

WORKING WITH CANCER

Supporting employees living with cancer to return to work



bupa.com/cancer uicc.org

PREFACE

Thanks to the advances that have been made in cancer diagnosis and treatment, more people than ever before are surviving cancer. Across the world, around 32.6 million people are still alive five years after their diagnosis, with many cancer survivors wanting to return to work. Cancer survivors cite both financial and emotional reasons for going back to work, with a job restoring normality, stability, social contact and income. For businesses, supporting people to come back to work after a cancer diagnosis improves their capacity to retain experienced employees, reduce sickness-related absence and help sustain a resilient, productive workforce.

Yet while the vast majority of employers want to do the right thing by their employees, research has uncovered the need for improved support from employers to help cancer survivors to transition back to the workplace effectively.

This resource was produced to help you understand and respond to the needs of your employees coming back to work after a cancer diagnosis. The focus of this guide is on four key actions that all businesses can take to support a successful return to work for their employees.

We also provide links to best practice tools and resources from around the world to assist you to build a comprehensive workplace initiative that best meets the needs of your workforce and your business.



"The 1000 Survivor Study by Cancer Council Queensland found employees' difficulties after surviving cancer extended long after diagnosis, with almost half of working cancer survivors surveyed being negatively affected in their jobs. Of the survivors who had these work concerns, 12% experienced employment discrimination, 10% were treated poorly on the job, 7% received a pay cut and nearly 6% felt they didn't get a job because of their cancer diagnosis."

Cancer Council Queensland CEO, and Board Member of the UICC Professor Jeff Dunn AO

What can employers do to support people living with cancer at work?

Employers can create a workplace culture where employees with a cancer diagnosis are encouraged to know that when they return to work they will be supported to adapt to the challenges they face from their illness.

1.

UNDERSTAND THE CHALLENGES FACED BY PEOPLE WITH CANCER

Improving awareness of the full impact of cancer and how this affects the return-to-work process among business leaders, line managers and co-workers can create a supportive workplace culture.

2

KEEP THE LINES OF COMMUNICATION OPEN

Talking with an employee about cancer, job modifications, legal rights and support programmes available at work will empower them to take control of their health and wellbeing.













3.

SUPPORT A FLEXIBLE RETURN TO WORK

Very often, people living with cancer need their employers to make some allowances such as changes in tasks or function, to support them to get back to work successfully. 4.

PREVENT DISCRIMINATION AND STIGMA

In many countries, employers have a legal obligation to make reasonable adjustments at work for people living with cancer and to ensure they are not at a disadvantage compared to other employees.

UNDERSTAND THE CHALLENGES FACED BY PEOPLE WITH CANCER



Improving awareness of the full impact of cancer and how this affects the return-to-work process is the first step in supporting employees to return to work after a cancer diagnosis.

Workplace communication channels can be used to equip senior business leaders, line managers and co-workers with knowledge of the effects of cancer treatment as part of a broader approach to managing cancer in your workplace along with other interventions that support your workforce to be healthy and productive.

Educating Your Workforce About The Full Impact Of Cancer: What We Know

- Cancer treatment can impact physical and emotional health. In a UK study, 57% of cancer survivors who were in work when diagnosed had to give up work or change their roles as a result of their diagnosis. Of these, 43% were not physically able to work and a quarter were not emotionally strong enough to work (25%). But getting people back to work successfully can be an important part of their recovery a job can restore routine, stability, social contact and income.
- Fatigue is one of the most common side effects of cancer and its treatment. Fatigue is different for every cancer patient some people experience fatigue a few days a month around the time of treatment while others experience it on a daily basis. Fatigue affects individuals' physical functioning, causing emotional distress and making it difficult to concentrate. Small adjustments at work, such as providing additional short breaks for rest and exercise, can make a difference.

- Some cancer patients experience treatment-related cognitive impairment. The typically mild form of cognitive change that some patients experience after chemotherapy is sometimes called "chemobrain". Even this mild change can affect memory and concentration levels and may make it difficult for a person to multi-task. For some people, a change in tasks or responsibilities may be part of the return-to-work process.
- Support needs may be long-term. For some people, support may be needed over many years after the initial diagnosis as they continue to live with the physical and emotional impacts of cancer. For people living with metastatic cancer, the most advanced stage of cancer, support needs are likely to be ongoing. It's important for employers to take a holistic approach to support and not focus solely on the first few days or weeks after a person returns to work.
- Cancer patients may be unprepared for the full emotional and physical effects of their treatment.
 We know that very few patients are advised by health professionals about the impact cancer treatment may have on their ability to work.⁴ Yet, many cancer survivors want to regain a sense of control over their own health and wellbeing. For employers, this means providing access to information and tools that empower patients to self-manage their health and help them to tailor support that meets their individual needs.

In a UK survey of line managers, 56% said the main barrier to employees with cancer being offered support in their workplace is a lack of awareness of their needs.³



FOR EMPLOYERS

Workplace Transitions For People Touched By Cancer

A free, web-based tool to help support communication between managers and employees around cancer and work: Understand side effects: "Chemo Brain" and Fatigue

www.workplacetransitions.org

Cancer Council Australia

Working with Cancer – Cancer impacts in the workplace www.cancer.org.au

Cancer + Careers

Educating yourself on cancer (English and Spanish) www.cancerandcareers.org

National Business Group On Health

An employer's guide to cancer treatment and prevention www.businessgrouphealth.org



FOR EMPLOYEES

Bupa - The Blue Room

An online information source for understanding life with cancer

www.theblueroom.bupa.com.au

Cancer Council Victoria

Cancer, work and you – A guide for people with cancer, their families and friends

www.cancervic.org.au

GEPAC - The Spanish Cancer Patient Group

A non-profit alliance of patients associations, and corporate members with a focus on interaction with patients creating a community feel through provision of news, events and services, including psychological and judicial help, maintaining appearances due to body changes caused by cancer, support online or on the phone for patients.

www.gepac.es

The National Coalition For Cancer Survivorship

The Cancer Survival Toolbox® is a free audio program created by leading cancer organizations to help people develop skills to better meet and understand the challenges of their illness. Available in English and Spanish.

www.canceradvocacy.org

LIVESTRONG

Employment Issues www.livestrong.org

KEEP THE LINES OF COMMUNICATION OPEN



Poor communication can be a barrier to providing your employee the support they need to transition back to work effectively. Talking with your employee about job modifications, legal rights and responsibilities and support programs available in your workplace will empower them to take control of their health and wellbeing and help ease their transition back to work.

Implement a communications plan

If an employee decides to discuss their cancer diagnosis, it is important to encourage open communication at all stages of the return-to-work-process:

- Schedule return-to-work meetings before your employee comes back to work. You should discuss:
 - What sort of support your organisation provides and where this can be sourced. For example, does your workplace provide access to free workplace counselling or can you provide resources or tools to assist them with the challenges ahead? Are these available through Human Resources or their Line Manager?
 - Encourage your employee to communicate the support they will need when they return to work. For example, will they need flexible working arrangements or a phased return-to-work to manage the physical and emotional impact of their diagnosis and treatment?
 - Agree the best approach for managing your employee's transition back to work. Creating a tailored adjustment plan with your employee that sets out changes in tasks, hours, or responsibilities and other agreed work accommodations is a vital part of the return-to-work process. For both employers and their employee, it is an important opportunity to be open and transparent on rights and responsibilities so that expectations are met on both sides.

- Be clear about your employee's wishes on confidentiality. Some employees may prefer not to share their diagnosis with other members of their team and an employer cannot divulge this information without the employee's consent.
- Agree on a plan for communicating with your employee when they are away from work. It is important for some employees working from home or on a flexible schedule to maintain communication and keep engaged in work and social activities where appropriate. Agreeing on a plan of when and how best to communicate is important to keep the lines of communication open.
- Convene regular consultations about managing workload. Once an employee is back at work, support needs may change over time. Ensuring open and honest communication about making adjustments to existing support plans is important.

In a recent study of public attitudes toward cancer and cancer patients in Korea, 72% believed that cancer patients would not be able to make a contribution to society.⁷



"Returning to work after a cancer diagnosis is hard for the employee, their employer and for fellow employees. Open and honest conversations about expectations and about what is and is not possible in terms of flexible work arrangements and job adjustments is critically important to avoid resentment and distress for all. The person returning to work will be unsure about what to share with the employer and will be concerned about discrimination and this is where positive and constructive conversations can really help."

Professor Sanchia Aranda, President-Elect UICC and CEO Cancer Council Australia



Maggie's & Unum

Returning to work after cancer ~ an employer's guide

www.resources.unum.co.uk

Cancer Council Australia

Role of managers and tips for employers

www.cancer.org.au

Macmillan Cancer Support

Work and Cancer: If you're an employer

www.macmillan.org.uk

Equip your workforce with the tools to communicate effectively about cancer

Training HR personnel and managers

Human Resources (HR) personnel and managers need to be equipped with the knowledge and resources to deal sensitively and effectively with people in the workforce who are affected by cancer.

A starting point is preparing ahead for the oftenchallenging conversation when an employee tells their manager or HR department about their cancer diagnosis. At this critical point, knowing how to respond appropriately can encourage open communication from the start and make any eventual challenges easier to work through. Workplace communication channels can be used to deliver best practice materials (web-based tools and toolkits; electronic and printed brochures) to guide managers on what to say, what information to give around available support, and other work issues to be aware of such as privacy, legal rights and responsibilities. Interactive sessions and workshops can also be conducted using educational tools designed for the workplace to better equip HR personnel and managers to deal with cancer at work.

Supporting co-workers

Managers and HR personnel can also play a role in managing the impact of a cancer diagnosis on coworkers. The reaction of a co-worker can differ depending on their experiences with family members or friends with cancer or even cultural beliefs about cancer – in some cases co-workers may even feel uncomfortable working with them.⁷ Using workplace communication channels and interactive sessions, co-workers can be provided with best practice materials to educate them on how best to respond and what to say as well as to dispel common myths about cancer.



TALKING ABOUT CANCER

Cancer Council NSW

Talking to your employee about cancer: The first conversation

www.cancercouncil.com.au

Macmillan Cancer Support

Cancer at Work: How to talk about cancer at work

www.macmillan.org.uk

Workplace Transitions For People Touched By Cancer

How to respond to the news

www.workplacetransitions.org

Support Co-workers

www.workplacetransitions.org

Cancer + Careers

When a Coworker Has Cancer: What to Say

www.cancerandcareers.org

American Cancer Society

When someone you work with has cancer (In English and Spanish)

www.cancer.org



TRAINING

Macmillan At Work: Training. Support. Knowledge.

In-house and open workshops designed for HR professionals and/or line managers

www.macmillan.org.uk

Working With Cancer

Training sessions about 'work and cancer' run on a bespoke basis depending on an organisation's needs. Some companies choose to arrange 60 minute or 90 minute 'Lunch and Learn' sessions for their line managers and their HR teams; others prefer to run longer, half-day sessions, or to make them part of wider briefings on health and wellbeing, or employment law.

www.workingwithcancer.co.uk

BREAST CANCER: A STORY HALF TOLD – SUPPORTING WORKPLACE CONVERSATIONS



Working Through Breast Cancer

The Supporting Workplace Conversations survey was commissioned by Pfizer and Cancer and Careers as part of the 'Breast Cancer, A Story Half Told' initiative.* It explores the experiences of over 1,000 breast cancer survivors including 189 with metastatic disease, the most advanced stage of breast cancer, who have worked or looked for work since their diagnosis.

The survey findings reveal some key messages for emplovers:

Women with breast cancer value work

Three out of four women surveyed feel that work aids in their recovery, a view shared almost unanimously by healthcare professionals surveyed. Women want to return to work for both financial and emotional reasons - nearly half of women with metastatic disease cited the desire to feel normal as a reason for wanting to work.



"Breast cancer is a diagnosis that can come with complicated treatment decisions as well as life decisions, including whether to work while undergoing treatment," said Dr. Julia Perkins Smith, Senior Medical Director, U.S. Breast Cancer Lead, Pfizer Oncology. "As this survey shows, working can provide not only financial but emotional value to women with breast cancer, including those with metastatic disease, who are always in treatment and may have a desire to maintain a feeling of normalcy even in the face of a challenging condition."

Dr. Julia Perkins Smith, Senior Medical Director, U.S. Breast Cancer Lead, Pfizer Oncology

Support from employers is paramount

Support from employers is key to helping women with breast cancer thrive in the workplace, but more needs to be done. Two-thirds of both oncologists and non-physician healthcare professionals surveyed feel there should be an improvement in how workplaces help women cope with breast cancer and treatment, as well as more support through the law. There was also a sizeable gap between what women with breast cancer report is available and what support employers report they provide:

Specific resources, advice or education for working during or after treatment



Employers 66% VS Women with Breast Cancer 8%

Availability of a support group in the workplace



Employers 58% VS Women with breast cancer 6%

Specific job modifications (such as additional break times or temporary work accommodation)



Employers 73% VS Women with breast cancer 22%

Greater communication can help women with breast cancer thrive in the workplace

Poor communication may explain the difference in perspective between women with breast cancer and their employers. Employers may overstate what they provide or women may not always be aware of what is available. The majority of women surveyed had not talked to someone at work about job modifications (51%), legal rights (72%) or programs to help them cope (73%)

^{*}The survey was commissioned by Pfizer and Cancer and Careers, and conducted online by Harris Poll from June 9 - 23, 2014. The survey involved 1,002 female breast cancer patients and survivors 18+ who have worked or looked for work since diagnosis (189 of these were metastatic breast cancer patients); separately, 102 employers (Human Resources or Employee Benefits managers, or executives with those responsibilities) in companies with 5+ employees in the US; 100 oncologists; 100 oncology nurses/ NPs, nurse navigators, and medical social workers who see breast cancer patients. Referenced with permission. All rights reserved.





SUPPORT A FLEXIBLE RETURN TO WORK



Employers can encourage a return to work by communicating to employees that they have flexible return to work policies and will make reasonable adjustments to assist employees with a cancer diagnosis to adapt to the challenges of their illness.

A smooth transition can be enabled by even small adjustments in tasks, hours, or responsibilities. Typical examples that your organisation could provide are:

- Supporting a phased return to work being as flexible as your business allows in supporting a person to take time to return to their position
- Agreeing with your employee on changing tasks (e.g. going on 'light duties') or responsibilities. This could be on a temporary or a permanent basis or involve a change in job if mutually agreed
- Altering performance targets
- Allowing extra breaks to deal with fatigue and/or flexibility in working hours
- Accommodating different physical needs in the workplace, e.g. adjusting for changes in mobility or physical functioning such as difficulty with stairs
- Having a flexible approach to time away from work for follow up appointments for treatment, rehabilitation and counselling. This includes time to participate in cancer support groups or buddy system

Other assistance that your organisation may consider includes providing free workplace counselling with a health professional, working with employees to put in place a workplace cancer support group, social network or buddy system, or extending leave beyond the statutory requirements. Supporting retraining if an employee cannot return to their previous role or even providing support for finding another job if the current one is no longer suitable could also be considered.

Different people need different help at different times

Often, the types of adjustments required will change over time. Continuing the conversation with your employee about how best to manage their workload is important.

Caregivers also need flexibility at work

Many cancer caregivers are in paid employment, and this dual role of caring and working can place significant stress and strain on an employee. They often face the same issues as patients such as needing time away from work to provide care as well as managing shifting responsibilities such as changes in childcare arrangements and domestic duties.8 Employers can be supportive by extending flexible workplace policies to caregivers, allowing extended leave, and providing access to resources such as workplace counselling.



When I had the bone marrow transplant, my colleague stepped into my role. At times, I worked from hospital, but I took 2-3 months of sick leave and eased back into work.

Cancer, Work and You, Cancer Council Victoria9



Maggie's & Unum

Creating a graduated return to work (GRTW) plan www.resources.unum.co.uk

Macmillan at Work

Macmillan at Work provides a range of expert training, consultancy options, and resources to help employers including an e-newsletter, and free work and cancer toolkit

www.macmillan.org.uk

Buddying guidelines: Guidelines developed alongside employers and people affected by cancer, designed to help organisations implement a buddying system in the workplace.

www.macmillan.org.uk

Cancer Council NSW

Supporting working carers www.cancercouncil.com.au

Death and bereavement www.cancercouncil.com.au

When an employee has advanced cancer

Sometimes an employee may be experiencing advanced cancer. This means their cancer may have progressed after treatment or they may have been diagnosed with advanced lifethreatening disease. Advanced cancer is often incurable but with the right care and support, many people can continue working for months or years and many either want to or have to work. And while workplace law in many countries supports a person to remain at work for as long as they want, the emotional and practical issues can make this a very challenging and distressing time for the person affected, their employer and their colleagues.

Open communication is paramount. Line managers and HR managers need to have honest conversations with their employee around reasonable adjustments within reason that can be put in place to support them to stay at work. Both the employer and the employee need to be prepared for this to change over time and seeking assistance from an occupational health professional may be important. Line managers and HR managers should also be prepared to talk to their team members who may be experiencing the emotional distress of their colleague having a terminal illness as well as dealing with practical issues such as sharing responsibilities.

PREVENT DISCRIMINATION **AND STIGMA**



Actions that employers take can reduce prejudices that prevent a person living with cancer to return to work successfully.

Cancer patients in many countries report experiencing discrimination in the workplace, and they often conceal their diagnosis for fear of losing their job or not being able to get a new job. Those returning to work can also come up against prejudice and misconceptions about their performance, or assumptions about the time off that will be required for treatment or rehabilitation. Often, they will not be aware of their legal rights or the legal responsibilities of their employers.

As an employer, you should be aware of your obligations to prevent discrimination at work and enforce workplace policies that ensure employees coping with cancer and their caregivers are not disadvantaged in recruitment, at work and when returning to work. 11 Employers should also be aware of the extent of their legal responsibility for the actions of their employees who may treat a colleague affected by cancer unfairly.

Although the law will differ in different countries, in some countries, cancer is considered to be a disability under national anti-discrimination legislation meaning that employers are required to make reasonable adjustments to support an employee to continue to work effectively. HR personnel and managers should be aware of national policies and laws on equal opportunities and workplace discrimination and be prepared to discuss these with their employee.

What is Discrimination?

Discrimination can occur in different ways.

- Direct discrimination This means treating a person affected by cancer less favourably than someone unaffected by cancer, for example denying a person a job or promotion because of their cancer diagnosis or history.
- Indirect discrimination This means treating a person affected by cancer the same as person unaffected by cancer, with the effect that the person affected by cancer is disadvantaged because they are not able to participate or to comply with a workplace condition. For example, requiring that employees in a manufacturing or retail role stand all day, when an employee's cancer makes standing for long periods difficult, may constitute indirect discrimination.

Employees with cancer also have the right not to be harassed or bullied by managers, staff or clients. This could include offensive or humiliating remarks, intimidation or exclusion.¹²



I am one of the lucky ones in that I was treated very well by a fantastic boss who has had experience of cancer and did everything they could to make me feel still part of the team. I was and still am very conscious of not letting anyone else know of my cancer who did not need to know because I may become unemployable in the future if it is known about amongst potential employers.

Making the law work better for people affected by cancer, unpublished comment¹¹

In a recent global survey, only about one in ten respondents said that they would tell their employers if they were diagnosed with cancer for fear of discrimination and stigma. 10



Resources

U.S. Equal Employment Opportunity Commission

Questions & Answers about Cancer in the Workplace and the Americans with Disabilities Act (ADA)

www.eeoc.gov

McCabe Centre For Law & Cancer, Cancer Council

Making the law work better for people affected by

www.mccabecentre.org



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I probably could have done with a few more weeks recovery at the time, but my employer was supportive to let me go back on reduced hours for a little while. I am now back to working full time, I need to work to remain sociable and for my well being, mentally I'm strong but physically I'm messed up, I'm speaking with my bosses about allowing me to work from home so that I can manage my condition and pain relief and hopefully stay in full time employment.

LIVESTRONG, unpublished

"All employees should have the right to be treated with dignity and respect at all times - especially those returning to work after experiencing cancer. To support them, a zero-tolerance approach to stigma and discrimination should be implemented and reinforced at both an individual and organisational level, with managers treating each case individually and as a unique situation. As current trends continue and more people will be returning to work with and after cancer, ensuring these individuals are supported is a crucial part of their road to recovery, and helps businesses to keep their workforce productive and engaged."

Dr. Fiona Adshead, Chief Wellbeing and Public Health Officer at Bupa

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