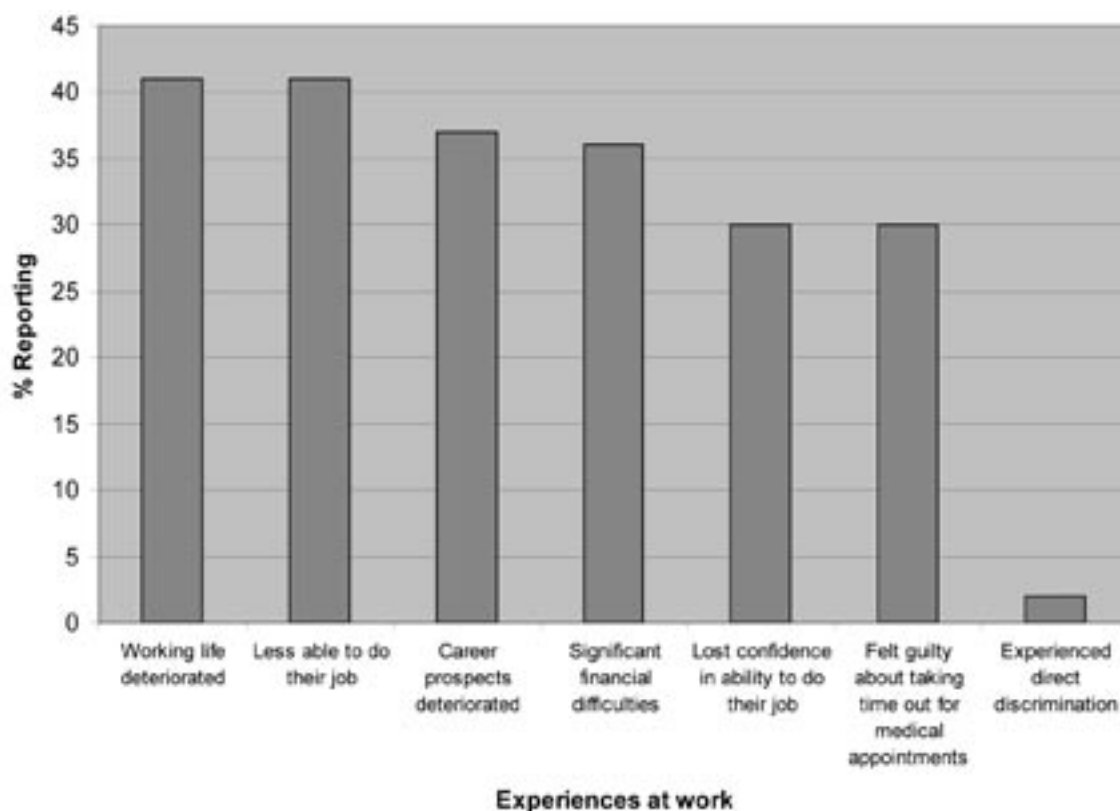
part-time before treatment; 12% during treatment; and 20% afterwards).

- More women took sick leave before and after cancer treatment than men. 46% of women took sick leave during treatment; 14% took sick leave afterwards. 31% of men took sick leave during treatment; 6% took sick leave afterwards.
- More men retired during or after cancer treatment. 3% of men retired during treatment; 8% retired afterwards. 1% of women took retirement during treatment; 3% afterwards.
- More men than women were unable to work during cancer treatment; slightly more men than women were unable to work afterwards. 19% of men were unable to work during treatment; 4% were unable to work afterwards. 13% of women were unable to work during treatment; 7% were unable to work afterwards.

The overall impact of cancer on working lives

5.2

- Just over a third (41%) said that their working life had deteriorated as a result of cancer. 42% had experienced no change; 12% said it had improved. Those who had experienced a deterioration were significantly less likely to have received work adjustment policies, adjustments to working hours and alternative work arrangements, return to work meetings and regular consultations about managing their workload.
- A large proportion (41%) felt less able to do their job as a result of their cancer. 50% said there had been no change; 5% said it had improved.
- More than a third (37%) said their career prospects had deteriorated; 54% said there had been no change, while 4% said they had improved. Those who experienced no change were significantly more likely to have received work adjustment policies, adjustments to working hours and alternative working arrangements, return to work meetings and regular consultations about managing workload.
- Over a third (36%) experienced significant financial difficulties. 38% of women had experienced this compared to 31% of men. Those employees not offered alternative working arrangements during and following cancer treatment were up to 15 times more likely to experience significant financial difficulties.
- 30% felt they had lost confidence in their ability to do their job during cancer treatment. More than twice as many women (35%) said this as men (15%).
- 30% felt guilty about taking time off for medical appointments and treatment. 33% of women said this, compared to 21% of men.
- A minority of respondents reported poor organisational practices. 2% said they had experienced direct discrimination (women only reported this); 6% reported they had been overlooked for promotion (3% of women and 4% of men); 7% had received changes to their job without their agreement (9% of women, 5% of men); 2% had felt pressure to resign (6% of women, 2% of men).



In addition:

- 58% of respondents said that continuing to work was important to them.
- 51% said it was important for their self-esteem. 53% of women said this, compared to 45% of men.
- 49% said that staying in or returning to work was important to them to retain an area of normality in their lives. 52% of women said this, compared to 45% of men.
- Almost a third (29%) reported that their overall job satisfaction had deteriorated. 55% said there had been no change; 12% said it had improved.
- 40% said that they felt out of touch with work during their cancer treatment. 43% of women said this compared to 32% of men.
- 25% said they feared disclosing their cancer to a new employer. A higher proportion of women (27%) said this compared to men (19%).
- 9% said they had been treated as if they could not do their job. Only 1% of men said this, compared to 12% of women.

5.3

Managing the impact of cancer treatment at work during and following treatment

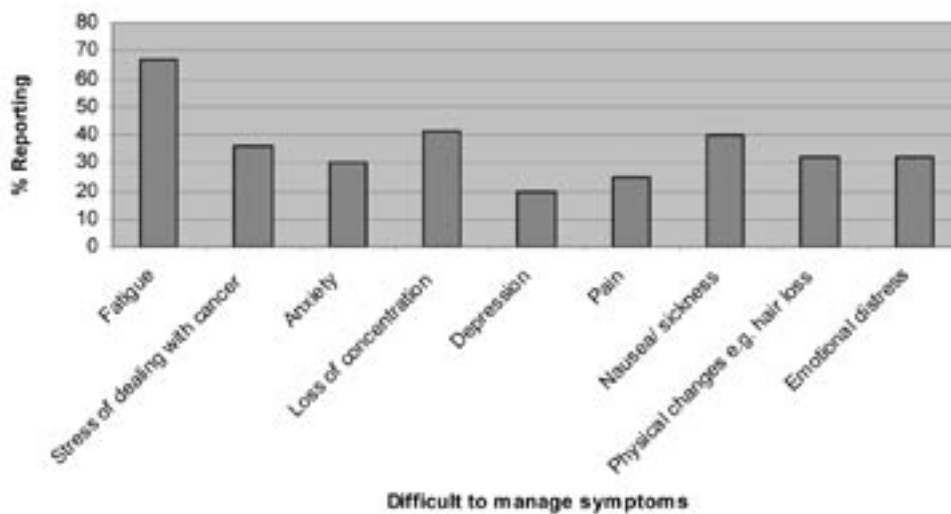
- Less than half of respondents (44%) had been informed by their doctor about how their cancer treatment would affect their ability to work.
- A huge majority (84%) found it difficult to manage side effects at work during cancer treatment; more than a half (56%) found side effects difficult to manage at work *following* treatment.
- People who had been informed of the impact of different treatments on their work by their doctor were twice as likely to feel comfortable talking about their cancer at work.

During treatment

- The most commonly reported side effect respondents found difficult to manage at work during cancer treatment was fatigue (67%), followed by loss of concentration (41%), nausea/sickness (40%) and the stress of dealing with cancer (36%).
- More than a quarter of respondents also found that emotional distress (32%), physical changes such as hair loss (32%) and anxiety (30%), were difficult side effects to manage during treatment.
- Those respondents undergoing chemotherapy found physical changes such as hair loss (90%) the most difficult side effect to manage at work during treatment, followed by nausea/sickness (82%) and emotional distress (68%).
- Those respondents undergoing surgery found pain (81%), loss of concentration (75%) and physical changes (74%) the most difficult side effects to manage at work during treatment, closely followed by anxiety (73%) and depression (70%).
- Those respondents undergoing radiotherapy found depression (70%), pain (69%) and loss of concentration (69%) the most difficult side effects to manage at work during treatment, closely followed by anxiety (64%).
- Those respondents undergoing oral medication found side effects less difficult to manage at work during treatment, although half of respondents reported pain, anxiety and stress (all 50%) as difficult to manage at work during this time.

5.3.1

Managing symptoms at work during treatment



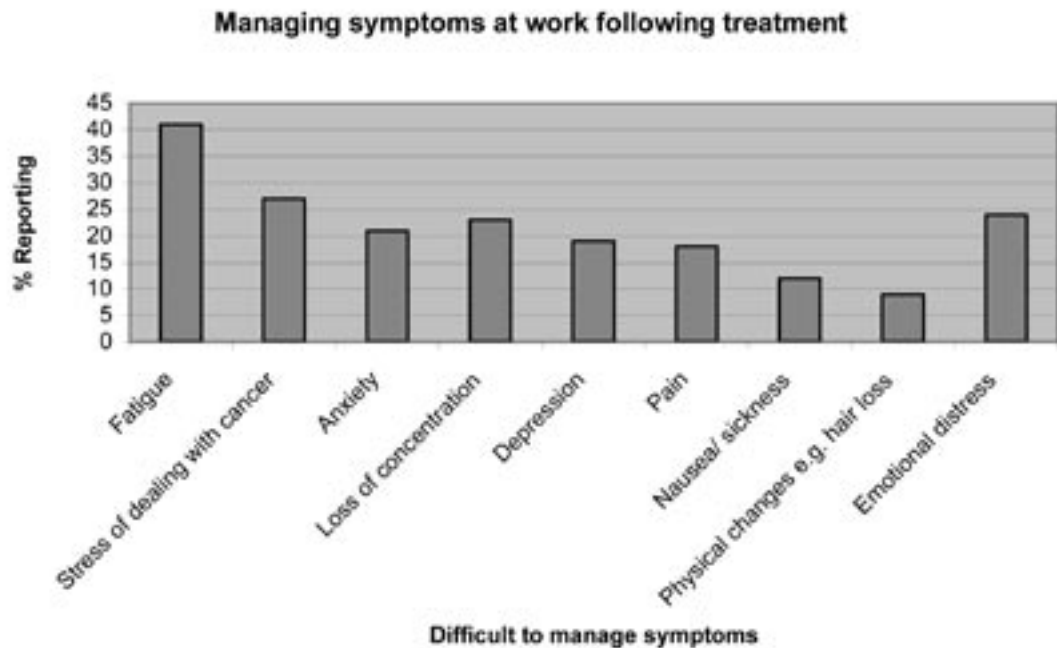
Following treatment

- Following treatment, the most commonly reported side effect respondents found difficult to manage at work was, again, fatigue (41%), followed by the stress of dealing with cancer (27%), and emotional distress (24%).
- Following treatment, those respondents who had undergone chemotherapy reported that fatigue was now the most difficult side effect to manage at work (62%), followed by emotional distress (57%) and physical changes (56%).
- Following treatment, those respondents who had undergone surgery found pain (81%), anxiety (79%), physical changes (78%) and emotional distress (78%) the most difficult side effect to manage at work, closely followed by loss of concentration (77%).
- Following treatment, those respondents who had undergone radiotherapy reported pain

5.3.2

(69%), stress (66%) and anxiety (68%) as the most difficult side effects to manage at work, closely followed by physical changes (67%).

- Following treatment, those respondents who had undergone oral treatment reported physical changes (78%), anxiety (68%) and stress (56%) as the most difficult side effects to manage at work.



5.4

Level of support offered to employees with cancer by line manager and colleagues

- Respondents judged that the level of support received from colleagues during treatment was marginally better than that received from line managers, although both were relatively high, with 77% of respondents saying they had received good or very good support from their colleagues during treatment and 74% rating support from their line manager as good or very good. However, 1 in 10 respondents indicated that the level of support received was poor.
- Respondents also judged that the level of support received from colleagues following treatment was marginally better than that received from line managers, although, again, both were relatively high, with 74% of respondents saying they had received good or very good support from their colleagues following treatment, and 72% rating support from their line manager following treatment as very good.
- A quarter of respondents (26%) said their relationship with their line manager had improved as a result of their cancer. More than two thirds (67%) said there had been no change, while 6% reported that the relationship had deteriorated during their illness.
- More than a third (35%) of respondents said their relationship with their colleagues had improved as a result of their cancer. More than half (57%) said there had been no change, while 6% reported that the relationship had deteriorated during their illness.

Managing cancer in the workplace

5.5

Services offered by employers to employees with cancer

5.5.1

Sick leave and medical appointments

- 84% of respondents said that their organisation offered paid time off to attend all medical appointments. 89% of large³⁰ organisations offered this, compared with 85% of medium-sized³¹ organisations and 76% of small³² organisations.
- 81% had been offered sick leave for the period in which the employee is entitled to receive Statutory Sick Pay (28 weeks), while 74% had been offered longer than this. A majority of respondents (74%) had received sick leave for longer than the period in which the employee is entitled to receive Statutory Sick Pay. 81% of large organisations had offered longer, compared to 71% of medium-size organisations and 63% of small organisations.

Private health insurance

- 24% of respondents had been offered private health insurance by their employer. 20% of large organisations offered this, compared to 30% of medium-sized organisations and 17% of small organisations.

Human resource/occupational health practices

- 58% had easy access to human resources or occupational health support. 65% of large organisations offered this, compared to 64% of medium-sized organisations and 29% of small organisations.

Work adjustments

- Less than half of respondents had been offered work adjustment policies (42%) or alternative working arrangements (46%). 49% of large organisations had offered these, compared to 39% of medium-sized organisations and 29% of small organisations. Just under a third of respondents (32%) said they were confident they could ask for changes or adjustment to their workplace. Only 10% of respondents had received physical adjustments to their work environment.
- Only half (51%) were offered regular consultations about managing their workload during treatment. Slightly more medium-sized organisations (55%) offered this than large organisations (49%) and small organisations (50%).
- 70% said their organisation offered them an option of working fewer/flexible contracted hours. Curiously, more small organisations (75%) offered this, compared to 70% of larger organisations and 66% of medium-sized organisations.
- 16% said changes in their job role had occurred with their agreement. The percentages were the same for both men and women.

Return to work policies

- 60% of respondents were offered a return to work meeting with their employer. 74% of larger organisations offered this compared to only 58% of medium-sized organisations and 37% of small organisations.
- 28% of respondents felt they needed more time off following treatment.

Counselling

- Only 30% had been offered counselling. Results were broadly similar for all organisations, with 34% of large organisations offering it, 30% of medium-sized organisations, and 23% of smaller organisations.

5.5.2

Information and support received by employees with cancer from their employers

- Only 18% of respondents said they had been offered any information about managing work issues associated with their cancer; only 28% had been offered support on managing work issues associated with their cancer. More medium-sized organisations had offered these (25% and 34% respectively), compared to large organisations (20 and 31% respectively) and small organisations (8% and 17% respectively).
- Only half (51%) were offered information about their statutory rights. Significantly more medium-sized organisations (63%) offered this than large (49%) or small (35%) organisations.
- Those who did not receive information about managing work issues associated with cancer were nearly four times more likely to report that their working life had deteriorated as a result of cancer than those who had been given information.
- Only half (50%) were offered any information on extra organisational benefits. Again, significantly more medium-sized organisations (67%) offered this than large (47%) or small (30%) organisations.
- Only 14% were offered information on how to talk to colleagues about their cancer. Again, more medium-sized organisations (29%) offered this than large (7%) or small (6%) organisations.
- Just under a quarter (24%) were offered support in talking about cancer to their colleagues. Again, more medium-sized organisations (32%) offered this than large (19%) or small (25%) organisations.
- Only 30% of respondents had been directed towards other sources of information and support. Again, more medium-sized organisations (50%) offered this than large (16%) or small (21%) organisations.
- 46% of respondents said that the information given to them at work was either poor or very poor. Only 35% said the information was good or very good.

5.5.3

Revealing news of a cancer diagnosis to employers

Telling a line manager

- A large majority (88%) of respondents had told their line manager about their cancer. A greater proportion of women (92%) did this compared to men (78%).
- Of those respondents who did not tell their line manager about their cancer, most (43%) wanted to keep that area of their life (ie work) normal and keep their cancer private. 27% were worried about job security and concerned that cancer had reduced their career prospects. 27% of those who did not tell their line manager did not expect to receive extra support.
- A large majority (83%) told their line manager at the time of their diagnosis. A greater proportion of women (84%) than men (77%) did this.

- 63% experienced some anxiety before revealing their cancer to their line manager, with 28% feeling very anxious. A greater proportion of women experienced anxiety (64%) than men (57%).
- Most told their line manager about their cancer because they needed to explain time off for appointments and treatment (62%). A third said they did so because they knew their line manager could offer emotional (30%) and practical (28%) support, because they knew they could talk in confidence (32%) and because it was hard to hide the emotions associated with illness and treatment.
- When the above figures are broken down by gender, a greater proportion of women (65%) than men (55%) told their line managers because they needed to explain time off for appointments and treatment. The second most popular reason for disclosing for women (36%) was because it was hard to hide the emotions associated with illness and treatment, while for men this was the sixth most popular reason (13%). The second most popular reason for disclosing for men was because they knew they could talk in confidence (33%). The third most popular reason for disclosing for women was because they believed their line manager could offer emotional support (33%) compared to 20% of men; for men the third most popular reason was because they believed their line manager could offer practical support (30%).

Telling colleagues

- A large majority (86%) of respondents had told their colleagues about their cancer. More women (88%) than men (80%) did this.
- Of those respondents who did not tell their colleagues about their cancer, most (48%) had not done so because they wanted to keep that area of their life normal. 44% said they wanted to keep their cancer private; 33% were concerned that the news would not be kept confidential.
- People who had been informed of the impact of different treatments on their work by their doctor were twice as likely to feel comfortable talking about their cancer at work.
- Most (67%) told their colleagues at the time of their diagnosis. Broadly the same amount of men (68%) and women (67%) did this. 61% experienced some anxiety before revealing their cancer to their colleagues, with 23% feeling very anxious. Women indicated that they were slightly more anxious than men when telling their colleagues about their cancer.
- Most told their colleagues about their cancer because they believed they could offer emotional support (42%). This was particularly the case for women. A third said they did so because they needed to explain time off for appointments and treatment (33%) and because it was hard to hide the emotions associated with illness and treatment (30%).

Awareness of the likely provisions of the amended Disability Discrimination Act

- Only 15% of respondents were aware that more cancer patients are likely to be protected from discrimination under the amended Disability Discrimination Act.

5.5.4

Conclusions

- The majority of employees with cancer say continuing to work is important to their self-esteem or important because they want to keep an area of their life normal. The majority reveal the fact that they have cancer to their employer, feel able to talk about it at work and receive a good level of support from line managers and colleagues. Most are offered time off to attend all medical appointments and extended sick leave.
- Despite this, a significant proportion of employees who have been diagnosed with cancer do not return to work after treatment. The costs of withdrawal from the labour market are substantial, in financial terms to employers and Government through loss of labour and skills, replacement costs, and sick or early-retirement pay and to employees through loss of earnings. There are also important costs to the individual's psychological well-being.
- While this withdrawal from the labour market can, for some, be related to the severity of the cancer and its symptoms, for others it is due to a loss of self-esteem and confidence in their ability to work effectively. (It should be noted that for cancer patients of working age, the survival rates are generally higher than for the elderly³³.) Many employees with cancer say that the disease has a negative impact on their overall working life, and that their career prospects and job satisfaction have deteriorated as a result of their cancer. Many, particularly women, feel out of touch, guilty at taking time off for medical appointments, lose confidence in their ability to do their job and fear disclosing their cancer to a new employer. For a significant number, these experiences are compounded by financial insecurity. The reasons for this can be found in the rest of the survey results.
- The vast majority of employees with cancer say they find the side effects of their treatment – fatigue, nausea, anxiety or depression – difficult to manage at work during treatment. Over half find them difficult to manage after treatment has finished and many say they need more time off work after treatment. Our research indicates that more could be done by both health professionals and employers to help employees with cancer anticipate and manage these side effects in the workplace.
- Less than half of employees with cancer are informed by their cancer doctor about how their treatment would affect their ability to work. As a result, many employees with cancer are unaware before treatment of how the side effects will impact on them. They are less able to talk about their cancer at work and, as a result, less able to ask for reasonable adjustments to their work. Under these circumstances, employees may continue or return to work with unrealistic expectations about what they can do, which may have an impact on their job satisfaction, confidence and withdrawal from work. Further and regular guidance and support is needed from health professionals by employees with cancer on the side effects of different treatments and the impact on their work, during and following treatment. These need to be better understood by employers to inform their management of employees with cancer.
- Even fewer employees who develop cancer are offered information about how to manage work issues associated with the disease by their employers. Less than one in five respondents to our survey have been offered this information. Crucially, those who have not been offered information about managing workplace issues associated with cancer are four times more likely to report that their working life has deteriorated as a result of cancer than those who have received it. Information is also lacking and/or of poor quality in a number of other areas: statutory rights; organisational benefits; talking about cancer in the workplace; other sources of information and support. Employers

need to improve their resources in these areas. Large and small-sized organisations are in particular need of improvement in all aspects of information provision.

- Large organisations are significantly better at offering employees with cancer paid time off to attend all medical appointments, extended sick leave, work adjustments, flexible/alternative working arrangements and return to work meetings than medium-sized or small organisations. This may be because medium and small-sized organisations face particular challenges relating to their capacity to cover for employees who request flexible working. They may wish to consider training in how to re-organise work and design jobs appropriately so that the business continues to thrive.
- In addition, many do not feel confident in asking for adjustments in the workplace and are not offered flexible working practices, regular consultations on managing workload, return to work policies or counselling. Those who report that their working life has deteriorated were significantly less likely to receive these adjustments; those who say that there has been no change in their career prospects were significantly more likely to have received these adjustments. More than a third of employees with cancer say they do not have easy access to support from occupational health or human resources, indicating that these departments need to raise awareness of their services and take a more proactive approach when assisting employees in managing their work.
- Given the significant impact of the emotional side effects of cancer treatment in the workplace, both during and after treatment, relatively few employees are offered counselling. This highlights the need for health professionals and employers either to provide such services or to direct employees to other sources of emotional support, both during and following treatment.
- Only 2% of employees reported direct discrimination. It is difficult, however, to know whether this figure is accurate as the majority of respondents seem unsure of their entitlements under the law. 85% of employees were unaware that cancer patients are likely to be classified as disabled under the new Disability Discrimination Act and only half of all respondents had been given information about their statutory rights.
- It is clear that organisations are struggling to know how best to support employees with cancer. Many are failing to provide the information, support and flexibility cancer patients need if they wish to continue or return to work during or following cancer treatment. This is not because employers lack sympathy or concern; instead, it can often be explained by a culture of ignorance within organisations as to the true needs of employees during and after treatment.
- Respondents feel well supported by colleagues and line managers, but are not generally supported by organisational policies, practices and information provision. Support seems to be dependent, therefore, on the relationship between line manager, colleagues and the employee concerned and could be undermined by an unsympathetic line manager or senior manager. It also helps to explain why many employees fear disclosing their cancer to a new employer. In addition, little information and support is available to help line managers and colleagues in their efforts to help employees with cancer, or to discuss the subject with them.
- Flexible working, return to work policies and the provision of comprehensive, high-quality information and support for employees with cancer need to be enshrined in organisational policy, championed by senior managers and made part of the culture of an organisation if they are to be accessible and fair, and if employees with cancer are to feel more confident about managing their cancer in the workplace, returning to work following treatment and staying in the labour market. Improved information and support is also needed for line managers and colleagues working alongside employees with cancer.

7

Recommendations

7.1

Policymakers

- As is proposed under the Disability Discrimination Bill the definition of 'disabled' under the Disability Discrimination Act (DDA) should be widened to specifically cover all people living with cancer. This will ensure they are automatically protected from discrimination in the workplace from the point of diagnosis and are treated fairly, equally and consistently.
- We must, however, ensure that confusion is not caused both for people with cancer and for employers, by the introduction of regulations enabling the Government to exclude specified cancers from the protection from the point of diagnosis. Where people with cancer are discriminated against, it is because they have cancer, not because they have a particular type of cancer.
- Most employees with cancer are unaware that the new Disability Discrimination Act will almost certainly protect them. Policymakers should ensure that a targeted education campaign raises awareness of the provisions of the new amended Act both in the workplace and in healthcare settings.

7.2

Health professionals

- Cancer doctors and nurses should ensure they have regular discussions with all patients who are working, or intending to commence work, about how different treatment options will impact on their ability to work.
- Cancer doctors and nurses should ensure they are aware of the findings in this report relating to the side effects patients find most difficult to manage in the workplace during and following different treatments.
- Cancer doctors and nurses should ensure they have regular discussions with all patients who are working about how the side effects of cancer and its treatment, particularly fatigue, can be managed to assess and assist their ability to work during and following treatment.
- Cancer doctors and nurses should ensure that such discussions with all patients who are working take place regularly at follow-up appointments.
- Health professionals should be trained in dealing with issues related to ability to work, including an overview of employment issues and the appropriate DDA-related legislation.
- Given the significant impact of the emotional side effects of cancer treatment in the workplace, primary care trusts should improve their emotional support and counselling services for cancer patients. Health professionals should provide cancer patients with information about services, or direct them to other sources of emotional support, both during and following treatment.

Employers

7.3

- Organisations of all sizes should review and enhance the levels of services, policies, information and support they offer employees who develop cancer in order to improve their experiences in the workplace and reduce the number of employees who fail to return to work following cancer treatment.
- Employers should update their knowledge of current and impending disability legislation and ensure managers, occupational health and human resources staff are trained in dealing with disability. Employers should ensure that staff are aware of the provisions of the Disability Discrimination Act (see section 8) and in particular that their staff are aware of the definition of 'disabled' under the Act. Many people with cancer are currently protected by the legislation. Amended legislation (expected to come into force in October 2005) will mean that almost all people with cancer are protected from the point of diagnosis.
- Managers, occupational health and human resources staff should be made aware of the fact that people who have had treatment for cancer are as productive as people who have not had cancer³⁴, that they take less time off work than other employees³⁵, and that, in general, they perform well in the workplace³⁶.
- Managers, occupational health and human resources staff should have a good understanding of cancer and its different treatments. They should be made aware of the findings of this report relating to the side effects patients find difficult to manage in the workplace during and following treatment, including those relating to the side effects of different treatments and their impact in the workplace.
- Employers should develop, review and improve where necessary their flexible working, work adjustment and return-to-work policies and ensure managers are supported and trained in these areas. Employers should work with staff representatives on developing and regularly reviewing the policies and how they work in practice.
- Employers should ensure that employees with cancer have a right to request flexible working and that, where possible, their requests are met. They should ensure that it is supported by senior management and reflected in the culture of the organisation and is not dependent on individual relationships between employees and line managers.
- Employers should improve the quantity and quality of the information they provide to employees with cancer, ensuring information comes from independent, reputable sources. They should be able to provide information on:
 - relevant statutory benefits
 - the employee's rights under the Disability Discrimination Act
 - their organisation's sick leave and sick pay policies
 - any relevant company benefits
 - flexible working/work adjustment policies
 - return to work policies
 - talking about their cancer to their colleagues. The information should come from reputable, independent sources such as CancerBACUP
 - other sources of information and support, such as specialist organisations and charity helplines.
- Employers may wish to consider resources such as CancerBACUP's Employee Benefit Initiative, which enables organisations to provide its employees with a dedicated free phone number to CancerBACUP's helpline and access to all its services.
- Given the significant impact of the emotional side effects of cancer treatment in

the workplace, both during and after treatment, employers should either provide counselling services or direct employees to other sources of emotional support, both during and following treatment.

- Managers, occupational health and human resources staff should also receive training and support in discussing cancer with employees affected by it and with other members of staff. This could be carried out within the context of managing other illnesses in the workplace.
- If the employee does not want colleagues to be told about their cancer, the employer should respect their wish for privacy, as should union representatives and human resources managers.
- If the employee would like colleagues to be told about their cancer by someone other than themselves, employers should arrange for this to be carried out in a sensitive manner by someone who has a good understanding of cancer and the effects of treatment and is able to deal with the reactions of those being told.
- Occupational health and human resources staff should ensure that they improve awareness amongst employees of the above policies, information and support. They should also improve the accessibility of their departments to employees with cancer.
- Employers should ensure that any work adjustments or flexible working agreed with employees who have cancer are regularly discussed and reviewed with the employee concerned. Employers should ensure that the employee leads any such discussions, where they are willing to do so. They should be supported in this by their occupational health or human resources staff and by their line manager.
- Employers who offer private health insurance should ensure that the policies they purchase cover patients throughout the course of their cancer. Many insurers currently do not do this, as previous research by CancerBACUP shows³⁷.

Tips for employers

8

Employers and the Disability Discrimination Act

8.1

The DDA makes it unlawful to 'discriminate unfairly' against current or prospective employees due to their disability. All employers in the UK (except the Armed Forces) are covered by this legislation. If an employer's work arrangements or facilities put disabled employees at substantial disadvantage, then they have to make 'reasonable adjustments' to these. In addition, employers are not allowed to 'take revenge' on an employee as a consequence of he/she asserting his/her disability rights.

Nearly all aspects of the employment cycle are covered, from recruitment through to dismissal and beyond (future job references for example). The DDA also covers employment benefits, including health insurance, concessions, canteens etc.

For people living with cancer this means that they cannot be dismissed (or not appointed) on the basis of their cancer diagnosis. It also means that employers are expected to make reasonable adjustments to their job to allow for their disability. This could mean:

- allowing an employee time off to attend medical appointments
- modifying a job description with the employee's agreement to take away tasks that cause particular difficulty
- allowing some flexibility in working hours
- allowing extra breaks to help an employee cope with fatigue
- temporarily allowing the employee to be restricted to 'light duties'
- adjusting performance targets to take into account the effect of sick leave/fatigue etc on the employee
- moving the employee to a post with more suitable duties (with the employee's agreement)
- moving a work base: for example, transferring to a ground-floor office if breathlessness makes climbing stairs difficult
- ensuring suitable access to premises for employees using wheelchairs/crutches etc
- providing toilet facilities appropriate for a disabled employee
- allowing working from home
- allowing 'phased (gradual) return' to work after extended sick leave
- providing appropriate software (such as voice-activated software for employees who cannot type)
- changing a job interview date/time so as not to clash with an applicant's medical appointment.

(For more information see CancerBACUP's *Work and cancer* booklet).

An employer will need to consider several factors when deciding whether an adjustment is reasonable, including the effectiveness of the adjustment for people with disabilities. Many

changes can be made at minimal cost and involve little inconvenience for the employer. Assistance with funding for some adjustments is available through the Government's Access to Work scheme.

What is considered 'reasonable adjustment' will depend on many different things, including:

- the cost of making the adjustment
- the amount of benefit for the employee
- the practicality of making the adjustment
- whether making the adjustment will affect the employer's business/service/financial situation
- whether or not financial assistance eg from the Access to Work scheme or voluntary organisations is available to an employer for such an adjustment.

NB: If an employee with cancer does not make their employer aware of their cancer then the employer does not have to make the 'reasonable adjustments' listed above.

8.2

Managing employees with cancer

8.2.1

First steps

As soon as an employer becomes aware that an employee has been diagnosed with cancer, their occupational health manager or human resources manager should suggest a confidential, supportive discussion with the employee concerned. The employee may wish to have a third party present such as a trade union or employee representative (this applies to all work discussions listed below). Be aware that the employee may not know in advance how the treatment will affect them and may need to take time off at short notice.

- Needless to say, the discussion should be sympathetic towards the employee and cover some or all of the following:
 - the employee's emotional reaction to their diagnosis and any resulting need for time off
 - whether and how they would like their line manager and colleagues to be told about their diagnosis
 - the likely impact of cancer treatment on their work and whether they would like colleagues to be told about this
 - reasonable time off to attend medical appointments
 - the likely impact of cancer treatment on their work and whether the employee needs to take sickness absence or agree a reduction in working hours
 - permission from the employee to obtain written advice from their doctor about the condition and recommendations for returning to work and time off.
- The employee should be offered information on:
 - relevant statutory benefits

- their rights under the Disability Discrimination Act
- their organisation's sick leave and sick pay policies
- any relevant company benefits
- flexible working/work adjustment policies
- return to work policies
- talking about their cancer to their colleagues. The employer should ensure this information come from reputable, independent sources such as CancerBACUP
- other sources of information and support, such as specialist organisations and charity helplines
- counselling.
- A further discussion should be held involving the occupational health or human resources manager, the employee concerned and their line manager to discuss and agree the above points.
- Notes should be made at every discussion to record any working arrangements made. These notes should be made available to the employee if they wish to see them. Regular reviews should also be arranged to monitor the working arrangements and to see if sufficient support is being offered.
- If the employee plans to work throughout some or all of their cancer treatment, they should be helped to do so by their employers. This may require reasonable adjustments being made to their working hours, workplace or workload. Their occupational health manager or human resources manager should discuss these with the employee.
- Employers should ensure that cancer information and support provided to employees from black and minority ethnic communities is culturally appropriate. It may be of help to direct employees towards additional services, such as CancerBACUP.
- Be aware that line managers and colleagues can provide good support to employees with cancer. They should also, where appropriate, be provided with relevant information, support and training.

Implementing flexible working/work adjustment policies

8.2.2

- After discussion with the employee, it might be helpful to:
 - ask the employee's colleagues to be supportive and to help with some of their work or temporarily reallocate some of their work within their team
 - find the employee a parking place near to their place of work
 - allow the employee to take a short break every now and again to rest or lie down as necessary
 - allow the employee to work from home, if possible
 - make the necessary technical and administrative changes to enable the employee to carry out their duties, for example they could take part in meetings via telephone or video conferencing
 - find the employee lighter work if their job involves physical exertion or heavy lifting
 - change the employee's hours so that they can travel to and from work at less busy times (outside the rush hour)
 - adjust performance targets to take into account the effect of sick leave/fatigue etc on the employee

- move the employee to a post with more suitable duties (with the employee's agreement)
 - appoint a colleague as their work 'buddy', if appropriate, who takes responsibility for keeping the employee abreast of developments during temporary absences for treatment or illness.
- Managers should ensure that regular consultations about managing work issues take place with the employee concerned. They should be aware that employees with cancer may experience varying levels of fatigue and other side effects during (and following) treatment and that any adjustments should be kept regularly under review.
- Employers should ensure that if the line manager of an employee who has (or has had) cancer changes, the employee concerned should be asked whether they would like the new line manager to be informed about their situation. Human resources staff should ask the employee how they would like this to be handled.

8.2.3

Sick leave

- If the employee has to take sick leave for cancer treatment, their employer should ask them if they would like their colleagues to keep in contact with them to keep them up to date on work matters, and, if so, how frequent they would like that contact to be.
- Employees who are absent through cancer treatment should be given the option of having regular discussions by phone or in person to review how their absence is being managed.
- Employers should be aware that physical and emotional side effects from cancer treatment can last for some time (ie weeks or months) beyond the end of treatment; they should also be aware that the end of treatment can be a physically and emotionally stressful period for employees who return to work at this time.

8.2.4

Returning to work

- Involve employees who are absent through cancer treatment in planning their return to work. Plan and discuss with the employee any reasonable adjustments they would prefer to have in place when they return to work. Some adjustments that employees returning to work have found useful include:
 - a phased return to work within a fixed timescale
 - a change to working hours or reduced working hours
 - a change to work patterns
 - changes to their role, temporary or otherwise
 - home working
 - telephone conferences to reduce travel
 - help with transport to and from work
 - moving tasks to more accessible areas;
 - making alterations to the premises or to their job station
 - dates when the plan will be reviewed, set by mutual agreement
 - any impact on the terms and conditions of their job
 - any training or refresher courses they may need.
- Carry out a return to work interview. Welcome the employee back to work after their absence and give them the opportunity to discuss their health or other concerns in

private or with employee representatives present.

- Be aware that the impact of cancer treatment can last after treatment is over. Very often the end of treatment is a stressful time for cancer patients and they may still be experiencing debilitating physical and emotional side effects. Have regular discussions with the employee about how the work adjustments are helping and how long they need to continue. Be aware that the employee may not be able to predict how long they will need such adjustments. The employee may also be keen to return to normal and over-optimistic about what they can manage at the outset.
- The above mirrors advice given to employers for rehabilitation after all long-term illnesses.

Tips for employees

9

The following advice is aimed at employees with cancer. Human resources professionals should direct employees who have been diagnosed with cancer towards this section in the course of discussions about managing cancer at work. The information is taken from CancerBACUP's new booklet *Work and cancer*.

Information about your cancer

9.1

- Find out as much as possible from your doctors and the healthcare staff at your hospital about your cancer, the likely effects of the cancer and whether it will make it difficult for you to work.
- Questions you may want to ask include:
 - What treatment(s) is/are available for my type of cancer?
 - How effective is the treatment likely to be?
 - How will my treatment affect my physical ability to do my job (eg Can I drive? Can I climb ladders? Can I work shifts? Can I travel by plane?)
 - Are there any treatment options that will make it easier for me to work?
 - What are the benefits and disadvantages of the treatment(s)?
 - How long will each treatment take and what does it involve?
 - Will I have to be admitted to hospital?
 - What are the possible side effects of treatment?
 - What can be done about the side effects of the treatment?
 - How much is the treatment likely to affect my day-to-day life?
 - Will I still be able to work while I am having the treatment?
 - What will happen if I do not want to have any treatment?
- You can also find information about your type of cancer from your employer's occupational health department, or from CancerBACUP. CancerBACUP has a detailed list of different cancer treatments and the side effects which may affect your ability to work.
- If your workplace has an occupational health adviser, or a human resources (personnel) department it is helpful to contact them early on to talk about the effect that your cancer may have on your ability to work.

9.2

Information about your rights

- Ask your employer or human resources manager for information about your statutory rights, your organisation's sickness policy and how much paid and unpaid time off you are entitled to, and any extra benefits offered by your employer. It may also be a good idea to take independent advice from your trade union representative, the Citizens Advice Bureau or your solicitor
- All employees who earn enough money to pay national insurance contributions are eligible to receive Statutory Sick Pay (SSP) if they are off sick for 4 days or more, for a maximum period of 28 weeks. The payment is made by the employer on behalf of the Government. Some large companies pay more than the basic rate of statutory sick pay.
- You may also be entitled to occupational sick pay. This will be detailed in your contract of employment/staff handbook or you could ask your human resources department for further information. Occupational sick pay is usually paid as a top-up to SSP (ie, you do not get both, but SSP becomes a part of your occupational sick pay).

9.3

Storing information

- When you are given information about your cancer, the treatments or how it may affect your work, it can be helpful to keep this together in a file or folder. You can also store medical reports, insurance claim forms, your work sickness policy and any relevant finance or benefit information in the same place. The NHS website has a secure place in which you can store all your electronic health information. It can be accessed at www.healthspace.nhs.uk

9.4

Emotional effects

- Your feelings and emotions following a cancer diagnosis may make it difficult for you to concentrate or work effectively. Most employers will be sympathetic to this, and your doctor can sign you off from work for a short time, if necessary.

9.5

Treatment and side effects

- Before treatment, it is often difficult to know exactly how it may affect you and it is helpful to let your employer know this, so that they are aware you may need to change your work plans at short notice.
- One of the most common side effects of cancer treatment is fatigue. Use the fatigue diary at the centre of the *Work and cancer* booklet to keep a record of your energy levels and plan your work around times when you have most energy.
- CancerBACUP's *Work and cancer* booklet has tips on how your employer can help you if you are suffering from fatigue.

9.6

Taking time off**Appointments**

- You may need to take time off for appointments and follow-up. It is good to give your employer as much warning as possible if you need time off, as if you give very

short notice your employer may be unable to agree to the request. In most cases, your employer must, by law, give you a reasonable amount of time off work to attend necessary hospital appointments but there is no absolute right to paid time off unless your contract of employment specifically states this.

Treatment

- You may also need to take time off during your treatment. This time off may be taken as sickness absence, or an agreed reduction in working hours or days per week.
- Taking a lot of time off can make you feel out of touch with what is going on at your workplace and can make you lose confidence in your ability to do your job well. It can help to talk honestly about these feelings and emotions to your employer and colleagues. Arrange with your employer to be kept informed of work matters if you wish, and designate who you would like to do this and how often.
- Your employer should be understanding of the fact that you are going through a very stressful time and should relate to you in a supportive manner to help you to cope with the cancer and its treatment. If this is not the case, refer to 9.8 below.

Telling your employer and colleagues about your cancer

- If you tell your employer that you have cancer, but do not want any of your colleagues to know, then your employer should not tell them. Union representatives and human resources managers should also respect your wish for privacy.
- If you want your colleagues to know about your cancer, but do not feel able to tell them yourself, your employer or personnel manager may be able to do this for you in a sensitive way.
- You do not have to tell your employer you have cancer by law. However, if you do not, and the cancer and its treatment affects your ability to do your job, this could cause problems. In extreme cases, it may lead to disciplinary action being taken against you.
- If you do not tell your employer about your cancer or about any unusual side effects, your employer is not bound to make the 'reasonable adjustments' required under the current or amended DDA.

Talking about your cancer at work

- Some people may avoid you because they are afraid of saying the wrong thing. You can help them by bringing up the subject and showing that you are willing to talk about the cancer.
- Telling your colleagues can be helpful, so that they can know what to expect – for example if fatigue affects your moods or concentration, etc. If you tell them your plan of action, it gives them the opportunity to support you.

Discrimination

- Research has shown that most employers do not discriminate against employees with cancer. Your employer should provide help and support to enable you to do your job. There are laws protecting the rights of workers who suffer from illnesses like cancer.
- Many people with cancer are protected by the Disability Discrimination Act, which prevents employers victimising or discriminating against people with a disability. CancerBACUP's *Work and cancer* booklet has more details about this and the

9.7

9.8

'reasonable adjustments' to workplaces and working practices that employers have a duty to make.

- If you feel that you are being discriminated against, you can work with your supervisor, manager or human resources department to resolve the problem informally. Talking openly to your manager about your needs and their needs may help to resolve the situation. If you feel unable to talk to your manager, you can ask someone in the human resources department or an occupational health adviser for help.

9.9

Unresolved problems

- Ask to see your employer's grievance policy. This should enable you to voice your concerns and resolve any problems.
- Get support from your union. Unions have the resources and expertise to deal with a range of workplace problems.
- Contact the organisations that give information about legal rights and employment issues. (Listed in the CancerBACUP *Work and cancer* booklet and at the end of this report.)
- The CancerBACUP *Work and cancer* booklet has more information about how to deal with unresolved workplace problems.
- Under the Disability Discrimination Act employees have to make a formal, written grievance within three months of the grievance taking place. The employer then has 28 days to resolve the issue. If the matter is not resolved, the employee must make an application to the employment tribunal within a further six months.

9.10

Taking time off sick

- Some people choose to stop working throughout their treatment, which could be a period of weeks, months or even years. When deciding whether you want to continue to work or whether you would like to take the whole time off sick, you may like to think about the issues below and also the financial considerations. Be aware that you may not know this in advance and remind your employer that your decision may change.
- It is helpful to contact an independent financial adviser (IFA) to get advice on your financial options. IFAs can assess your individual situation and recommend the best course of action.
- If you have any private insurance cover for Income Replacement; Life Insurance; Loan or Mortgage Protection or Critical Illness, you should speak to your insurance company or financial adviser as soon as possible.

9.11

Benefits

- If you are still unable to work after receiving SSP for 28 weeks or your contract ends before that time and you are still unable to work, you may be able to claim Incapacity Benefit. People who are not eligible for Incapacity Benefit because they have not paid the relevant national insurance contributions can apply for Income Support.
- The CancerBACUP *Work and cancer* booklet has more information about benefits for cancer patients.

Going back to work following treatment

9.12

- Hold a return to work meeting with your employer, human resources department or occupational health staff. If you are still coping with some of the effects of cancer treatment, you can discuss any changes that can be made to your work to help you. If your workplace has an occupational health adviser, your manager can arrange for you to see them and agree a 'return to work' plan. The adviser can see you from time to time until you are fully back at work.
- If you feel that things have moved on while you were away, ask for time or training to catch up with the developments.
- If you feel that you cannot cope with your old job and would like to reduce your hours (go part-time) or need to change your job description, you should discuss this with your employer or the human resource manager as soon as possible. They should be willing to be flexible about your work arrangements to allow you to go on working as much as you can.

Returning to work – financial considerations

9.13

- If you are considering going back to work after treatment, whether full-time or part-time, it is important to think about the financial impact of your decision regarding benefits and insurance policies. CancerBACUP's *Work and cancer* booklet has more information about this.

Giving up work

9.14

- Some people choose to give up work completely when they are diagnosed with cancer. If work has been the major focus of your life it can be difficult to adjust to not working. It may help to talk to someone about the emotions you may have. Some find that having cancer gives them the opportunity to rethink their career choice and to make a change in their working lives. The Department for Education and Skills can offer careers advice and there are independent careers advisers listed in the Yellow Pages.
- You will need to think carefully about the effect of giving up work on your finances and it is important to get advice from an independent financial adviser. You will need to consider the money you will receive from a state, occupational or private pension and from any other sources such as savings, shares or benefits.

Early retirement

9.15

- If you want to take early retirement on health grounds or for personal reasons, it is essential to take advice from your pension administrator. You may be able to take early payment of your pension on the grounds of ill health, but this will depend on the rules of your own particular pension scheme.

After treatment

9.16

- Research has shown that people who have had treatment for cancer are as productive as people who have not had cancer. They also take less time off work than other employees. It may be helpful to let your employer and your colleagues know this.

9.17

Planning tips for employees with cancer

- Talk to your employer and colleagues about deadlines and what you can manage.
- Keep a diary to note how you feel and see if patterns emerge – this will help you to judge peak performance hours.
- Talk to your employer about a change of duties if necessary.
- Plan a reduced or more flexible schedule – look at the days you are needed at work and schedule your time around this.
- Delegate work when possible.
- If appropriate and possible, name a person to assess which phone calls you need to take, forward important emails, etc.
- Let colleagues know how you will manage things, how to contact you, and when you will check in with them.
- It may help to work from home when possible, if you feel this would be to your benefit.
- Talk to your doctors about the best times for appointments and treatments: for example, Friday afternoons to allow you to recover over the weekend.
- Try complementary therapies eg meditation and massage to reduce stress (see CancerBACUP's booklet *Cancer and complementary therapies*).
- Eat as well as you can to boost energy (see CancerBACUP's booklet *Diet and cancer*).
- Plan a period of rest after a period of activity. Short naps and rest periods are useful.
- Some people also find that they need to rest after meals.
- It is also important to plan your days around your treatment. Try and avoid anything energetic or stressful for 24 hours before and after your treatments.

9.18

For colleagues

- Colleagues can provide great support for employees with cancer. If a close colleague is diagnosed with cancer, ask your occupational health or human resources department for information about how to talk about cancer and how you can help support your colleague in the workplace, or contact the organisations listed at the end of this report. CancerBACUP has several booklets which can help.

Case histories: experiences of work and cancer

10

A) I am 48 and live with my husband and son in Huddersfield, West Yorkshire

I am a customer advisor for a bank with over 1000 employees. I was diagnosed with breast cancer in January 2003.

I told my manager as soon as I was diagnosed. I knew I could talk in confidence and believed she could offer both emotional and practical support. I didn't go back to work after my diagnosis, so she offered to tell my colleagues about my situation.

I had the surgery a week and a half after diagnosis and then went through chemotherapy and radiotherapy. I responded well to the treatments. It was thoughtful of my line manager to contact me while I was going through treatment. However, I was traumatised and didn't feel like talking to many people, so my husband took the calls. I did feel able to talk to one of my colleagues; she came to see me and we had lunch together.

My company did not put pressure on me to return and allowed me to decide when I felt ready. I was offered paid time off for all medical appointments, generous sick leave and easy access to occupational health support.

I went back in January 2004, two months after the treatment finished. They were very supportive and offered me a phased return, which I accepted.

My doctor didn't warn me of the potential side effects, which would have been helpful as I didn't realise how much the treatment had taken out of me. I wanted to go back to normal – to pretend it had never happened. I didn't want to accept the impact cancer had had on my life.

When I returned to work, I found it difficult to manage the pain and tiredness. It was really helpful to have had informal chats with my line manager about this and to talk about my progress and how I was coping.

I also received some information booklets from CancerBACUP. They were given to me at the breast cancer unit where I had my treatment. The fatigue booklet was particularly helpful. I gave it to my colleagues who, after reading it, understood better what I was going through.

In June 2004, I was involved in a car accident. I suffered whiplash. This, combined with the cancer fatigue, meant I had to go on sick leave again. I returned to work mid January 2005.

My work again had a plan in place to phase me back in over a three-month period and everything is going fine. I am having regular meetings with my new manager and have also

been offered longer breaks.

Because of the support I have received, I have been confident about making changes to the way in which I work and in asking for adjustments in the workplace.

I have felt in control of decisions about my working arrangements. My employer has been flexible and my manager and colleagues have been fully supportive. This has made all the difference at this difficult time. Without this understanding I would have found it more difficult to return to work.

B) I am 56 and live in Kent

Dealing with the cancer and its treatment was tough. Being discriminated against and losing my job made things so much worse. I have not been able to find permanent work since, which has made it harder to move on.

I was a teacher and head of the kindergarten department at an independent school. I was diagnosed with breast cancer in March 2000. I told the headteacher and my colleagues immediately. They were really supportive and I took time off for treatment.

I returned in January 2001 for 10 months until it was found the cancer had spread to my liver and more treatment was needed. I told the new headteacher and my colleagues straight away because it was hard to hide my emotions and because I needed to explain time off for appointments and treatment. At first, the headteacher was supportive. I took time off for chemotherapy sessions.

My cancer doctors had warned me about the side effects and given me some of CancerBACUP's booklets. I also signed a form to confirm I had been warned about side effects in advance. This was really useful as I knew what to expect.

I realised I would not be fit enough to continue in my original job during treatment, but I did want to continue working to some extent – it was important for my self-esteem. The headteacher agreed for me to change jobs during my treatment and found me administrative work in the office with less responsibility and fewer hours. However, although he agreed for me to come in only when I felt strong enough, he soon became irritated that I couldn't manage the standard hours of 8:30am to 4:30pm. I began to feel guilty about the time I was not in the office.

I developed hand-foot syndrome. The skin on my hands and feet became sore and peeling, I was extremely tired and my arms and legs ached. The tiredness made it really difficult to concentrate and perform the simplest tasks. Despite this, I was pleased to have been offered this job in the office and to be coming in.

The treatment was successful. In April 2002 doctors said I was fit to return to my original job on a gradual phased basis. At this point the school insisted I either return full-time or accept a

severance package – a choice which soon changed to accepting severance or being dismissed. I was dismissed on 28 August 2002. I was absolutely devastated.

With the help of my union, I took my case to an employment tribunal, which ruled in March 2003 that there had been no justification for the dismissal. I have tried extensively and unsuccessfully to find a permanent job since being cleared to return to full-time work.

I have lost a lot of confidence because of what has happened. My career prospects and ability to do my job have been severely damaged as a result of the experience. I feared disclosing my cancer to a new employer because I believed they wouldn't want to employ me because of it.

I still don't understand why the school fired me. I loved working there and miss the children.

I did not have easy access to HR support and was not offered the legal minimum sick leave or counselling. I was offered no information or support in managing work issues associated with my cancer.

My employer could not understand why I would need a phased and flexible return to my job. He had no understanding of the impact of cancer treatment and its side effects.

If CancerBACUP's new booklet about work and cancer had been available at the time, perhaps I would have known my rights and been more confident in pointing these out to my employer. I may still be working there now.

C) I work in a shop in Dorset

I was diagnosed with breast cancer in June 2004. I felt extremely anxious about telling my line manager and colleagues, but did it as soon as I was diagnosed because it was hard to hide my emotions and I needed to explain time off for treatment. I also believed my colleagues could offer emotional support.

Colleagues were surprised to see me return to work just seven weeks after surgery. Some people thought I should have given up work until my treatment was finished, but I had to work as I don't get paid when I'm not there and I needed the money.

I have recently finished chemotherapy and will have to take tamoxifen for five years. I am still experiencing side effects, including extreme fatigue. My overall working life and ability to do the job have deteriorated. I find it really difficult to reduce the pain and to keep the fatigue and other symptoms of cancer from interfering with the things I want to do. I make more mistakes due to a lack of concentration and feel tired and under pressure. Because of my lack of energy, I find it very difficult to deal with the stress when it gets busy in the shop, especially on delivery days.

I have not been offered any information or support in managing cancer at work and find it hard to deal with the depression, anxiety and the stress I've experienced since being

diagnosed. I have had to struggle with constant weight gain, the loss of a breast and hair loss. I feel less like my old self, lack confidence and need to take anti-depressants.

I can talk about my cancer at work and feel my colleagues now understand cancer and its treatment. The cancer has actually improved my relationship with them as they are sympathetic to what I am going through.

Sadly, my work doesn't offer the opportunity to work fewer or more flexible hours and my boss hasn't been at all understanding. He offered me no time off to attend medical appointments and instead asked me to organise them for before or after my shifts. He asked me when I would need time off for treatment, but never asked how it was going or how I felt. Just after the chemotherapy sessions he understood I needed some time off, but I didn't get paid for it. As a result I always felt compelled to go back to work after a few days.

My boss expects me to do the same things I did before the treatment. He doesn't understand that the side effects go on after the treatment finishes. I get annoyed about this but just have to put up with it as I don't want to lose my job. It is really difficult for somebody over 50 to find a job and having cancer makes it even more difficult.

If I did find a new job I would be afraid of telling a new employer about my cancer as I fear they would discriminate against me.

It was incredibly hard to work through my cancer treatment. I wish I could have reduced my hours, particularly during the weeks when I had treatment. It's still difficult now because of the ongoing side effects. It would have been so much easier if I'd been working for an organisation that offered flexible working arrangements. It would also help a great deal to have more support and understanding from my boss. I have had no information about my rights or entitlements so I have no idea whether or not I am being treated fairly.

D) I am 33 and live with my husband in Essex

I was diagnosed with non-hodgkins lymphoma in May 2004. I was instantly anxious about the treatment I'd have to go through and what would happen afterwards.

I had already told my supervisor and some of my colleagues that I was having a biopsy on my neck, so when the results came through I spoke to my supervisor straight away. He was supportive and agreed to talk to my colleagues about my situation, which was a relief.

I went through eight sessions of chemotherapy. Working during treatment would have been difficult. My job as an automotive engineer means that I'm working on one project for two to three months at a time and my chemotherapy was every three weeks. Also, I generally felt tired and sick the week after each chemo and don't think I could have coped mentally with work, as I couldn't concentrate for long periods. Added to this, half-way through my treatment my hair thinned considerably and I felt very self-conscious.

My oncologist had warned me about the side effects of the treatment. I decided it would be easier and for me and my employer if I didn't work at all during this time. I was confident my organisation would be happy with this as I knew the sickness policy was fair. My supervisor agreed and said I should take all the time I needed. This arrangement worked well, although I missed the mental stimulation and contact with colleagues. I did pop in every few weeks to catch up with them.

My supervisor offered to keep in touch with me while I was off work. He kept in touch by email and phone and came round to see me once. He asked me how I was feeling and how the treatment was going. My colleagues were also great. They also kept in touch through email and phone calls. They kept me up to date with all the gossip and sent me many bunches of flowers and cards. It meant so much to know they were thinking of me; they are very thoughtful.

I have been back at work since the beginning of December. It's going really well and I am back to a kind of normality. I saw the company doctor a month before I returned to work. He suggested I came back to work part-time and then gradually built up my hours over three months, as coming back directly full-time would have been a shock. My supervisor was more than happy for me to do this. I saw the company doctor again on my first week back at work and now see him every six weeks. It is extremely helpful and reassuring as I feel the company is looking after me and making sure I can cope with the hours. This doctor also told me about a counselling service provided by the company. I went to two sessions and found them really helpful.

In addition, I have an informal meeting with my supervisor once a fortnight. Again, this is really reassuring for me to get this support. I know he is happy about me doing part-time work and he is always keen to make sure everything is ok.

Because of the support from the company doctor and my supervisor, I have only really needed to have contact with HR for administration matters.

I am really lucky to work for an organisation that has a really good sickness policy, a company doctor and a well thought out return to work policy where I could come back part-time at first and build up my hours gradually. My colleagues and supervisor have been sensitive to the emotional impact of a cancer diagnosis and the side effects of the disease. Without this flexibility, support and understanding coming back would have been much more difficult.

E) I am 26 and live in Edinburgh

I am a university researcher and student. Prior to the onset of cancer, I was an extremely fit and healthy young man. My friends even considered me a fitness freak due to the number of miles I ran in the hills around Edinburgh every week. My health and fitness greatly helped me to be confident in all aspects of my life, including work. When I was diagnosed, the last thing I considered was how much my confidence would be affected.

At the end of July 2004, I was diagnosed with malignant melanoma and was given a prognosis of only 40% chance of surviving five years. Such a bleak prognosis for a young man rattled my confidence in a big way.

I told my manager as soon as I was diagnosed as I needed to explain time off for appointments and treatment. I told my colleagues when I realised I could no longer hide it. Given the prognosis, I was quite anxious about telling people at work.

I had my first surgery in August and the second at the end of September. My line manager was very supportive. He offered me a new one-year contract, pointed out that my health was the most important thing and told me to come back when I felt ready. I returned to work one month later. When I returned I had regular informal chats with my manager. He would come to me and ask me how I was getting on. Knowing I had the support of somebody else was really helpful as, in my job, I work on my own.

I wish my cancer doctors had warned me about how treatment might affect my work. I found it difficult to manage the stress of dealing with cancer, the anxiety, the pain and the emotional distress. I felt really tired and found it difficult to concentrate. I realised that perhaps I could have done with more time off to think about my life and what had happened to me.

However, at the same time, I felt returning to work was important to my self-esteem and saw it as a very significant step to returning to a "normal life". Initially, it was hard to go back to work because of my loss of confidence, but my manager helped by encouraging me to do the things I enjoyed most. I am grateful for the autonomy and trust my manager gave me, as at the time I felt the cancer had taken control away from me.

I know my company has good policies and certainly could have had access to HR, but I didn't feel I needed it because my line manager was so supportive. My colleagues were also supportive and friendly. They were genuinely concerned and showed interest about how I was. One of them had gone through a similar experience and invited me to have a chat around a cup of coffee. It was quite useful for me to get this support and it made me feel I was able to talk about my cancer at work.

I hardly suffered any financial difficulties. My organisation gave me paid time off to attend medical appointments but as I work part-time and do a lot at home, it was easy to adapt my working hours to my medical appointments. I now go for check-ups every three months and that works well for me.

I feel that my job satisfaction and relationships with my line manager and colleagues have improved because of the support they showed me. In return, I am more empathetic towards other people and more aware of the problems they might have to deal with in their lives.

Returning to my normal life – and particularly running again and returning to work – have been crucial to my recovery from cancer.

Further information

11

CancerBACUP – National Cancer Information Service

The cancer information specialist nurses give information on all aspects of cancer and its treatment, and on the practical and emotional aspects of living with cancer.

Tel: **020 7739 2280**, or Freephone: **0808 800 1234**

Lines are open Monday–Friday, 9am–8pm. An interpreting service is available for people whose first language is not English.

Calls to the Cancer Information Service are confidential. Sometimes another member of our team may listen to a call for training purposes and to maintain quality.

You can also fax enquiries to **020 7696 9002** or email them to **info@cancerbacup.org**

or write to:

CancerBACUP, 3 Bath Place, Rivington Street, London, EC2A 3JR. Office: 020 7696 9003

CancerBACUP Scotland, Suite 2, 3rd Floor, Cranston House, 104/114 Argyle Street, Glasgow, G2 8BH. Office: 0141 223 7676 Freephone: 0808 800 1234

Website www.cancerbacup.org.uk

CancerBACUP's award-winning website includes the full text of all our publications, a database of support groups and other services for cancer patients.

Local centres

- **London**
The Vicky Clement-Jones CancerBACUP Information Centre, King George V Building, St Bartholomew's Hospital, London, EC1A 7BE
Tel: 020 7601 7936
- CancerBACUP Information Centre, The London Clinic
20 Devonshire Place
London, W1G 6BW
Tel: 020 7616 7628
- CancerBACUP Information Centre, Charing Cross Hospital
Fulham Palace Road
London, W6 8RF
Tel: 020 8383 0171

- **Manchester**
Cancer Information Centre
The Christie Hospital
Wilmslow Road
Withington
Manchester, M20 4BX
Tel: 0161 446 8100
- **Nottingham**
CancerBACUP Information Centre, Oncology Block
Nottingham City Hospital
Hucknall Road
Nottingham, NG5 1PB
Tel: 0115 840 2650
- **Coventry**
CancerBACUP Information Centre, The Walsgrave Hospital
Clifford Bridge Road
Walsgrave
Coventry, CV2 2DX
Tel: 02476 535 099
- **Ipswich**
Cancer Information Centre, Woolverstone Wing,
Ipswich Hospital, Heath Road, Ipswich, IP4 5PD
Tel: 01473 715748
- **Jersey**
CancerBACUP Jersey
Gervais Les Gros Resource Centre, Mont les Vaux, St Aubin, Jersey, JE3 8AA
Tel: 01534 498 235
Freephone: 0800 735 0275
- **Torbay**
Cancer Support Centre
The Lodge
Torbay Hospital Annexe
Newton Road
Torquay, TQ2 7AA
Tel: 01803 617 521

Other useful organisations

Access to Work scheme

Tel: 0845 6060 234

Textphone: 0845 6055 255

Website: www.jobcentreplus.gov.uk

Administered by the Government's Department for Work and Pensions. This scheme is provided through disability employment advisors based at local offices of Jobcentre Plus. It provides advice and practical support to disabled people and their employers to help overcome work-related obstacles resulting from a disability.

Cancer Counselling Trust

Caspari House, 1 Noel Road, London, N1 8HQ

Tel: 020 7704 1137

Email: support@cctrust.org.uk

Website: www.cctrust.org.uk

Offers face-to-face and telephone counselling sessions to cancer patients, their families and friends. Also offers support if a friend or relative has died of cancer. The trust is staffed by a team of experienced cancer counsellors.

Carers UK

Ruth Pitter House, 20–25 Glasshouse Yard, London, EC1A 4JT

Tel: 0808 808 7777 Fax: 020 7490 8824

Minicom: 020 7251 8969

Email: info@ukcarers.org

Website: carersonline.org.uk

Offers information and support to professionals, relatives, and friends who are carers. Has 117 local and regional covering England, Northern Ireland, Scotland and Wales. Will put people in contact with carers support groups in their area.

Citizens Advice Bureau

Myddleton House, 115–123 Pentonville Road, London, N1 9LZ

Tel: 020 7833 2181

Website: www.citizensadvice.org.uk

Provides details of local offices of the Citizens Advice Bureau which can give legal advice and assistance with employment and disability rights problems.

Disability Alliance

Universal House, 88–94 Wentworth Street, London, E1 7SA

Tel: 020 7247 8776

Minicom: 020 7247 8776

Website: www.disabilityalliance.org

Registered charity which provides advice about benefit entitlements for people with disabilities.

The Disability Law Service (DLS)

39–45 Cavell Street, Whitechapel, London E1 2BP

Tel: 020 7791 9800

Minicom: 020 7791 9801

Email: advice@dls.org.uk

A registered charity offering free confidential legal advice on disability discrimination in employment to people with disabilities, their families and carers. Can take on certain cases on behalf of disabled employees or job applicants. In addition to employment law advice, DLS also

offers advice in other categories of law: community care, education, consumer/contract, welfare benefits.

Disability Living Foundation

380–384 Harrow Road, London, W9 2HU
Tel: 0845 130 9177 (charged at local call rate)
10am–1pm, Mon–Fri
Textphone: 020 7432 8009

Provides information and advice on products and equipment to assist independent living.

Department for Work and Pensions

www.dwp.gov.uk or www.disability.gov.uk

Disability Rights Commission (DRC)

Freepost MID 02164,
Stratford-upon-Avon, Warwickshire, CV37 9HY
Tel: 08457 622 633
Textphone: 08457 622 644
Website: www.drc-gb.org
Email: enquiry@drc-gb.org

A national organisation set up by the Government to monitor and combat disability discrimination and promote equality for disabled people. It operates a telephone helpline for people who believe that they may be experiencing disability discrimination at work. Also publishes useful guides and leaflets which can be obtained from their helpline or website. In some cases, the DRC will advise and represent disabled people who make disability discrimination claims.

IFA Promotions

Tel: 0800 085 3250
Website: www.unbiased.co.uk
Gives details of independent financial advisors.

Law Centres Federation

Duchess House, 18–19 Warren Street, London, W1P 5DB
Tel: 020 7387 8570
Website: www.lawcentres.org.uk

Provides details of local law centres which can give legal advice and assistance with employment claims.

Law Society

Ipsley Court, Berrington Close, Redditch, Worcestershire, B98 0TD
Tel: 020 7242 1222

Email: info.services@lawsociety.org.uk

Website: www.lawsociety.org.uk

Provides details of solicitors who can advise on discrimination and employment cases.

Legal Services Commission

29–37 Red Lion Street, London, WC1R 4PP

Tel: 0845 3434345

Website: www.clsdirect.org.uk

The Government organisation that oversees legal aid. Provides contact details for approved solicitors and other specialist organisations who may be able to advise and assist you, subject to eligibility, under the free Legal Help scheme.

Macmillan Cancer Relief

89 Albert Embankment, London, SE1 7UQ

Tel: 0808 808 2020 (Macmillan CancerLine, Mon–Fri 9am–6pm)

Tel: 020 7840 7840

Email: cancerline@macmillan.org.uk

Website: www.macmillan.org.uk

A national charity providing expert treatment and care through specialist Macmillan nurses and doctors and grants for patients in financial difficulties. The Macmillan CancerLine gives information for patients and their carers about Macmillan services.

National Debtline

The Arch, 48–52 Floodgate Street, Birmingham, B5 5SL

Tel: 0808 808 4000

Website: www.nationaldebtline.co.uk

Gives advice to anyone worried about debt.

Helpful books, videos and CD-ROMs

A guide to grants for individuals in need 2004/2005

Alan French

Directory of Social Change, 2004

ISBN 1903991528 £20.95

Contains details of a wide range of charities and trusts that provide financial assistance to people in need.

Challenging cancer: fighting back, taking control, finding options (2nd ed)

Maurice Slevin and Nina Kfir

Class Publishing, 2002

ISBN 1859590683 £14.99

Written by a cancer specialist and psychotherapist, this book aims to help people make sense of a cancer diagnosis to regain control of their lives.

The chemotherapy and radiation therapy survival guide: Information, suggestions, and support to help get you through treatment (2nd Ed)

Judith McKay and Nancee Hirano

New Harbinger Publications, 1998

ISBN 1572240709 £12.99

Gives information about treatment, coping with side effects, where to get support and how to eat well. Also has information on bone marrow transplants.

Disability rights handbook (on CD-ROM)

Disability Alliance – published each year, currently 29th edition for April 2004–April 2005

ISBN 903335191 £17.51

Covers benefit entitlements, rights at work and other disability issues. Available from Disability Alliance.

Understanding cancer

Gareth Rees

Family Doctor Publications, 2002

ISBN 1898205515 £3.50

Clearly written and well-illustrated providing information on what cancer is, how the diagnosis is made and treatments. Diagnostic tests are explained and illustrated. Also touches briefly on symptom control, clinical trials and complementary treatments.

What you really need to know about cancer: a comprehensive guide for patients and their families (revised edition)

Robert Buckman

Pan, 1997

ISBN 0330336282 £9.99

Covers the nature and causes of cancer, surveys the commonest types of the disease and describes methods of detection, treatment and prevention.

Video

Chemotherapy and radiotherapy (English, Italian versions)

Chemotherapy and radiotherapy by Asian patients for Asian patients (Urdu, Hindi, Gujarati, Bengali versions)

This video for patients about to have cancer treatment gives an overview of treatment, risks

of side effects and methods used to alleviate them. It features patients talking about their experiences. Saeed Jaffrey and Rani Singh also contribute to the Asian language versions. Available from CancerBACUP.

Websites

A lot of information about cancer is available on the Internet. Some websites are excellent, others have misleading or out of date information. The sites listed below have accurate information and are regularly updated.

www.cancerbacup.org.uk (CancerBACUP)

- Contains over 4,500 pages of accurate, up-to-date information on all aspects of cancer and a searchable database of other organisations.
- Allows you to send questions to specialist cancer nurses by email and has a question-and-answer section.
- Includes all CancerBACUP's 67 booklets and 200+ factsheets.
- Recommends further reading.
- Provides guidance for health professionals and others on controversial cancer topics.
- Includes *CancerBACUP News*.
- Offers links to recommended cancer websites around the world.
- Has a special search engine for cancer research clinical trials available to cancer patients in the UK and Europe

www.cancerhelp.org.uk (Cancer Research UK)

Contains patient information on all types of cancer and has a cancer research clinical trials database.

www.compactlaw.co.uk/ivillage (iVillage – work and career)

Discusses unfair dismissal, wrongful dismissal, redundancy, discrimination, maternity and paternity rights, flexible working, and statutory sick pay.

www.dipex.org (Database of individual patient experiences)

Contains information about some cancers and has video and audio clips of people talking about their experiences of cancer and its treatments. Also contains discussion of the physical, social and psychological effects of cancer.

www.disabilityalliance.org (Disability Alliance)

Has detailed information on all aspects of disability, including benefits.

www.dwp.gov.uk (Department for Work and Pensions)

Gives information on all aspects of work and benefits.

www.intelihealth.com (drug and medicines information)

Easy-to-use and free from medical jargon. Has patient information leaflets which can be printed.

www.nci.nih.gov (National Cancer Institute – National Institute of Health – USA)

Gives comprehensive information on cancer and treatments.

www.nelh.nhs.uk (UK National Electronic Library for Health)

National UK health information site – covers all aspects of health, illness and treatments.

www.sofa.org (Society of Financial Advisers)

Searchable database of independent financial advisors.

www.workingaftercancer.co.uk (Working after cancer)

Set up by a man who had cancer, this site has practical advice and tips on employment issues.

CancerBACUP has a wide range of booklets and factsheets about all types of cancer, cancer treatments and living with cancer. These include:

- Understanding cancer research trials
- Understanding chemotherapy
- Understanding radiotherapy
- Understanding the NHS cancer referral guidelines
- CancerBACUP recipes
- Cancer and complementary therapies
- Controlling cancer pain
- Controlling the symptoms of cancer
- Coping at home:
caring for someone with advanced cancer
- Coping with advanced cancer
- Coping with fatigue
- Coping with hair loss
- Work and cancer
- Dying with cancer
- The emotional effects of cancer
- Lost for words: how to talk to someone with cancer
- Sexuality and cancer
- Travel and cancer
- Diet and cancer
- What do I tell the children?
A guide for a parent with cancer
- Adjusting to life after cancer treatment
- Who can ever understand? Talking about your cancer

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Work and cancer survey

PART 1: ABOUT YOU

The answers you give to the following questions are confidential; they will not be used to identify individuals. Please circle or write the answer that best applies to you in the space provided.

1. Are you male or female?

- a Male
- b Female

2. How old are you?

..... years

3. Do you consider yourself to have a disability? (not related to cancer)

- a No
- b Yes *(please specify below)*

.....

4. What type of cancer do you/did you have?

.....

5. What is your ethnic group?

- a White British
- b White Irish
- c Other White *(please write in)*
.....
- d Black Caribbean
- e Black African
- f Other Black *(please write in)*
.....
- g Indian
- h Pakistani
- i Bangladeshi
- j Chinese
- k Other Asian *(please write in)*
.....
- L Mixed ethnic origin *(please write in)*
.....
- m Other ethnic group *(please write in)*
.....

6. When were you first diagnosed? Date:

7. Are you receiving/have you received any treatment for your cancer? (please circle only one answer)

- a Yes (currently)
- b Yes (completed)
- c No ***(please go straight to question 10)***
- d Not yet ***(please go straight to question 10)***

8. What types of treatment are you receiving/have you received for your cancer? (please circle all that apply)

- a Oral medication (including oral chemotherapy)
 - b Surgery
 - c Chemotherapy
 - d Radiotherapy
 - e Other (please specify)
-

9. Did your cancer doctor inform you about the impact of different cancer treatments on your ability to work? (please circle only one answer)

- a Yes
- b No
- c Not sure / can't remember

PART 2: ABOUT YOUR EMPLOYMENT

This section asks you about the organisation for which you work. If you are not currently working, please respond with the organisation for which you were working during your cancer diagnosis and treatment in mind.

10. What best describes your employment status before, during and following your cancer treatment? *(please tick all that apply)*

	Before treatment	During treatment	After treatment
Working full-time			
Working part-time			
Self-employed			
On sick leave			
Unemployed			
Retired			
Unable to work			
Other			

11. What is/was your main occupation? *(please state below)*

Official use only				
-------------------	--	--	--	--

.....

12. Approximately how many people does/did your organisation employ? *(please circle only one answer)*

- | | | | |
|---|-------------------------|---|---------------------|
| a | N/A I was self employed | d | 50 – 199 |
| b | 1 - 10 employees | e | 200 – 1000 |
| c | 11 – 49 | f | Over 1000 employees |

PART 3: ABOUT DISCLOSING YOUR CANCER AT WORK

This section asks you about telling your line manager and work colleagues about your cancer. If you are not currently working, please answer with the organisation for which you were working during your cancer diagnosis and treatment in mind.

13. Have you told/did you tell your line manager about your cancer? *(please circle only one answer)*

- | | | | |
|---|-----|---|---------------------------|
| a | Yes | c | Not sure / can't remember |
| b | No | d | Not applicable (N/A) |

14. Have you told/did you tell your colleagues about your cancer?
(please circle only one answer)

- a Yes c Not sure/can't remember
 b No d N/A

NB: If you have not told anyone at work about your cancer, please go to question 18

15. When did you tell your line manager and colleagues about your cancer?
(please tick one box each for line manager and colleagues)

	Line Manager	Colleagues
As soon as I was diagnosed		
When my treatment began		
When I realised I could no longer hide it		
When it started to affect my relationships at work		
When it started to affect my work		
Other (please specify)		

16. What persuaded you to tell your line manager and colleagues about your cancer? *(please tick all that apply)*

	Line Manager	Colleagues
It was hard to hide the emotions associated with illness and treatment		
It was hard to hide the physical effects of illness and treatment		
I needed to explain time off for appointments and treatment		
I knew I could talk in confidence		
I believed they could offer emotional support		
I believed they could offer practical support		
I knew the organisation had good health policies and benefits		
I needed to know about the organisation's health policies and benefits		
Other (please specify)		

17. **What best describes your feelings when telling your line manager and colleagues about your cancer?** (please circle one answer each for line manager and colleagues)

	Not at all anxious			Extremely anxious	
Line manager	1	2	3	4	5
Colleagues	1	2	3	4	5

18. **If you have not told/did not tell your line manager and/or colleagues about your cancer, why was this?** (please tick all that apply)

	Line Manager	Colleagues
To keep that area of my life normal		
To keep my cancer private		
Not sure who to tell in my organisation		
Concerned that it would not be kept confidential		
Did not expect to receive extra support		
Concerned I might be treated unfairly		
Worried about job security		
Worried about reduced career prospects		
Other (please specify)		

PART 4: ABOUT THE IMPACT OF CANCER ON YOUR WORK

This section asks you about the impact of cancer on your work. If you are not currently working, please respond with the organisation for which you were working during your cancer diagnosis and treatment in mind.

19. **Have you experienced any of the following at work as a result of your cancer?** (please tick all that apply)

- Treated as if I can't/couldn't do my job
- Overlooked for promotion
- Stigmatised by others at work
- Reduced career prospects
- Changes in my job role occurred without my agreement
- Changes in my job role occurred with my agreement
- Discrimination
- Felt pressure to resign
- Offered early retirement
- Asked to leave the organisation
- Fear/feared disclosing my cancer to a new employer

20. **Approximately how much time have you had off work due to your cancer?**

..... months days

21. Approximately how much of your annual leave have you used/did you use for medical appointments and/or treatments related to your cancer?

..... months days

22. To what extent have you suffered financial difficulties as a result of the impact of cancer on your work? (please circle only one answer)

- a A great deal
- b A significant amount
- c Hardly any
- d None at all
- e Don't know

23. Which of the following side effects are/were difficult to manage at work during and following your cancer treatment?

(Please tick all that apply)

	During treatment	Following treatment
Fatigue		
Stress of dealing with cancer		
Anxiety		
Loss of concentration		
Depression		
Pain		
Nausea/Sickness		
Physical changes eg hair loss		
Emotional distress		
Other (please specify)		

24. How has your working life changed as a result of your cancer?

(Please tick all that apply)

	Improved	No change	Deteriorated
Your job satisfaction			
Your relationship with your line manager			
Your relationship with your colleagues			
Your career prospects			
Your overall working life			
Your ability to do your job			
Other (please specify)			

25. If you have you changed jobs because of your cancer, please use this space to tell us how and why this changed.

PART 5: MANAGING YOUR CANCER AT WORK

This section asks you about how you manage(d) your cancer at work during and after your cancer treatment. If you are not currently working, please respond with the organisation for which you were working during your cancer diagnosis and treatment in mind.

26. Has/did your organisation offered/offer you the following policies/services and have they/would they have helped? *(please tick all that apply)*

	Yes	No	Has/would have helped
Paid time off to attend all medical appointments			
Paid time off to attend some medical appointments			
The legal minimum sick leave (28 weeks)			
More than the legal minimum sick leave			
Easy access to Human Resources or Occupational Health support			
Work adjustment policies (e.g. change of job description)			
Counselling			
Working fewer/flexible contracted hours			
Flexible/alternative working arrangements eg working from home			
Adjustment of physical environment eg access, doors			
Private health insurance			
Return to work meeting with employer			
Other (please specify)			

27. Have you been/were you offered any information in managing work issues associated with your cancer? *(please circle only one answer)*

- a Yes c Not sure/can't remember
- b No

28. Have you been/were you offered any support in managing work issues associated with your cancer?

(please circle only one answer)

- a Yes c Not sure/can't remember
- b No

NB: If you were not offered any information OR support in managing work issues, please go to question 31

29. Did the information and support you were offered include any of the following and have they/would they have helped?

(please tick all that apply)

	Yes	No	Has helped/would have helped
Information about your statutory rights, e.g. Incapacity Benefit			
Information about any extra rights offered by your organisation, e.g. additional paid sick leave			
Information on how to talk about your cancer to colleagues			
Support in talking about your cancer to your colleagues			
Regular consultation about managing your workload during treatment			
Advice about other sources of information and support			
Other (please specify)			

30. Please rate the following aspects of information and support in managing work issues associated with your cancer. *(please circle appropriately)*

	Very poor				Very good
Information given to me at work about managing work issues associated with cancer	1	2	3	4	5
The level of support from my line manager during treatment	1	2	3	4	5
The level of support from my line manager following treatment	1	2	3	4	5
The level of support from my colleagues during treatment	1	2	3	4	5
The level of support from my colleagues following treatment	1	2	3	4	5

31. Please let us know if you agree with the following statements.
(please tick all that apply)

- I feel/felt able to talk about my cancer at work
- I feel/felt my employer understands/understood cancer and cancer treatment
- I feel/felt my colleagues understand/understood cancer and cancer treatment
- I feel/felt stigmatised by others at work
- I feel/felt guilty about taking time off for medical appointments/treatment
- I feel/felt out of touch with work during my cancer treatment
- I have lost/lost confidence in my ability to do my job during my cancer treatment
- I feel/felt continuing to work is/was important to my self-esteem
- I feel/felt glad to have an area of my life (ie work) which is/was relatively normal
- I fear/feared disclosing my cancer to a new employer
- I feel/felt I need/ed more time off work following my cancer treatment

32. In managing your cancer at work, how confident are/were you that you can/could do the following? (please circle appropriately)

	Not at all confident					Totally confident	
	1	2	3	4	5	N/A	
Reduce your physical discomfort or pain at work?	1	2	3	4	5	N/A	
Keep the fatigue caused by your cancer or its treatment from interfering with the things you want to do at work?	1	2	3	4	5	N/A	
Keep the symptoms of your cancer or the side effects of its treatment from interfering with the things you want to do at work?	1	2	3	4	5	N/A	
Follow your medication regimen/routine at work?	1	2	3	4	5	N/A	
Reduce the emotional distress caused by your cancer or its treatment so that it does not affect your everyday work?	1	2	3	4	5	N/A	
Make changes yourself to the way in which you work?	1	2	3	4	5	N/A	
Ask for changes/adjustments in your work or workplace?	1	2	3	4	5	N/A	

33. Are you aware that from October 2004 cancer patients may be classified as disabled under the Disability Discrimination Act?
(please circle only one answer)

- a Yes
- b No

Thank you for your time. Information on how to return this questionnaire can be found at the end of this document. Please return as soon as possible, but by November 1st at the latest.

The findings of this survey will be posted on the CancerBACUP website later in the year. This survey will also guide our forthcoming campaign 'Cancer and Work'. We are also planning to hold a series of focus groups and interviews to gain further information about cancer and work. If you are interested in participating, please contact Jill Morrell (address at the end of this document) to register your interest.

CancerBACUP's Employee Benefit Initiative

CancerBACUP's Employee Benefit Initiative Scheme provides companies with a dedicated freephone number to the CancerBACUP helpline for their employees, including access to all publications and the Cancer in Your Language interpreting service.

It offers a 'bespoke doorway' for companies, linking up with existing employee assistance benefit programmes and enabling businesses to provide a valuable and unique service to their employees.

The Scheme was founded by Hilary Cropper, former Chief Executive of Xansa, who died of ovarian cancer in 2004. She used the CancerBACUP service and recognised the need for information, advice and support for employees.

Three companies have adopted the scheme so far – Rank, Next and BSkyB.

This report presents the findings of new research into how cancer affects working lives. It draws conclusions from the research and ends with a series of recommendations for policymakers, health professionals and employers, together with tips on good practice for employers and advice for employees.

At present, many organisations are struggling to provide the information, support and flexibility employees with cancer need if they wish to continue working or return to work following treatment. As a result, a large proportion of employees with cancer experience deterioration to their working lives. Many leave the workforce. The consequences are serious for the individual and there is a loss of knowledge and skills from the labour market.

We hope this report will assist health professionals, employers and employees in improving guidance and support for employees with cancer.