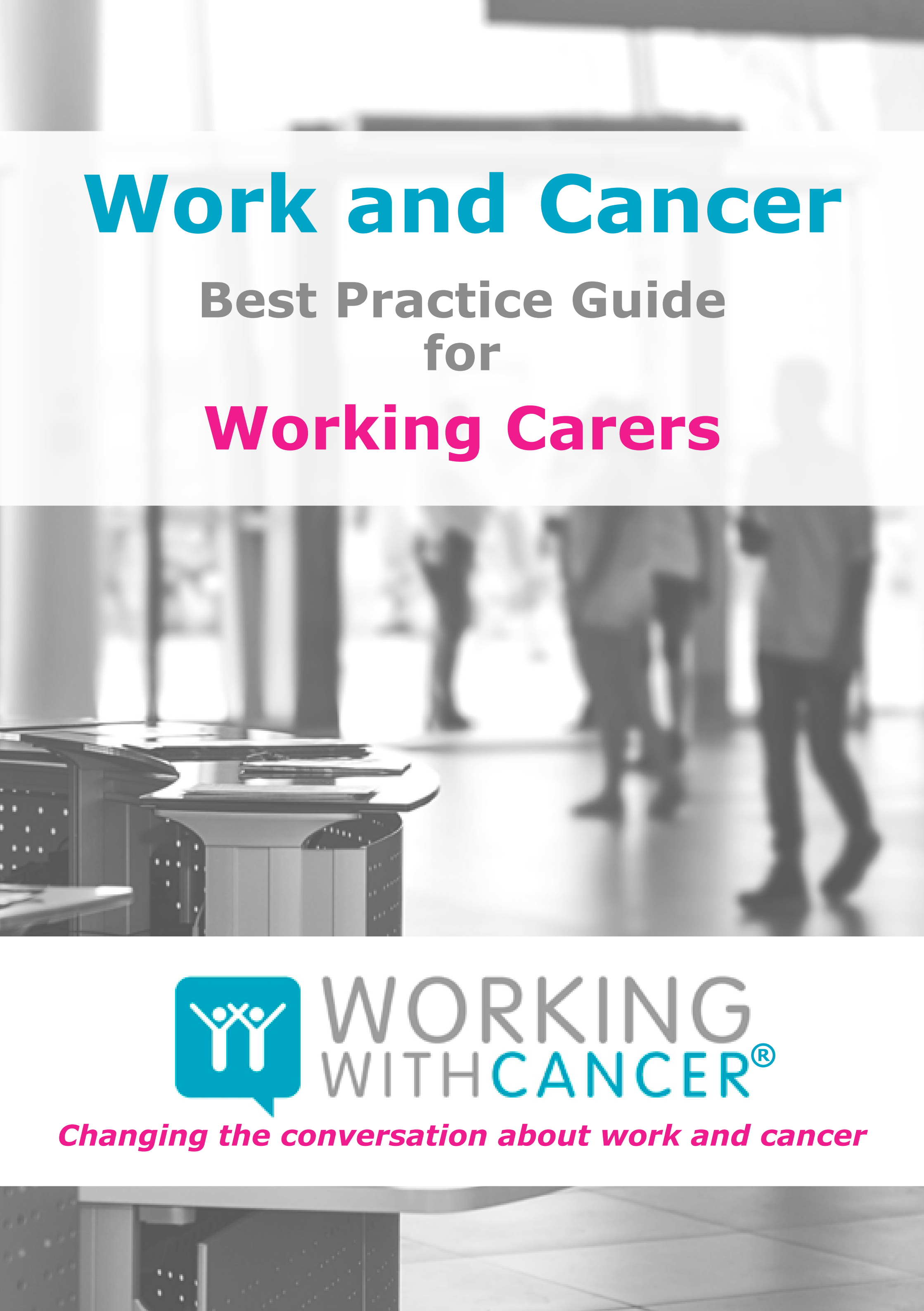
Work and Cancer

Best Practice Guide
for
Working Carers



WORKING WITH CANCER®

Changing the conversation about work and cancer

About this Guide

This Guide is a part of a series of four Best Practice Guides:

1. Best Practice Guide for Line Managers
2. Best Practice Guide for Employees
3. Best Practice Guide for Working Carers
4. Best Practice Guide for Colleagues

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Working With Cancer®

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ABOUT WORKING WITH CANCER®

Founded in June 2014, Working With Cancer® is a Social Enterprise which advises employers, employees with cancer, and working carers about returning to work, remaining in work or finding employment at any stage during or after cancer treatment.

Working With Cancer® provides 3 main services:

Consultancy
Training
Coaching

Working throughout the UK, our associates are all cancer survivors or have been working carers, and are trained professionals with wide-ranging business experience and expertise.

> ***"Once heard, the diagnosis of cancer can never be forgotten. Whatever your prognosis, whatever your hopes, whatever your personality, the second that you know that you have cancer your life changes irrevocably."***
>
> *Dr Peter Harvey, Consultant Clinical Psychologist*

CHANGING THE CONVERSATION ABOUT WORK AND CANCER

The purpose of this Best Practice Guide

The purpose of this guide is to:

- Help you understand the challenges you may face in managing and coping with work while caring for a loved one with cancer.
- Set out what is regarded as best practice support for working carers.
- Provide practical advice and guidance on how to successfully manage work whilst caring.

Cancer and work statistics

According to Cancer Research UK, 1 in 2 people in the UK born after 1960 will be diagnosed with some form of cancer during their lifetime.

The four most common cancers are lung, breast, bowel and prostate cancer. These four types of cancer account for around four in ten of all cancers diagnosed, and have been amongst the most commonly diagnosed worldwide since 1975.

In the UK 120,000 people of working age are diagnosed with cancer each year.

Although survival rates for patients with cancer vary significantly depending on the type and stage of their cancer, with the increasing effectiveness of cancer treatments and a steady improvement in survival rates, returning to work has become increasingly important for patients and for society as a whole.

Not surprisingly for those of working age, the majority want to continue to lead full lives and, if at all possible, return to work. However, although many are able to continue working, the average return to work rate is only 64% after 18 months, and those surviving cancer are 1.4 times more likely to be unemployed, and three times more likely to receive disability benefits.

It is also estimated that there are 1.5 million people in the UK caring for someone with cancer and that in any workplace at least 1 in 9 people are working whilst juggling their caring responsibilities. All the evidence suggests that carrying on working benefits a carer, their employer, the person they care for and the wider community as a whole.

Working With Cancer® has created four guides that have been tailored to meet the needs of four different audiences:

1. Line managers
2. Employees diagnosed with cancer
3. Employees who are working carers
4. Colleagues

We would encourage you to read the guide most relevant to you and, if possible, all four guides in order to get a comprehensive picture of how to support any employee affected by cancer.

For more information about managing work and cancer please read on or visit the Working With Cancer® website:

www.workingwithcancer.co.uk

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SUMMARY AND KEY MESSAGES

Seven key messages:

1. Recognise you are a carer and let your line manager know
2. Ask for support from family, friends and specialist organisations
3. Talk to your line manager and HR colleagues as early as possible
4. Look after your own health and wellbeing
5. Actively seek out information and support
6. Stay connected with work
7. Make a gradual transition back to work

Summary and key messages

A diagnosis of cancer has a profound impact on the person diagnosed and it also affects their family, friends and colleagues. The emotional and psychological toll on the person diagnosed is well documented and in this guide, we focus on the impact of a cancer diagnosis on the person who is a carer and who is working.

Caring for someone with cancer usually takes place within an existing relationship of love and affection, and the contribution that carers make to an individual's health and wellbeing, to family stability and to society more broadly shouldn't be underestimated.

It can sometimes be very hard to manage work and caring at the same time, and many carers will feel torn between caring for their loved one and fulfilling their work responsibilities. Planning ahead, looking after yourself, being ready and willing to ask for support from family, friends and specialist organisations, as well as talking as openly and honestly as possible with your line manager will be very important to you as you balance working and your new caring responsibilities.

New caring responsibilities can sometimes be the trigger for a carer to leave their employment or significantly reduce their working hours, especially if the employer is not supportive. Any carer clearly has a lot going on in their life and will benefit greatly from working within an organisation that has a policy and set of initiatives for working carers, and an enabling culture in which talking about cancer is already accepted practice, and talking about cancer and caring is the norm.

1

INTRODUCTION FOR CARERS

> ***"There are only four kinds of people in the world - those who have been caregivers, those who are currently caregivers, those who will be caregivers and those who will need caregivers."***
>
> *- Rosalynn Carter - Former First Lady of the USA and founder of the Rosalynn Carter Institute of Caregiving -*

1.1 What do we mean by the term "carer"?

People taking care of a loved one affected by a chronic disease or a disability are referred to as "informal carers". A working carer is someone who has significant caring responsibilities, who is also working and where their caring role has an impact on their working lives.

An employee is a working carer if they provide unpaid support to someone who could not manage without this help. They might be caring for:

- A mother, father, son, daughter, spouse or civil partner
- Anyone who lives with them, other than a tenant, lodger, boarder or employee, for example, a close friend
- Someone who relies on them for help if they become ill or needs care arrangements to be made for them.

There is evidence that once you spend more than 5 hours a week caring, it impacts on your work, health and often earnings potential. It is estimated that there are currently 100 million informal care givers in Europe and up to a third of these may be supporting someone with cancer.

1.2 Are you a working carer?

Identifying yourself as a carer may well be the most significant first step that you take on your journey to successfully managing work and caring responsibilities. One of the challenges faced by those who find themselves "helping out" is that they do not identify themselves as a carer and therefore they do not reach out to friends and work colleagues to share their experiences, or to specialist organisations to get the support they need. Self-identifying as a carer, and having support through a concerned line manager to do so, may well be a milestone to a more fulfilling and positive experience of being a working carer.

2

WHAT CANCER IS, HOW IT IS TREATED, COMMON SIDE EFFECTS AND IMPACT ON (RETURN TO) WORK

In this chapter, you'll learn more about what cancer is, how it is treated and its side effects. Having a better understanding of cancer and its potential impact should enable you to offer better support to your loved one and manage your work more effectively

2.1 What is cancer?

Cancer is a group of diseases involving abnormal cell growth with the potential to invade or spread to other parts of the body.

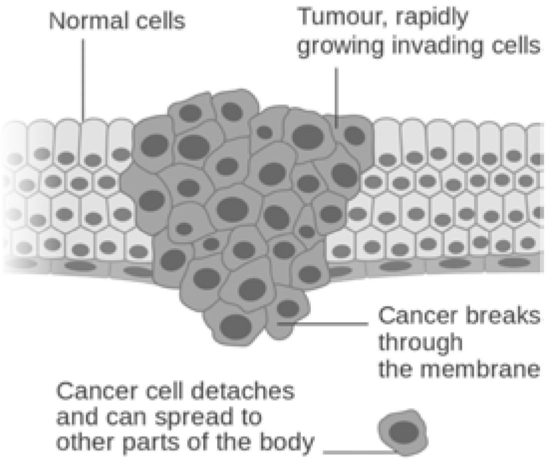
Possible signs and symptoms include a lump, abnormal bleeding, a prolonged cough, unexplained weight loss and a change in bowel movements.

While these symptoms may indicate cancer, they can also have other causes.

There are more than 200 different types of cancer, and each is diagnosed and treated in a particular way.

The 4 most common types of cancer are:

- breast cancer,
- prostate cancer,
- lung cancer,
- bowel cancer.



2.2 How is cancer treated?

Many treatment options for cancer exist. The primary ones include:

Surgery: surgery is the primary method of treatment for most isolated, solid cancers and can involve removing a tumour, an entire organ or just the affected organ and surrounding tissue.

Chemotherapy: chemotherapy is a treatment where medication is used to kill cancer cells. The drugs disrupt the way cancer cells grow and divide but they also affect normal cells. Chemotherapy may be used if cancer has spread or there's a risk it will.

Radiation therapy: uses X Rays and similar rays to treat the disease, to destroy or shrink tumours and to destroy cells adjoining the tumour to prevent its spread.

Hormone therapy: some hormones accelerate the growth of some cancers; a hormonal treatment uses medicines to block or lower the amount of hormones in the body to slow down or stop the growth of these cancers (e.g. breast and prostate cancer).

Immunotherapy: also called biological therapy, this treatment method is still new and is a type of cancer treatment that boosts the body's natural defences to fight cancer. It works by helping the immune system to recognise and attack cancer cells.

Clinical trials: often used as a last resort but can be very successful (e.g. using modified Herpes virus to control skin cancer).

Most often, a mix of the above treatments is used to treat cancer. The treatments used will depend on the type, location and grade of cancer, as well as the patient's general health and preferences.

2.3 Treatment side effects

The most common side effects of cancer treatment are:

Surgery: pain after surgery and permanent missing body tissue. When lymph glands are removed it can also lead to lymphoedema causing swelling in the body's tissues.

Chemotherapy: as well as killing cancer cells, chemotherapy can damage healthy, fast-growing cells in the body, such as blood cells, skin cells and cells in the stomach. This can cause a range of unpleasant side effects, such as:

- fatigue
- feeling sick and vomiting
- hair loss
- increased risk of picking up infections
- a sore mouth
- dry, sore or itchy skin
- diarrhoea or constipation
- infertility
- numbness and tingling in the hands and feet (neuropathy)
- chemo-brain (symptoms are being unusually disorganised, short term memory loss, mental fogginess, difficulty concentrating and taking longer to finish routine tasks).

Radiation therapy: fatigue most of the time, sore and red skin.

Hormone therapy: this can cause a range of unpleasant side effects such as:

- tiredness
- menopausal symptoms
- hair thinning
- muscle and bone thinning
- weight gain
- memory problems
- headaches, moods swings
- a decrease of libido
- depression
- infertility

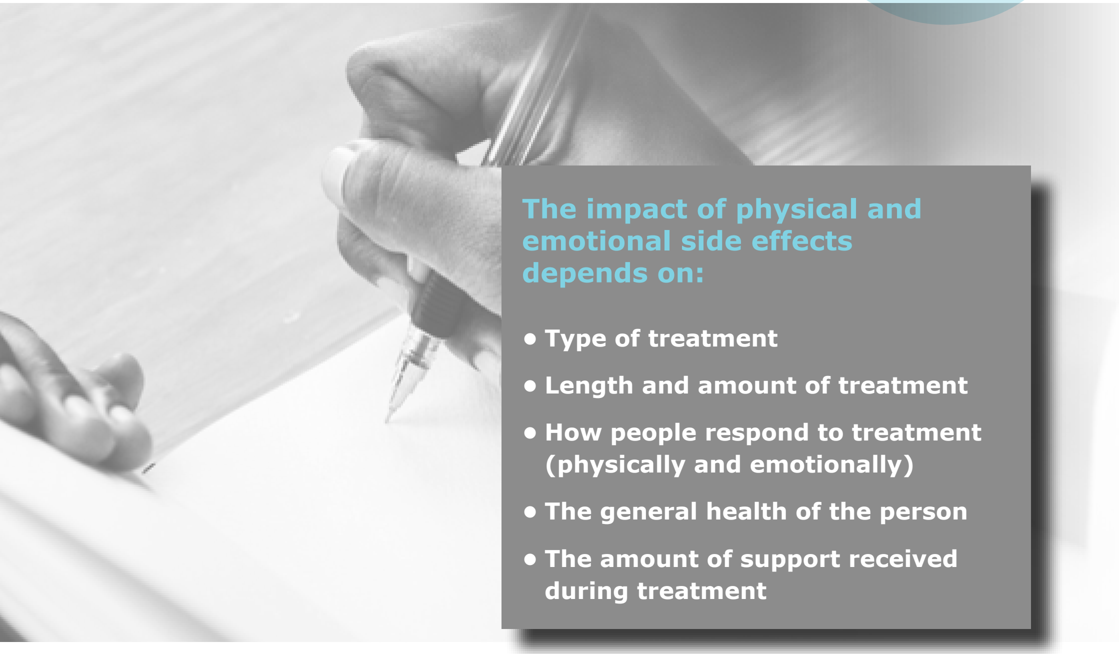
Immunotherapy: fatigue, diarrhoea, fever.

Clinical trials: these new treatments often have unknown side effects.

2.4 The impact of side effects on (return to) work

Whether the person who you are caring for has finished their cancer treatment, or is still undergoing it, it’s very likely that they will experience side effects. Some people have side effects which last for months or, in some cases, years after the treatment has finished. These include both physical and emotional side effects.

Most side effects fade with time, but to a varying extent will need to be carefully managed, particularly if the person who you are caring for is returning to work.



The impact of physical and emotional side effects depends on:

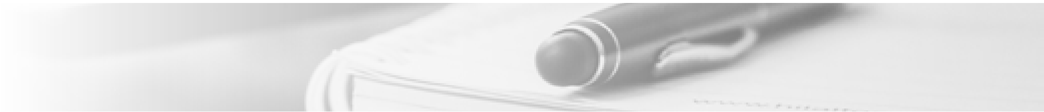
- **Type of treatment**
- **Length and amount of treatment**
- **How people respond to treatment (physically and emotionally)**
- **The general health of the person**
- **The amount of support received during treatment**

2.5 Impact of physical side effects on work

Many physical side effects are 'invisible' and it is wrong to assume that if an individual looks, well they must therefore be well enough to do their normal work. Understanding the physical side effects of cancer treatment is important, with the most common side effects being:

Symptom	Short description	Examples of impact on work
Fatigue	Extreme tiredness that affects between 70 to 80% of people undergoing treatment and/or after treatment. Fatigue makes you feel like you can't do things at your normal pace and it might not go away even after rest. People may also feel breathless and dizzy and struggle to do relatively simple tasks. It can last for weeks, months or years after the end of treatment.	• Can make it difficult to work the usual number of hours • Can affect concentration • Can limit the amount / level of responsibility at work • Can limit the amount of physical work and delay recovery
Pain or limited movement	Wounds from surgery may take some time to heal, so may cause pain or a loss of flexibility and/or strength as a result. This can be temporary or permanent.	• Can limit the amount of physical work • Can limit the amount of travel.
Risk of infection	Chemotherapy can cause a drop in the white blood cell count, which could put an individual at risk of infection. These effects usually begin around 7 to 10 days after each treatment and return to normal between 21 and 28 days.	• Alternative transport to work when commuting by public transport • The need for a contained desk space, avoiding an open-plan work environment
Changes in appearance	Common changes are hair-loss, changes to skin or nails, weight loss or gain. There may also be scars due to surgery. Keep in mind however that in many cases appearance improves over time as the body heals. The treatment of head and neck cancers can be particularly noticeable.	• Can cause embarrassment and loss of confidence and reluctance to be around others/attend meetings.

Symptom	Short description	Examples of impact on work
Neuropathy	Numbness or tingling of the hands and/or the feet, caused by some chemotherapy drugs. This is most likely temporary but can sometimes last for years or even be permanent.	• Can make it difficult to operate a keyboard or machines at work • Can make it difficult to drive a car or lorries
Lymphoedema	Lymphoedema is a long-term (chronic) condition that causes swelling in the body’s tissues. It usually develops in the arms or legs. Sometimes sections of the lymphatic system have to be (partly) removed during surgery for cancer e.g. when the cancer has spread to these lymph nodes. It is often a (life-long) risk after breast cancer surgery when the lymph nodes in the armpit have been removed.	• Can cause embarrassment and loss of confidence • The need for time-off to see a special lymphoedema masseur on a regular basis • Avoid working with sharp objects • The need to wear a support sleeve or extra protection such as gloves
Risk of bleeding	After undergoing cancer treatment, people may find their platelet cells are low and this increases the likelihood of bleeding and/or bruising.	• Not able to contribute to activities that could cause a cut or bruise • Physical activity limited
Needing to eat little and/or often	The individual may need to snack regularly to keep energy levels up during or after cancer treatment. They may need to bring snacks to work.	• Regular breaks for little snacks
Using the toilet more often	This is a common side effect especially during and after treatment of the bladder, prostate or bowel.	• Can limit travel to and from work • May need to be positioned closer to toilet facilities in the office • May need extra breaks



2.6 Impact of emotional side effects on work

Research shows that it is common for people to experience the emotional impact of cancer particularly after treatment has finished. The emotional processing of a cancer experience often happens at the same time someone might be considering returning to work. Internal struggles and shifts in priorities often make it difficult to make decisions about work. This may result in some hesitation to move forward with returning to work and may be interpreted by others as a loss of interest in working.

On the outside the emotional impact of cancer isn't always visible and, as with the physical impact, the assumption that the person 'looks OK and therefore must be OK' is easily made.
Understanding the emotional and psychological impact of cancer treatment is important, with the most common side effects being:

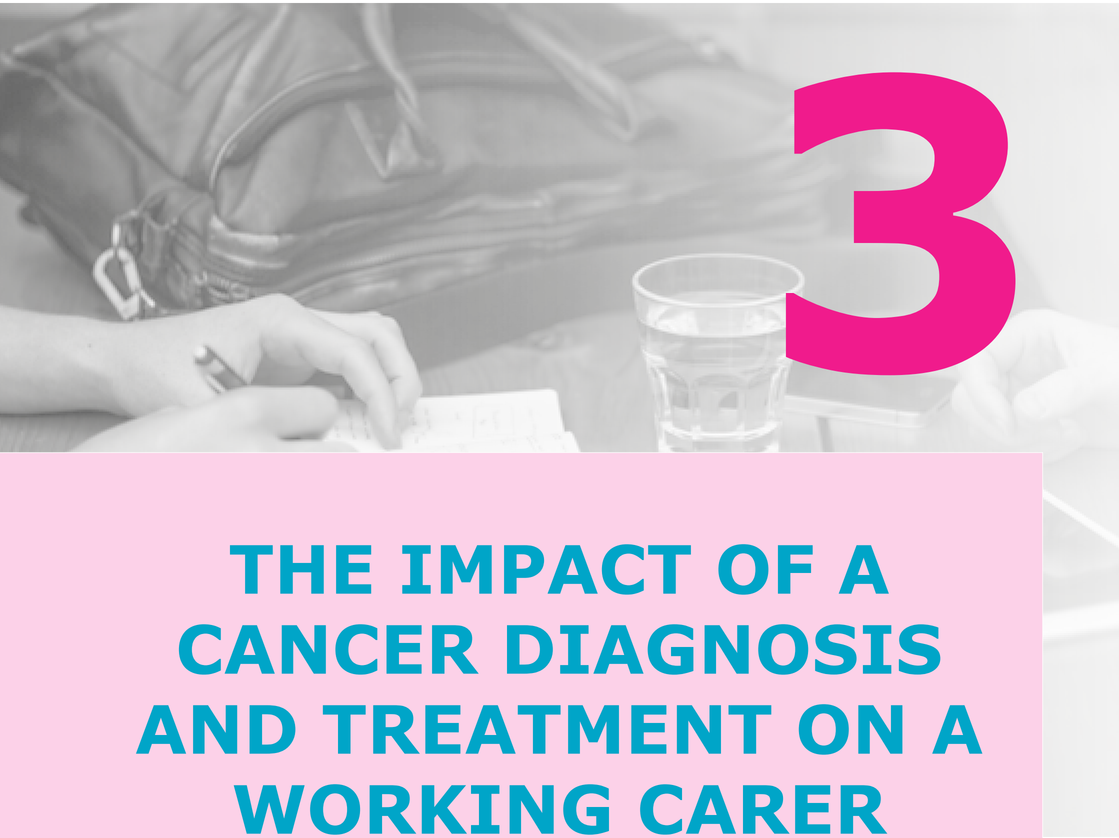
Symptom	Short description	Examples of impact on work
Living with uncertainty	45% of those diagnosed with cancer become fearful that their cancer will return (fear of recurrence) where every little ache or pain can cause panic.	• Panic attacks at work • Hyperventilation • Withdrawal from work and colleagues • Becoming anxious or stressed just prior to medical follow-up appointments • May need time off prior to these and/or afterwards to cope with this anxiety
Loss of confidence	Most experience a 'loss of self' compared to how they felt before their diagnosis. Cancer changes the way people experience their physical and emotional abilities, and the outlook on their work and life.	• Common tasks at work which were done with ease and confidence pre-diagnosis can now become more challenging

Symptom	Short description	Examples of impact on work
Cognitive problems	Often called a 'chemo-brain' as a result of chemotherapy, causing difficulty in concentrating and in remembering information. *NB: This is a physical side effect which is exacerbated by stress i.e. it is both physical and emotional.*	• Difficulty in following instructions, in planning work, in making decisions and in learning new tasks • Generally, feeling 'slow' in thinking
Depression	Affects up to 25% of cancer patients, regardless of the point in their cancer journey (compared to 7% of the general population).	• Can cause loss of interest and engagement with work, life and colleagues
A shift in priorities	A critical illness often makes people more aware of their mortality. It is common for people to become more focused on how they spend their time, which includes how much they work and what kind of work they do. Some may feel they would like to spend more time with their family and want to cut back on work. Others may want to focus more on engaging in meaningful work. Research has identified this as a "change of priorities," and it has been found to both motivate and deter some cancer patients in returning or staying at work.	• Loss of interest in work • Questioning work-load and/or work responsibilities • Quitting their job • In need of a career change

2.7 Cancer isn't over when treatment is over

It's normal for people to feel low and experience grief, guilt, helplessness; to feel 'lost in limbo', and find it hard to make decisions. It can be difficult to put one's finger on a specific cause as it's often a mix of things; the treatment itself and the emotional response to a life-threatening diagnosis. Also, it can be challenging to find a way forward after treatment, including finding a 'new normal' in both work and life.

Many of these side effects described above can be treatet or prevented, although the physical side effects of e.g. chemo and radiotherapy can last for a long time after treatment has finished. Overcoming the emotional side effects of a cancer diagnosis and treatment usually takes longer. It's important to be aware that these 'invisible' side effects are common and to be aware of them.



3

THE IMPACT OF A CANCER DIAGNOSIS AND TREATMENT ON A WORKING CARER

3.1 Adjusting to the new role

Becoming a carer can be a very demanding, stressful and challenging experience. But it can also be a very rewarding experience over time and some people get a lot of satisfaction from being able to look after a family member and loved one when they are not well. Becoming a carer may also bring people together, as family and friends become more closely involved. Each situation will be different depending on the type of cancer diagnosed, the treatment regime, the prognosis as well as the response of other family members and friends. Equally important is the way the person diagnosed with cancer is able to handle their own emotions, as well as the physical impact of treatment.

You will need time to adjust to your new caring role. You may well experience a range of intense and unsettling emotions. These include:

- **Feeling that you are not in control:** Becoming a carer often happens quite suddenly and can lead to big changes in your life for which you have had no time to prepare.
- **Sadness:** It is usual to feel sad from time to time when someone you care for is very ill, experiencing pain or just going through a very hard time.
- **Anxiety:** Change isn't easy to cope with at the best of times. Your life may suddenly have changed in ways that you still don't fully understand; you now have new and possibly challenging responsibilities. In these circumstances it is normal to feel anxious at times.
- **Guilt:** It is hard to witness someone you love go through the shock of a cancer diagnosis and the pain and discomfort of treatment that follows. You may wish that you could take the pain away, especially if the cancer patient is a child and you may feel guilty that you are not able to do more. It is not unusual to feel guilt sometimes and it helps to talk about and share these feelings rather than bottle them up.
- **Anger:** Feelings of anger often come to the surface when we feel that a situation is out of our control or when we have a deep sense that what is happening to our loved one is unfair. You may also feel angry about the changes you have had to make to your day to day life even as you want to do your very best to support them. These feelings are natural and normal even if at times you may find them a little disturbing. Once again talk to others and, if necessary, talk to a professional counsellor to help you understand and work through the anger you feel.

Alongside dealing with your concern for your loved one and managing your own emotions you may be worried about how your colleagues and line manager will respond, and have concerns about being able to manage your work responsibilities.

3.2 You are not on your own

It is important at this early stage to remember that you are not alone and that you do not have to do everything on your own. It's okay to ask for help.

With so much going on you may find it helpful to make contact with specialist support services or cancer charities who will be able to guide you through these early stages.

Often speaking with your line manager, HR team and colleagues can be a source of good information, as well as support.

Family and friends may well want to be actively involved and be there for you emotionally. Please understand that being a carer may well be a long journey, 'a marathon and not a sprint'.

In summary, asking for and accepting support is important for you, your family and for the person undergoing treatment so that they do not feel that they have become a burden on you.

3.3 Assessing your care work load and time commitments

Start planning! Life can suddenly become very busy when a loved one has a diagnosis of cancer.
As a carer you will need to assess the different tasks to be performed and you may want to use your practical work skills to plan and organise your time and set yourself some priorities. These may include:

- Gathering and absorbing an enormous range of new and sometimes complex information about the type of cancer and the treatment options
- Daily personal care, healthcare and emotional care for the person with cancer
- Additional household tasks of cleaning and cooking
- Attending medical appointments and engaging regularly with the health care team
- Supporting children and other family members

At first it may seem that there is simply not enough time in the day to manage work and caring responsibilities well. This may lead to feelings of frustration and guilt, both in relation to the person you are caring for as well as your work colleagues. Some people respond by wanting to put their own life on hold and to focus only on the person who is ill. It is important as a carer to realise that life does go on and that staying connected to work and to your friends and the community more broadly will be of great benefit to you over the longer term. Work can be a source of energy, connection with people outside the caring situation, as well as social and financial support. It is important therefore for you to keep your own life and needs, including work, on track as much as possible.

3.4 Milestones on the road of a working carer

Getting the right balance between being a carer and an employee, alongside being able to take care of yourself and possibly other family members can be a challenging, but not an impossible task.

Balancing these different roles is made all the more difficult because of the changing nature of the disease, as well as the needs of the person undergoing treatment. This uncertainty is at its most acute in the first months after diagnosis and treatment but you may well be facing many months or indeed years of changing caring responsibilities. Your experience as a carer will evolve over time and you may find you transition through a number of different phases:

- **Early days:** at this very early stage when everything is happening quickly you may feel overwhelmed and in shock. This is a particularly challenging time and often the focus is simply on getting through each day.
- **The first 4 - 16 weeks:** you now understand more clearly the nature of the diagnosis and treatment, you are able to plan more clearly and are beginning to have a better sense of the pattern of your caring responsibilities and the demands on your time.
- **4 to 12 months:** by now you are gaining more experience and confidence in your role as a working carer. Your forward planning is paying off and except for unforeseen events, of which there may be a few, or emergencies, you are becoming an expert carer and undoubtedly an important part of the health and care team looking after your loved one.
- **The caring role is at an end** due to the recovery of your loved one/ friend or, sadly, their death. The months after caring involve recovering from the stress and strain of the caring role and/or managing the affairs of a the deceased and coping with bereavement.
- **Moving forward** - you will now be entering a new phase of living and working well as you absorb the intense emotional and physical experience that you have been through and look to the future.

3.5 Conversations with children

As a carer you may find that you are a pivotal point of communication between your loved one who has had a cancer diagnosis and the rest of the family, as well as friends.

If you and your loved one are parents, then sharing this information with your child or children may feel daunting but it is important that you do this if possible

It's important to be honest with children because:

- They will sense something is wrong and may imagine the worst if they are not told otherwise.
- They can be anxious if they aren't told about what is happening around them.
- They may feel betrayed or even stop trusting you if they hear the news from someone else.
- If you pretend that everything is fine, children may feel that they have to keep their worries to themselves and feel yet more anxious.

Thinking through and preparing what you are going to say and how you are going to say it so that your language is clear and simple will be helpful, and try and do this together with your partner. A good message to get across is that having cancer is not a secret and does not need to be hidden from other people.

You will need to consider when you tell your children, and if the news is best shared with the family all together or one child at a time, depending on their ages, followed by everyone being together.

Be prepared to answer questions but you do not need to have all the answers in this first conversation, as often neither you nor your loved one have the full picture about treatment and prognosis. In this first conversation it is helpful to share what you know, for example:

- the name of the cancer;
- in which part of the body the cancer is; and
- how the cancer will be treated.

Children will look for reassurance and to know how the routines of their lives are going to be affected. Being honest about what is known and what is not yet clear at this early stage will make sense, especially as time goes on and the situation changes. Older children may want to visit the treatment centre or to know how they can help/ be involved. If it is possible to have another trusted adult present, that may also help to reassure younger children. Talking about cancer and sharing feelings is hard for many people, but it can be even harder to hide thoughts and feelings and so it is important to reassure children that feeling sad, upset and anxious is normal. Spending time together can be a source of great support and comfort and keeps the lines of communication open.

4

WHY WORK IS IMPORTANT FOR CARERS

Work is often an important part of our lives and our identities so carrying on working whilst caring for someone is something many of us want to do, regardless of the potential difficulties.

Work is important to all of us and for many different reasons:

- It is a source of external stimulation and gives you access to a variety of social networks, and in some cases to close and enduring friendships.
- Work may well be a place of peer support through an employee carer's network.
- Work can help you maintain your identity outside of the caring role and bolster your overall confidence and self-esteem.
- Earning a living and being financially stable is important for all of us but particularly for carers who may now be the sole 'breadwinner' for their families.
- Maintaining a positive and open engagement with your work colleagues and your line manager may well support your career development.

Although it may not be easy to acknowledge at the early stages of being a working carer when there are so many different pressures on your time, your energy and your emotions, your continuing engagement with work may well play a key role in helping you maintain your overall wellbeing over the longer term. Your line manager and the HR team will be committed to helping you keep your job and maintain your career prospects through the period that you are a working carer, so remember to stay connected and communicate on a regular basis about how your situation is evolving.

4.1 Assessing the financial impact of being a working carer

If you are one of the major financial contributors to your household being a working carer can bring with it unwanted stress and many questions and concerns. Some of these questions may relate to your current employment, others may relate to your broader financial situation.

As a working carer you do have the right to request flexible working and to have time off in emergencies, and your company may well offer you additional support. It is natural to have concerns about the impact of your new caring responsibilities on your finances and you may need to review your financial commitments and priorities, seeking expert help if possible.

If you do have to reduce your hours such that your income and benefits are impacted, you will find various sources of information and advice about managing your finances, accessing benefits and debt management, and about insurance on Working With Cancer's website: **www.workingwithcancer.co.uk**.

5

LIVING AND WORKING WELL

5.1 Living well as a carer

Looking after yourself may not seem like a priority as you dedicate your time and energy to caring for someone else but if you think about what might happen if you then become unwell, it is clear that maintaining your own health and wellbeing is very important. Being in good physical and emotional health enables you to support your loved one or friend with regular and better quality care. The person that you are caring for will be relieved to see that you are looking after yourself and not weighed down by caring for them.

As we have acknowledged in this guide a cancer diagnosis has a profound impact on everyone close to the person with cancer. It is important not to underestimate the emotional strain, and sheer physical demands of additional caring responsibilities, alongside the sense of loss of control. These may lead to physical and psychological signs of stress which you should be aware of. Symptoms of stress include, anxiety, depression, lack of appetite, difficulty concentrating and feeling generally unwell and tired. In order to minimise the impact of any such symptoms on your day to day life you may want to develop a wellbeing plan that includes:

- Staying physically active. Do what you enjoy which could be anything from regular walking, swimming, and gardening to active hiking and running.
- Keeping up with friends and people outside of the caring environment
- Eating regularly and healthily.
- Getting a good night’s sleep whenever possible .
- Arranging substitute care and taking a complete break from time to time .
- Reaching out for advice and support to community groups as well as to specialist cancer or care organisations.
- Staying in regular contact with your own doctor who can help you monitor how you are doing overall .

When you have worked out what activities suit you best share your wellbeing plan with family and friends, ask for their involvement in either joining you or relieving you of caring responsibilities from time to time. You may have to buy in care to allow yourself a real break or have local social services and/or charities support you and your loved one/friend.

Your line manager will also want to hear about your plans for staying active and well during this time. While more employers are realising the benefits of supporting working carers, for the employee asking for support in a work situation may not come easily, even though it is one of the keys to maintaining both physical and mental wellbeing at this very demanding time. In the very early days and weeks following your loved one/friend's cancer diagnosis you may well be feeling very vulnerable and perhaps reluctant to talk with others about what is going on. However, this is exactly the time to reach out for the support and care that your line manager and the HR team can offer you.

Work can be a source of energy, connection with people outside the caring situation, as well as providing social and financial support. It is important therefore for you to keep your own life and needs, including work, on track as much as possible.

5.2 Important conversations at work

In the early weeks following a cancer diagnosis it is often the case that the treatment is not clear and therefore you are going to need some flexibility while treatment plans settle and you know more clearly what you will need to do as a working carer.

Once you learn more about the implications in terms of treatment schedules, you may need to change some of your work responsibilities or reduce your hours for a period.

Depending on the intensity of the caring role, and particularly if you are caring for a child with a cancer diagnosis where overnight stays in hospital may be required, you may have to take leave sometimes without a great deal of notice, or even give up work for a little while.

Telling your line manager:

It is important to talk to your line manager as soon as you are aware of your circumstances and discuss what work arrangements can be put in place to ease the pressure of work at this difficult time.

- Plan to speak with your line manager at a time that works for you both.
- Make sure you both have plenty of time for this meeting. This is a conversation that you do not want to rush.
- Take some time before the meeting to think through what information you want to share and what information is essential you share. Your line manager will need to have a clear understanding about what is happening in your life now in order to be able to support you. Of course, you do not need to go into detail about the treatment that your loved one/friend is undergoing if this is not comfortable for you.
- Although it's early days it will be very helpful to think about how your new caring role might impact on your work and to talk through some of the ways your time is being taken up with routine medical and caring needs, as well as possible emergencies.
- You know your situation best - both the routine requirements of your job and the new demands of your caring role - and so if you can share your thoughts about what might work well, this gives your line manager a positive place to start from as they think about how they and the HR team can support you.

Talking with your colleagues: If you feel ready and able to speak with your colleagues, they may well prove to be a great source of support and may also be willing and able to help provide additional cover at work.

Getting advice from HR: Do please seek advice from the HR team who can provide information about the organisation's workplace policies or initiatives for working carers and discuss the options for taking leave.

5.3 Your rights at work

Working carers for those with cancer are protected by the Equality Act 2010 (and in Northern Ireland the DDA) from direct disability discrimination, harassment and victimisation as set out below:

Direct disability discrimination

This applies when an employee who is a carer associated with someone who has cancer receives less favourable treatment than a colleague.

> ***Examples are:*** *not recruiting, or promoting, or training someone because they are a carer for someone with cancer.*

Harassment

Harassment occurs when an employee who is a carer experiences behaviour from another employee which is offensive or makes them feel distressed or intimidated. This could be abusive comments or jokes, graffiti or insulting gestures. Whether or not the behaviour is harassment will depend on how the affected employee views the behaviour and on how reasonable it was for them to have felt harassed by it.

> ***Examples are:*** *an employee who is a carer being teased about or people making offensive remarks about the time off they are taking from work to support a loved one.*

Victimisation

If an employee believes they have been treated unfairly because they have complained about discrimination or harassment or because they have helped someone who has been discriminated against make a complaint, this is called victimisation and is unlawful under the Equality Act or DDA.

This only partly applies in Northern Ireland where an employee would need to prove that they had been treated less favourably than someone who had not made a complaint.

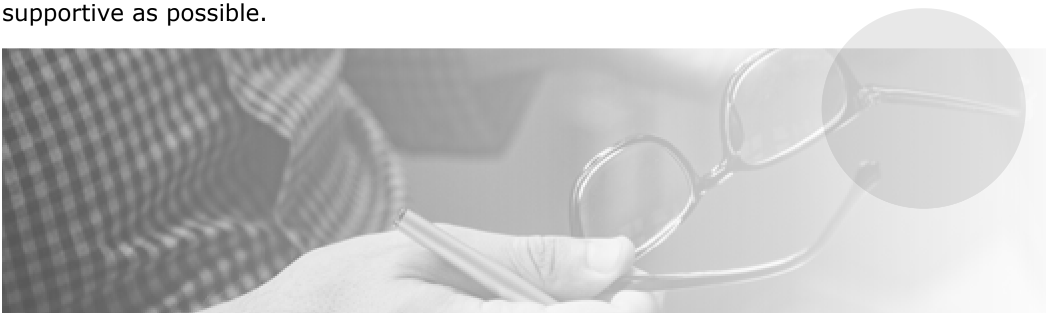
You should also note that employers can also be held vicariously liable for how their employees behave at work where this results in direct discrimination and harassment.

5.4 Work place policies

Your HR team will also talk to you about the various ways the organisation may be able to support you. Areas for discussion can include:

- **Flexible hours or working from home**
  Under the Children and Families Act 2014 and the Flexible Working Regulations 2015 (Northern Ireland), you can make a request for flexible working once a year. There is no automatic right to this and your request can be refused if flexible working is considered not viable for business reasons.
- **Time off to cope with emergencies**
  Carers can request a reasonable amount of unpaid time off work to look after a dependant in an emergency, for example if there is a need to make last minute care arrangements or to attend an unplanned medical appointment. How much time off you are allowed is at each company’s discretion.
- **Unpaid Leave, Sabbaticals, Parental Leave (if you have a child), Compassionate Leave, Career Breaks**
  Your company may have policies allowing other types of leave to be taken (paid or unpaid) which may be worth discussing depending on your circumstances.

Let your HR team know what you need from them. They will want to be as supportive as possible.



5.5 Joining or setting up a Carers Support Group

It is often the case that being able to share your thoughts and feelings with colleagues in the same or a similar situation can boost your morale and prove immensely useful. It can also provide another helpful support network where you can share information and resources.

You may want to join or encourage your organisation to set up a Carers Support Group where you will find peer support for working carers. To find out what currently exists or how you might go about setting up a Support Group, you should start by speaking to a member of the HR team.

6

IF YOUR CHILD HAS CANCER

No one is ever prepared to hear that their child has a life-threatening illness. Parents and family members have a lot to manage after a child is first diagnosed with cancer and the first few weeks can be overwhelming.

Understandably, you will feel worried and stressed as you come to terms with the diagnosis and what it means for your child to go through treatment. You'll worry that your child will suffer and that your family life is going to be completely disrupted.

You may also feel overwhelmed by painful and powerful emotions. These reactions are normal – remember that health care professionals, as well as specialist cancer organisations, are there to help you. You will also need time to adjust to the ever changing emotional and practical demands of this new caring role.

It is sometimes very difficult for working carers to know how to manage work, and how and when to return to work. Talk with your line manager and with your HR team as soon as possible following your child's diagnosis with cancer so that they can guide you through the workplace policies that will support you at this very difficult time.

The information in these guidelines about living well and looking after your own physical and psychological health are equally important if you are a parent of a child who has been diagnosed with cancer.

7

CARING FOR SOMEONE WITH ADVANCED CANCER

7.1 What is advanced cancer?

Advanced cancer is defined as cancer that is unlikely to be cured. Healthcare professionals may also use the terms secondary, metastatic, terminal or progressive cancer to describe it. Advanced cancer may be primary or secondary cancer:

- Primary cancer refers to the first mass of cancer cells (tumour) in an organ or tissue. The tumour is confined to its original site, such as the bowel. This is called cancer in situ, carcinoma in situ or localised cancer.
- If cancer cells from the primary site move through the body's bloodstream or lymph vessels to a new site, they can multiply and form other malignant tumours (metastases). This is known as secondary or metastatic cancer. Secondary cancer keeps the name of the original, primary cancer. For example, bowel cancer that has spread to the liver is still called metastatic bowel cancer, even when the person has symptoms caused by cancer in the liver.

Some people's cancer may be advanced when they are first diagnosed. For others, the cancer may spread or come back (recur) after initial treatment.

Although medical treatments may not be able to cure advanced cancer, some treatments may still be able to slow its growth or spread, sometimes for months or even years. Palliative care can also help manage cancer symptoms, which may include pain, and can reduce side effects from cancer treatments. At any stage of advanced cancer, a range of other palliative care services can enhance quality of life.

7.2 Treatment options for advanced cancer

The treatment options for advanced cancer will depend on the purpose of treatment – whether it's to try to cure the cancer, keep the cancer from spreading, or to control symptoms.

Treatment will depend on where the cancer started, how far it has spread, the individual's general health and preferences. The most common treatments include chemotherapy, radiotherapy, surgery, targeted therapy, hormone therapy, immunotherapy, or a combination of these. Sometimes, treatment is available through clinical trials.

Treatments can be used for different reasons, so it's important to understand the aim of each treatment. As the cancer progresses, the aim may change from trying to cure the cancer, to controlling the cancer, to relieving symptoms and improving quality of life.

7.3 The impact of living and working with advanced cancer

Coping with feelings and emotions

Most people living with advanced cancer experience a wide range of feelings and emotions as they come to accept the diagnosis. Living with the uncertainty that comes with advanced cancer can be physically and emotionally demanding.

They are likely to feel a range of strong emotions feeling shocked and frightened, or angry about their sudden change of circumstances. Many people find that these feelings become easier to manage with time, as they start making decisions and plans.

Talking to others can also be very helpful. This could be someone close, or they might prefer to talk to someone they are not so close to - a coach, counsellor or members of a support group. Complementary therapies may also help to reduce stress and anxiety.

In some cases when feelings are very difficult to cope with, they might benefit from therapeutic, psychological support.

Life after diagnosis

Knowing that their cancer might not be curable can give an individual the chance to decide what's important to them and how they want to live their life. Concentrating on what they can enjoy and achieve can be satisfying.

But during this time, many people can also carry on with their day-to-day lives – including continuing to work – as it provides a sense of normality as well as continuing financial security.

7.4 Your role as a working carer

Until now you and your loved one have approached their cancer treatment hoping for remission or recovery. If this is no longer the case then you may both be trying to come to terms with the new diagnosis, living with and sharing many painful emotions such as fear, anger, sadness and grief. You are also likely to be facing new choices and decisions about your loved one's longer term care, how to tell and then support your family and friends and about planning for your future. Making these transitions as a working carer can be very challenging as you try to balance work commitments with the impact of new demands on your time, energy and emotions.

All the issues outlined earlier in this section about planning ahead, looking after yourself, asking for help, communicating with colleagues and being open with your line manager are even more important as you navigate this challenging new dimension to your life as a working carer.

You may find that you have to respond to more unplanned demands on your time and therefore need more flexibility in your work schedule including paid or unpaid leave. Once again understanding your company policy in this area will be important as well as maintaining clear and open communication with your line manager so that they understand something of what you are going through and can support you in the best way possible.

8

CARING FOR SOMEONE WHO IS TERMINALLY ILL

> ***"WWC helped me when my wife died.***
> ***They provided good advice on how to handle work.***
> ***Also ideas on how to handle life at home.***
> ***In the end they helped me negotiate a contract that is the best for me and my children."***
>
> *A Coachee of WWC*

Looking after someone as they reach the end of their life can be emotionally and physically draining. As a carer you may well need to have more planned time off work. You may also find it helpful to ask for advice and to make use of services that will provide emotional support or counselling to you as a carer.

If there are important decisions to be made about continuing care at home or having more specialist care in a hospital or hospice, you should actively seek information from the specialists to help you make the right decision for you and your loved one.

If you have been the main carer over a period of time, other family members may well want to be more closely involved, and possibly in making decisions about any end of life care plan. This may be a source of support to you or may be an additional pressure. Your decision will have your loved one's best interests at heart and you will have the support of the professionals i.e. doctors and nurses.

When the person that you have been caring for dies, you will of course need to take planned time off work. If there are children who were close to the person who died, you will also want to give them extra time and support. You may also need time off work to sort out practical things, such as arranging the funeral and sorting out all the many legal and other issues that arise after a death. Aim to keep your line manager and HR team informed about what is happening, how you are, and any additional time away from work that you may need.

9

RETURNING TO WORK AFTER BEING A WORKING CARER

It will be important to pace your return to work and not to overdo things as you readjust to the demands of everyday working life.
Your role as a working carer will have been demanding on you both physically and emotionally and it may be several months before you feel you have returned to 'normal'.

9.1 When your caring responsibilities have come to an end

As the person that you are caring for recovers from cancer or enters a stable period in their long-term cancer treatment it is likely that you will want to consider your work situation and what the future holds for you. Having maintained regular engagement with work, your colleagues and line manager, you are in a good place now to consider your longer-term future.

Many cultures do not value the immense contribution that caring makes to the quality of personal and family life and we also underestimate the range of skills that carers learn along the way and the different experiences that enhance their ability to cope much better with the day to day stresses and strains of working life. Your line manager and HR team will already have played a key role in supporting you as a working carer. They will have been committed to ensuring that your role and career possibilities have not been compromised by the caring role that you had to fulfil. Once you have settled back into your normal work routine it may be useful for you to have conversations with your line manager and your HR team about how you have added to your range of skills and experience, albeit through extremely challenging times.

9.2 Returning to work after a bereavement

It will be important for you to take the time you need to grieve for the death of a loved one and to adjust to your feelings of loss. You may feel vulnerable and unsure at this time and you will want to have the support of your family and friends. Make sure you are also aware of the support services your organisation provides to employees going through a bereavement, including emotional support and counselling.

Maintaining regular contact with your line manager should mean that they understand something of what you have been going through and can support your return to work. You may, for example, be able to agree more flexible hours or a phased return or even a sabbatical until such time as you feel able to get back to a routine.

You may find that your emotions are very close to the surface when you see your colleagues for the first time as you return to work. This is entirely understandable. Some people will want to talk about the person who has died, while others will not. It is important that you do what is best for you and let your line manager and colleagues know what is right for you.

It is not unusual for the full impact of a bereavement to be delayed for some months after it has happened, leaving you feeling vulnerable and confused at a time when there is not as much support around you. Again, it is important to recognise what is happening and to actively look for support. The HR team should be able to support you at this very difficult and demanding time.

10

SEVEN KEY MESSAGES

Recognise you are a carer and let your line manager know.

1

Self-identifying as a carer and having support through a concerned line manager to do so is a significant milestone to a more fulfilling and positive experience of being a working carer.

Ask for support

2

You are not alone. Ask for help from family, friends and specialist organisations especially in the early days and weeks when so much is happening so quickly.

Talk to your line manager and HR colleagues as soon as possible

3

In a work situation this may not come easily even though it is one of the keys to maintaining both physical and mental wellbeing at this very demanding time. This may well alleviate some of the pressure and worry that you feel.

Look after your own health and wellbeing

4

Develop a wellbeing plan and share this with friends, family and also your line manager.

Actively look for information and support

5

Use the wide range of resources that are available to you including: friends and family, work colleagues, your line manager and HR, health care professionals, social services, specialist patient groups and cancer charities. All will be vital in ensuring your ability to balance work and caring.

Stay connected with work

6

Maintaining a close connection with work colleagues, your line manager and the HR team is an important part of balancing your caring role with your work and career opportunities.

Make a gradual transition back to work

7

Returning to work after your caring role has ended is an important transition and you will need to pace yourself in the early months so as not to become overwhelmed.

11

CHECKLIST & FURTHER RESOURCES

Checklist for Working Carers

In addition to developing this Best Practice Guide we have provided a comprehensive checklist of questions for you to consider. Is there any more that you or others can or should do to obtain or provide advice, guidance or support?

There are also three more Guides in this series that you may want to get hold of;

- Best Practice Guide for Line Managers
- Best Practice Guide for Employees with cancer
- Best Practice Guide for Colleagues

There is also space at the back of this guide where you can write your own notes.

1. DIAGNOSIS

How far do you understand your loved one’s/friend’s diagnosis and treatment plan?

Is there any more medical information you need or information about specialist community support? Who can help you obtain that?

Have you let other family members, friends and neighbours know? Is there someone who can help you with this?

Have you spoken with your line manager yet?

What information and support do you need to help you prepare for a conversation with your line manager?

Do you have a copy of the Best Practice Guide for Working Carers?

What about HR? Have you been in touch? Are you aware of the health and other support services available?

What information do you want to share with immediate colleagues, other managers and third parties?
Speaking with your line manager and HR may help you work this out.

2. DURING TREATMENT

What if any new arrangements do you need to put in place during this period?
Flexible working, adjustment of hours worked, duties performed
Have you discussed these with your line manager and your team?

Are you making enough time to plan ahead so that you, and hopefully others, can manage the many new activities and responsibilities involved in caring for a loved one?

Have you thought about how you are looking after yourself as you work and care for your loved one?

Do you have a plan that will support you to stay physically and emotionally well over the coming months?

Have you considered joining in or setting up a Carers’ network within your organisation for peer-to-peer support?

If a performance review is to take place during the time that you are a working carer how will you handle this? From whom should you seek advice about what to do?

Do you want to talk about your career development and hear about new job opportunities during this period? If so, do let your line manager and HR know this.

Are you aware of the services that might support you?

3. BEFORE RETURNING TO WORK	4. AFTER RETURNING TO WORK
How clear are you about the support you will need on returning to work? If you have been taking 'care leave' or other special leave e.g. bereavement leave (either full or part-time), when do you plan to have a return to work conversation with your line manager? How will this be organised and who do you want to be present? If it is the case that your loved one has died, how far are you aware of the options available to support your return to work? From whom can you seek this information and advice? What information do you wish to share with colleagues and others about your return to work and how and when do you want to do this? Are you continuing to pay attention to your own health and wellbeing as you prepare to return to work? What support do you have in place with friends, family or specialist agencies? Do you think you might need any adjustments in flexible working, hours worked, or duties performed? Do you want to discuss this with your line manager and/or HR? Have you thought about arranging time with your line manager and/or HR to discuss what, if any, arrangements you may need to ensure that you have time and support to get to grips with any changes in people, systems and processes during your absence?	What arrangements have you made with your line manager and HR to check-in and discuss how your return to work is going and how well any workplace adjustments are working out? Are you making enough time to re engage with colleagues and friends at work as you settle back in? How are you monitoring your health, stamina and energy as you return to work? Are you aware of services that can help you with this? Do you want to plan to have a career development conversation when you are back at work? How can you best prepare for this and what support is available?

FURTHER RESOURCES

Resources	Contact details
HR Advisor	
Employee Assistance Programme	
Employee Support Group	
Working With Cancer®	
Other organisations	

NOTES

If you have any feedback about this Best Practice Guide, please get in touch with us.

For further information and resources please visit our website at:

www.workingwithcancer.co.uk

Working With Cancer®

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