# Working while caring for someone with cancer

Work and cancer series





When Kate got her diagnosis, after the doctors and the specialist nurse had left, I went to speak to the Macmillan nurse alone because I wanted to find out a bit more about what was going to happen.

Mark, who cared for his wife Kate

# The Macmillan work and cancer series

This booklet is part of a series. Macmillan produces a range of other information about work and cancer.

### For people living with cancer

- Work and cancer
- Your rights at work when you are affected by cancer

### For employers

- 10 top tips for line managers
- Managing cancer in the workplace

## For self-employed people with cancer

Self-employment and cancer

You can order our booklets and leaflets for free. Visit be.macmillan.org.uk or call us on 0808 808 00 00.



# **About this booklet**

This booklet is about working while caring for someone with cancer. It is for carers.

You are a carer if you give any unpaid help and support to someone with cancer who could not manage without your help. You do not have to be living with the person you care for. This booklet aims to help you cope with balancing work and caring. We have included information about:

- getting support at work
- flexible working
- your rights at work
- talking about cancer with your employer and the people you work with.

There is also advice for people who are self-employed.

#### How to use this booklet

This booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the contents list to help you.

It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

On pages 96 to 106, there are details of other organisations that can help.

If you find this booklet helpful, you could pass it on to your family and friends. They may also want information to help them support you.

#### **Quotes**

In this booklet, we have included quotes from people who worked while caring for someone with cancer. These are from people who have chosen to share their story with us.

This includes Mark, who is on the cover of this booklet. To share your experience, visit macmillan.org.uk/shareyourstory

### Financial help from Macmillan

You can call the Macmillan Support Line on 0808 808 00 00. We have financial specialists who can help you deal with money worries:

- Our financial guides can give you guidance on your personal finances, such as pensions, insurance, mortgages and estate planning.
- Our welfare rights advisers can help you apply for benefits and other financial support.
- Our energy advisers can help you try to reduce your heating and electricity costs.
- Our work support team can also give you advice and support about financial issues at work.

We can also give you information about Macmillan Grants. Please note the opening times may vary by service. Our booklet <u>Help with the cost</u> of cancer has lots more information.

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# Caring for someone with cancer

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# What is a carer?

You are a carer if you give any unpaid help or support to someone with cancer who could not manage without your help. You may not see yourself as a carer. You may just think you are helping out. Understanding that you are a carer is important to get the support you need. As well as caring for someone, you may also have a job or children.

Being a carer might not be something you planned for. It may happen quickly after someone is diagnosed, or you might take on more caring responsibilities later.

Being a carer can be rewarding. But the physical and emotional demands can be difficult. It is important to get the practical, emotional and financial support you need. If you keep working, you may also need support at work.

Getting the right balance between caring and working can be difficult. But it can be possible. If you keep working while caring, it can benefit you, your employer and the person you are caring for.

As a carer, it is important to look after your own well-being and health needs.

"I changed a lot [of things at work], mostly without thinking. I needed to use time where I could, such as working on the train commute, to give me the ability to care for Kate, carry out tasks at home and juggle work."

Mark

# Different ways of caring

Being a carer for someone can mean different things, including:

- giving emotional support and being there to listen
- helping with everyday tasks, such as shopping, cooking, cleaning or collecting prescriptions
- driving, or going with them to appointments
- talking to or contacting others on their behalf, such as health and social care professionals
- giving medication, changing dressings and helping with other healthcare tasks
- helping with personal care, such as helping them wash, eat, dress or use the toilet.

Every caring situation is different. It will depend on what the person needs and what you are able to offer. You may be the main carer, or share caring with family or friends. How much care you provide can change over time.

Try not to take on everything yourself. Even if you are the main or only carer, there may be ways you can get help.

We have information about the help and support that may be available for carers at macmillan.org.uk/carers



# Making decisions about caring

It is important to try to find a balance between the support you want to give and what you are able to do. This can be difficult when you are trying to balance caring and working.

Before you make any decisions, you may want to:

- talk to your manager or employer about possible flexible working arrangements or policies that help carers
- talk to other people in your life about the help they can offer you or the person you are caring for
- find out about <u>practical or financial support</u> that you or the person you are caring for may be able to get.

It is important to involve the person you are caring for in any decisions about their care. They may already feel as if they have less control over their life.

Health and social care professionals can also support you. You can ask them questions about caring. But they cannot share medical information about the person you are caring for unless that person gives permission. This is called consent.

You can ask their cancer doctor or specialist nurse about organising a carer's assessment. This is done by social services. It can help to find out what kind of support you might need. You may also be able to get financial help, such as benefits or grants. We have more information in our booklet Looking after someone with cancer.

<u>Carers UK</u> has information and guides on how to get a carer's assessment. <u>Carers Trust</u> has information about local organisations that can help with practical support. "I hadn't realised how worried I had become - it was very much an unconscious thing. And so with work being so busy and with not having time to really process the information, I went to my GP to ask for help. "

Prue, who cared for her husband Dave

# How you might feel

Looking after someone you care about can cause many different feelings, such as sadness, anger, guilt or loneliness.

When you are trying to balance caring and working, these feelings may be hard to cope with at times.

You may feel you are not doing enough for the person you are caring for. Or you may feel that you are not able to do your best at work. These thoughts can make you feel guilty. You might also worry that you are putting pressure on the people you work with.

Try to be kind to yourself. It can help to focus on the good things you are doing to help the person you are caring for. It is also important to look after yourself while you are caring.

You could get support in different ways. You might find it helpful to talk to your family, your partner, a friend, a support group or someone at work about how you are feeling.

If you want to, you can tell your manager and the people you work with about your situation. Talk to them about how it may affect you at work. Your workplace may have a support network, such as a carers' network, that could help.

You might find it easier to talk to people who do not know you personally. If your employer has an employee assistance programme (EAP), you could use that to contact a counsellor. Or you could ask your GP to refer you to one.

Our cancer support specialists can give you more information on how to find a counsellor, or they can listen if you just want someone to talk to. You can call them free on **0808 808 00 00**.

You can also find out about services in your area by visiting macmillan.org.uk/inyourarea

We have more information in our booklet Looking after someone with cancer.

"I spoke to a counsellor at our local hospital. After an hour of pouring my heart out, they helped me realise I needed to take some pressure off, and my GP signed me off work with stress. "

Stephen, who cared for his wife



# Work and being a carer

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# Services we mention

We use the terms 'manager' and 'employer' in our information, but different people at your workplace may be involved. Many services may be able to help.

#### The services we mention include:

- Cancer team this is the cancer team at the hospital. It may include oncologists, radiologists and cancer nurses. In some services, it may also include a social worker.
- GP services this is your doctor's surgery.
- Occupational health professionals these may include workplace health and safety advisers, nurses, physiotherapists, counsellors and GPs. They may not be available at every workplace. Your work may offer an external occupational health service. You can learn more from your employer or HR manager.
- Line manager this is who you directly report to at work.
- HR manager this is someone in the human resources or recruitment team at your work.
- Advisory services these are organisations that offer guidance. including helping resolve work disputes.
- Charities and support groups these may include a Macmillan work support adviser, other cancer support charities, carer organisations, local support groups and online forums.
- Unions these are trade or labour unions you may be a member of.
- Social services these are services provided by the government to help people in need. They can include care at home, specialist equipment and help at home, such as shopping or cleaning.

# **Example questions**

On pages <u>32 to 33</u>, <u>48 to 51</u>, <u>72 to 73</u> and <u>76 to 79</u>, there are example questions you may like to ask about your situation. We advise who might be best at answering these. Depending on the country you live in, the person you ask may be different.

If you are unsure who to ask, you can call our support line on 0808 808 00 00. They may be able to answer your question or tell you who would be best placed to answer it.



# Working while caring

Balancing working and caring can be difficult. But if you decide to keep working, it can have some benefits. It can:

- give you the chance to socialise
- give you the chance to meet and share experiences with other carers in your workplace - this could be through a staff carers' network
- reduce money worries
- give you a separate identity from being a carer this can be good for your confidence.

You might feel that working is an important part of who you are. Looking after yourself when you are a carer can include having your own work goals. For example, you might want to do some training or learn new skills at work.

You might need to make some changes or delay new training or learning. But you may also learn new skills as a carer that can help you in your working life.

Supporting working carers also has benefits for employers. For example, your workplace may agree to more flexible working patterns. This means they can keep valuable and skilled staff. It can also help employees feel more committed to their employer.

Try to talk to your manager or HR department (if you have one) about your situation as soon as possible. They can tell you about the support available at your workplace, and the ways they can help you.



Going into work did keep a sense of normality, and my commute gave me time to comprehend some of what was going on.

Mark

# **Diagnosis and treatment**

It is important to know what might happen when the person you are caring for has tests or treatment. This may help you understand what the impact on your work might be. Knowing more about what to expect can help you plan ahead.

The person you are caring for may want you to be with them at different times. The support they need will depend on their situation. It may change from day to day.

We have information about different types of cancer and cancer treatments. We also have information about talking with someone who has cancer in our booklet Talking with someone who has cancer.

My manager was able to give me the flexibility to attend appointments or known treatment days at short notice.

Mark

## **Tests and diagnosis**

Having tests and waiting for the results can be a difficult time. The person you are caring for may need a few visits to hospital before a diagnosis is made. Tests and appointments can take up a lot of time. You may need to think about whether you will need time off work for this.

If the person you are caring for is a family member, partner, or close friend, you may find their diagnosis hard to cope with. You might have a lot of different feelings. This could affect you at work. You may need some time off work to deal with the diagnosis.

It can take time to understand your feelings. It may help to tell your manager about your situation so they can support you.

# **During treatment**

The person you are caring for may need to have a combination of different treatments. The healthcare team at the hospital will tell them what is involved.

Understanding the treatments can help you know how much support you will need to give them. You can then think about any changes you might need to make at work. Talk to your manager about this. For example, you could suggest flexible working or reducing hours while the person you are caring for is having treatment.

The person you are caring for may need to stay in hospital while they have treatment. If the hospital is close to where they live, they may be treated as an outpatient. This means having treatment at hospital without staying overnight. If this happens, you might need to drop them off or pick them up from appointments. But you may not need to stay with them for every appointment. This will depend on their treatment and how they react.

However, if the hospital is far away you may need to take more time off work for travel and overnight stays.

After treatment, the person you are caring for may need more support with their recovery. They may need to go to hospital for things like physiotherapy or speech therapy.

You could ask them when they think they will want you there the most. This can help you plan. There may be times you do not need to be with them. It is also important to think about the help you can get from others.

When we got to the hospital, I contacted my line manager. He was really understanding. He asked me to keep him updated over the next few days, but gave me a week of compassionate leave to start with.

Mark

#### Surgery

If the person you are caring for has surgery, they may need to spend some time in hospital. How long they stay in hospital will depend on the type of surgery they have had.

Regularly visiting them in hospital can be very tiring. It can be more difficult if you are balancing this with work.

You may need time off work to care for them when they come home, or to take them to hospital for follow-up appointments.

#### Radiotherapy

Radiotherapy uses high-energy rays (radiation) to destroy cancer cells. A course of treatment may take several weeks.

Each radiotherapy treatment only takes a few minutes. But travelling to and from the hospital, and waiting in hospital for treatment, can take up a large part of the day. Sometimes the radiotherapy team can plan treatment in the morning or late afternoon. This could mean you need less time off work. Ask the radiotherapy team if this is possible.

#### Chemotherapy, targeted therapy and immunotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. Targeted therapy uses drugs to find and attack cancer cells. Immunotherapy treatment uses the immune system to find and attack cancer cells. The immune system protects the body against illness and infection. Some people may have a combination of these treatments.

People can have chemotherapy, targeted therapy and immunotherapy as an outpatient. Depending on the drugs the person is having it can take up a large part of the day. They may need to stay in hospital for a while.

They may have the drugs into a vein (intravenously), as tablets or as an injection. The nurse will explain how often treatment will be. Knowing this can help you plan time off work, if you need it.

The person you are caring for may need someone with them at home for the first few days after treatment. It is hard to know how they will react until they start treatment. Their reactions might change as they keep having treatment. If they have certain side effects such as an infection, you might need to take extra time off work to care for them.

It is important to tell your manager that some things can be unpredictable. This may mean you need time off work at short notice.

#### Hormonal therapy

Hormonal therapy works by altering the production or activity of particular hormones in the body. It can be given as tablets or injections. Ask the person you are caring for how they are feeling when they are taking hormonal therapy. This will give you an idea about what help they may need and how it may affect your working day.



"I was given some leaflets at work by someone who worked for Macmillan. They described how Macmillan's there not just for those people with cancer, but for the families and those close to them as well. I found that very reassuring. "

Prue, who cared for her husband Dave

### **Help from others**

It is important to think about how other people can help. This can help you balance working and caring. It can also help you look after yourself. Make sure you involve the person you are caring for when you are thinking about who to ask for help.

Friends, family and neighbours are often keen to help. But they may not know what to do. You could start by:

- making a list of everyday tasks you may need help with
- · asking people what they can do to help you
- asking people how often they can help.

You can then ask people to do specific things. It might help to make a rota of who is helping with what.

We have more information about coping when someone has cancer in our booklets <u>Looking after someone with cancer</u> and <u>Cancer and relationships</u>.

You can order our booklets and leaflets for free. Visit <u>be.macmillan.org.uk</u> or call us on **0808 808 00 00**.



# Planning for hospital visits

Try to plan ahead for hospital visits and agree the time off work with your manager. There are other things you can do to save time or make things easier:

- If you plan to drive to the hospital, find out about parking. You could find out where the parking is, and if you have to pay. Some hospitals give people with cancer free car parking or discounts.
- Give yourself plenty of time. Hospital visits can sometimes take longer than expected.
- If the person you are caring for needs help with transport, ask the hospital what support is available. Some areas have local voluntary groups to provide practical help for people in need.

Once Kate was on the ward, I was able to think more clearly. I told friends and relatives so someone could be with Kate in hospital while I was working.

Mark

#### After treatment

When treatment ends, the person you are caring for may need regular follow-up appointments. They may also need scans, or other support such as physiotherapy or speech therapy.

The end of treatment can be a difficult time. The person you are caring for may feel worried because they are not seeing their cancer doctor and specialist nurse as much. They may still be coping with treatment side effects and difficult feelings. They may also be feeling some uncertainty or worrying about the cancer coming back.

We have more information in our booklets <u>Side effects of cancer</u> treatment, <u>How are you feeling? The emotional effects of cancer</u> and Worrying about cancer coming back.

It takes time to recover and adjust to life after cancer treatment. Try to offer as much help as you can.

It is hard to say how long the person you are caring for will need your help after cancer treatment ends. This will depend on how treatment has affected them. Talk to them regularly to find out how they are feeling and what support they may need.

# **Questions about caring** during treatment

This table shows questions you may have if you work while caring for someone having cancer treatment.

	Cancer team	GP services	Occupational health professionals
I would like to go to hospital appointments with the person I am caring for. How long is each appointment likely to be? Could they take longer than expected? How far in advance can appointments be made?	•		
If the person I am caring for has an appointment, do I need to do anything before it? For example, bring a list of their medication, or ask if they need a repeat prescription?	•		
If the person I am caring for needs to stay in hospital and visiting hours are only when I am at work, can I visit at different times?	•		
When am I most likely to need to take time off work or work less to provide care?	•		
Does the hospital have free Wi-Fi so I can access work emails?	•		
Can repeat prescriptions be delivered to my local pharmacy, so I can collect them outside working hours?	•	•	



A tick in a circle shows the service or person most likely able to answer your question.



A simple tick shows a service or person who may also be able to help.

We explain these roles and services on page 18.

Line manager	HR manager	Advisory services	Charities and support groups	Unions	Social services

# Talking to people at work

It can help to tell your employer you are caring for someone with cancer. You can explain how this might affect your work. It may be a difficult and stressful time for you, and you may feel your life has completely changed. You do not have to tell your manager, employer or colleagues that you are caring for someone with cancer. But talking to your employer can:

- help them be sensitive to the changes and feelings you are coping with
- help them understand your needs so they can support you better
- mean you are less likely to have problems in the future for example, if you ask for flexible working, they will understand your situation.

Try to find out if your employer has policies or guidance on supporting carers. You can do this by speaking to human resources (HR) or your manager, or checking your contract, employee handbook or intranet, if you have them.

We use the terms 'manager' or 'employer' but different people at your workplace might be involved. You may want to talk to some of the following people:

- your line manager they are often the first person you talk to
- an HR manager
- your trade union representative, if you are a member.

You can ask your employer to keep this information confidential. This means they will not tell anyone else what you have told them.



"I've had to make changes to the way I do things. Work have been amazing. They allowed me to occasionally work from home, which means I can sort things out here, like the cooking. "

Mark

## What you can do

The first step is to have a meeting with your employer. This is so you can tell them about your responsibilities as a carer. This might be with your manager, or HR department, if your employer has one. We have some <u>example questions</u> you might like to use.

If you feel nervous, you can ask your employer in advance if you can bring someone with you to the meeting. This could be a work colleague. In more formal meetings you may be able to take a trade union representative, if you are a member. It is a good idea to meet in a private place where you will not be interrupted. Make sure both you and your manager have plenty of time to talk.

Your manager may make notes at the meeting. You can ask for a copy of these. The notes should not be shared with anyone else without your permission. It may be helpful to write your own notes. This will help you remember what was said and can be used if anything unexpected happens later.

You can ask in advance if you can record the meeting. This may be useful if you have problems writing. If you want to record the meeting, everyone attending has to agree to this before you do it.

It may help to tell your manager that things might change while the person you are caring for is having treatment. But you could explain the treatment the person will have and what care you think they will need.

Tell your manager that you may need time off. It may help to explain that sometimes this time off could be at short notice. Try to explain your caring responsibilities and any concerns you have about balancing caring and working.

You can ask what leave you can take. For example, there may be a policy for emergency time off that you can use. You may also want to ask what other support is available. This could include:

- making changes to your working pattern
- finding out about staff networks
- accessing an employee assistance programme (EAP).

At the meeting, your manager may ask how you are coping and what your concerns about work are. They may also ask if you would like your colleagues to know about your situation, and how much information you would like them to have.

If you decide to tell your colleagues, you might prefer not to tell them yourself. You can ask your manager or someone else you work with to do this.

Your manager may ask you how you think being a carer will affect:

- you personally
- how often you can work
- your ability to manage your work or responsibilities
- your ability to do your job in the short and long term.

You and your manager can talk about ways of doing your job that suit your situation. Your manager will need to think about things such as how to balance your time off work with the workload of the rest of the team.

If your employer has policies or guidance on supporting carers, you should talk to your manager about these. You should be able to agree a way they can be applied to assist and support you. An HR manager should also know about your legal rights as a carer and be able to assist you and your manager.

If your employer does not have policies or guidance on supporting carers, it may be difficult for them to make decisions. Macmillan has a resource called <u>Your work and cancer toolkit</u>. It contains information that may be helpful to your employer.

It is usually useful for you and your manager to have regular meetings. You can review how any changes are going, and make sure you are getting enough support. Your manager should always discuss any possible changes to your work plan with you.

We have more information on our website about the ways we can support employers. Visit macmillan.org.uk/employers



### How your employer can support you

You may want to talk to your manager or HR department about things your employer can do to help you as a carer. Employers can support carers in different ways. Try to think about the help you might need.

#### Some employers offer:

- flexible working
- access to a private telephone, so you can make or receive private calls
- access to personal emails, so you can contact the hospital or other people during work hours
- a reserved car parking space, to make getting in and out of work quicker and easier
- a buddy or mentor at work who can support you.

As well as talking to your manager or an HR manager, you may be able to:

- talk to an occupational health adviser about extra support you might need
- get support or counselling from an employee assistance programme (EAP) counsellor
- contact local support and networking groups through your employer.



## Information from your employer

You can ask your employer for information about:

- flexible working and work adjustment policies
- leave policies, which may include carer's leave, emergency leave and parental leave, and how using any of these policies might affect your pay
- absence policies covering sick leave and sick pay
- any relevant company benefits you could get, such as employee assistance programmes, occupational health and counselling services.

Not all employers offer the same benefits. Some employers may not be able to say yes to requests for flexibility or changes to your role. But all employers should be able to give you information about your legal rights.

Employees have certain legal rights. This is regardless of the number of hours per week you work. This includes having paid holidays, the right to ask for flexible working, and reasonable time off work to look after dependants in an emergency.

Someone who is not an employee, such as an agency or freelance worker, will not have the same protections under employment law as an employee. If you are in this situation, it is important to get advice from an experienced adviser. You can contact the Macmillan Work Support team, Advice NI in Northern Ireland or your local Citizens Advice in England, Scotland and Wales.

Your employer should also be able to give you more information about:

- relevant statutory benefits
- how to talk to your colleagues about cancer and the challenges of being a carer
- specialist organisations, relevant charity helplines and websites, such as Macmillan and Carers UK
- counselling services that may be available to you.

My employer has been brilliant. I've been off work on full pay, doing 1 day a week when possible. Earlier this year my boss told me that I should transfer from carer's to sick leave which would mean I'd get Statutory Sick Pay. II

Nicola, who cared for her daughter

## Talking to other people at work

Talking to the people you work with about being a carer can be difficult. You may worry about their reactions or think that it will be awkward. You may decide to tell people you feel closest to at first. They may be able to help you plan how to tell others.

Colleagues can often be supportive, and having someone who will listen to you can be helpful. You may find other employees are carers too. If so, it may be useful to share your experiences and have someone who understands.

Talking to others at work can:

- give you someone to talk to
- give them a chance to support you
- mean you are able to tell them when you need help
- give them a chance to suggest helpful ways of coping with your work
- make you feel more connected to the people you work with.

#### If you do not want to tell your colleagues

You may prefer not to tell your colleagues. You might want to keep your work life as normal as possible. It is important that your wish for privacy is respected. You have a right to ask that information should be confidential and only passed on in a 'need to know' basis.

Do not feel under pressure to explain things if you do not want to. You know what is best for you and your situation.

## **Making decisions** about work

You may need to make some decisions about work. You might think about stopping work or taking early retirement to care for someone. This could affect your life in different ways. So it is something you need to think about carefully.

#### Stopping work could:

- affect your finances
- make you feel isolated from friends at work
- mean that you cannot keep your skills up to date
- make it harder to get back into the job market later on.

You may find it helpful to find out more about your rights as a carer and an employee before making your decision. For more information about this, you can contact <u>Carers UK</u> or <u>Working Families</u>.

You can also speak to a Macmillan work support adviser on 0808 808 00 00.

### **Finances**

When you are making decisions about work, it may be important to think about your finances.

Stopping work could affect your finances. This might include your income, pension and any employee benefits you are entitled to. Our financial guides can help with managing your finances. Call them free on **0808 808 00 00**.

If early retirement is an option, discuss it with your employer. For some people, it could be the right decision. But for others, it can leave them financially worse off. Our financial guides can discuss this with you.

Our booklet Looking after someone with cancer has more information about benefits you may be able to get as a carer.

## If you are self-employed

If you are self-employed, you may have more control over your working life than someone who is employed. But you will not have the same employment law rights and protection. You and your family may also depend on the income from your business. This can put extra pressure on you as a carer if your working life is affected.

We have more information in our booklet Self-employment and cancer. You can talk through your options with a Macmillan work support adviser on 0808 808 00 00.

You can order our booklets and leaflets for free. Visit be.macmillan.org.uk or call us on 0808 808 00 00.





# **Questions about** work arrangements

The tables on the following pages show questions you may have about working while caring.

	Cancer team	GP services	Occupational health professionals
Where can I learn about my legal rights as a working carer?			
I am self-employed. What support can I get to keep my business running while I am caring?			
Being a carer is having an impact on my physical and mental health. How can I make sure I stay physically healthy and take care of my mental health while working and caring?		•	•
Are there courses or counselling services that could help me manage my work and caring responsibilities better?			•
Does my employer have a policy for supporting carers? What types of paid and unpaid leave are available?			
Can I have flexible working to help me balance my work and caring responsibilities? For example, could I change my working hours? Can I have this in writing?			



A tick in a circle shows the service or person most likely able to answer your question.



A simple tick shows a service or person who may also be able to help.

We explain these roles and services on page 18.

Line manager	HR manager	Advisory services	Charities and support groups	Unions	Social services
•	•	•	•		
<b>~</b>	<b>~</b>	<b>~</b>	•		
•	•			<b>~</b>	
•	•	<b>~</b>		<b>~</b>	

	Cancer team	GP services	Occupational health professionals
Could flexible working affect any employee benefits I have, such as death-in-service benefit or my pension?			
If I take a large amount of time off work to care, how much notice do I have to give before I go back? Can I stay informed about any changes that happen? For example, changes to team members or policy.			
Can my work be organised so that I can take time off at short notice if I need to? For example, what if I need to take time off if there is a problem with care arrangements? Who should I tell at work if I need to take time off at short notice?			
Would it be okay for me to make short personal phone calls or send personal emails or text messages during work hours? For example, could I do this if I need to contact the person I care for or let them contact me?			
Can we agree on what to tell people at work about my situation and how it will affect my work? For example, what will we tell colleagues, other managers and clients?			
Can we have regular meetings to review my working arrangements?			

Line manager	HR manager	Advisory services	Charities and support groups	Unions	Social services
•	•	•		<b>~</b>	
	•			<b>*</b>	
•	<b>~</b>				
•					
•	•				
•	<b>~</b>				



# Your rights at work

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# Your legal rights as a working carer

You may have certain rights at work that could help make it easier to keep working while you are caring. These include the right to ask for flexible working, or to take time off work in an emergency.

## Flexible working

If you are a carer, flexible working could help make it easier for you to keep working while caring for someone. Carers have a legal right to request flexible working. Right now, this right only applies if you:

- are an employee
- have worked for your employer for at least 26 continuous weeks before your request.

This law is currently in the process of being changed.

Flexible working arrangements could include:

- working from home
- flexible start or finish times
- compressed working hours this means working your normal number of hours but over fewer days
- annualised working hours this means working your normal number of hours per month or year, in a flexible way
- job-sharing
- working part-time
- flexible annual leave to fit in with alternative care arrangements.

## Requesting flexible working

Check your working policies and procedures. If your employer has a process for flexible working requests, you should follow it.

#### Formal flexible working request

To make a formal flexible working request:

- You must make your request in writing. Your employer may have a specific flexible working request form you can use.
- You should date the request and state it is being made under the statutory flexible working provisions.
- Write the change you are asking for and what date you would like this to start. You should also explain any impacts you think this could have on your employer and how these can be addressed.
- You can only make a certain number of requests in a 12-month period - it can be helpful to check this when making the request so you know how many you can make.
- Your employer must consider your request in a fair way.
- Your employer must make a decision within a certain time. How long they get to decide depends on where in the UK your company is based. You can check with your employer or visit gov.uk or nidirect.gov.uk for more information.
- If your employer agrees, this will permanently change the terms and conditions in your employment contract, unless you agree otherwise.
- If your employer does not agree, they must write to you and explain why. You may be able to appeal this decision or complain to an employment tribunal or industrial tribunal. This is an independent body that makes decisions in legal disputes between employees and employers.

The following organisations have more information about your right to request flexible working and making a request:

- The Advisory, Conciliation and Arbitration Service (Acas).
- The Labour Relations Agency (LRA) in Northern Ireland.
- · Carers UK.

#### Informal flexible working request

You can also make an informal request for flexible working arrangements. This means it is not requested under flexible working legislation. This could be useful if you want to make a temporary or small change to the way you work now, and need the change to happen quickly. It may also be helpful if you want to try out a change before making it permanent.

Your employer does not legally have to consider or agree to an informal request for flexible working.

After about 6 months, HR advised I should apply for flexible working. I was required to work 37 hours but could do this at any time during the week to ensure I could attend important medical appointments with Kate.

Mark

#### If your employer refuses your request

You do not have a right to flexible working. You only have a right to ask for it. An employer can refuse a request for flexible working if it is not in the best interests of the business. This might be because it would be too expensive or could affect the performance of the business.

If your employer refuses your request, you may be allowed to appeal. However, you are not legally entitled to appeal, so this will depend on your employer's policy. You may have some new information that would help them reconsider their decision.

It is a good idea to get advice from:

- your trade union representative, if you are a member of a union
- a staff representative
- an HR manager
- the Macmillan Work Support team call **0808 808 00 00**
- an organisation called Working Families.

If you are not allowed to appeal, you could raise a complaint with your employer. This is called a grievance. You could suggest involving Acas, or the LRA in Northern Ireland. They can help you and your employer discuss the possible options.

Some situations may involve a compromise. For example, your employer may agree to you working from home for a few days a week, rather than working from home every day.

## Time off in an emergency

As a carer, you also have the legal right to take a reasonable amount of time off work to deal with an emergency that involves the person you care for. If you are an employee, you have this right under the following laws:

- The Employment Rights Act 1996, if you live in England, Scotland or Wales.
- The Employment Rights (Northern Ireland) Order 1996, if you live in Northern Ireland.

The person you are caring for is called your dependant. This person could be:

- a parent, child, spouse or civil partner
- anyone who lives with you, but is not a tenant, lodger, boarder or employee
- someone who relies on you to help them if they become ill
- someone who needs you to make care arrangements for them.

An emergency might include:

- an unexpected change or problem with care arrangements
- the person you care for becoming ill, giving birth, being injured, being assaulted or having an accident
- you needing to make care arrangements when your dependant is ill or injured - this could mean arranging for a temporary carer, but not taking extra time off to care for the dependant yourself
- the death of a dependant
- you having to deal with an unexpected incident that involves your child during school hours.

You do not need to have been in your job for a certain amount of time before you can take time off in an emergency. But how much time off you can have depends on the situation. Your employer may consider what has happened, and decide how close your relationship is to the dependant and whether someone else could help instead.

To use this type of time off, you must tell your employer about the emergency as soon as possible. If you can, tell them when you expect to return to work. The time off is likely to be unpaid, but this depends on your employer's policies.

Your legal right to time off in an emergency does not apply if you want to take planned time off to care for someone. For example, it would not apply if you want to take them to a medical appointment.

Your employer may have a policy for other types of time off for carers. Or you could talk to them about arranging time off. Some options could be:

- carer's leave (paid or unpaid)
- parental leave
- compassionate leave
- flexible working
- borrowing holiday days from next year or buying additional days
- career breaks and sabbaticals (usually unpaid) make sure you have all the details about these as they may affect your employment rights.

It is up to your employer to decide whether or not to agree to these other types of time off.

Macmillan has more information about being a carer at macmillan.org.uk/ carer Carers UK can also give you advice about employment issues and rights for carers, including time off.



## How carers are protected from discrimination

If you experience discrimination at work as a carer, you can contact the Macmillan support line and speak to our Work Support team. There are also organisations that can give you advice on your employment rights. Contact Advice NI or Citizens Advice in England, Scotland and Wales for more information

If you are a carer, there are laws that protect you from being discriminated against at work because of your association with a Disabled person. If someone has had cancer, the law considers this a disability. Being discriminated against because of your association with a Disabled person is called associative discrimination.

- If you live in England, Scotland or Wales, the Equality Act 2010 protects you.
- If you live in Northern Ireland, the Disability Discrimination Act 1995 protects you.

Carers may be protected against associative discrimination in situations where they have experienced 1 or more of these types of discrimination:

- direct disability discrimination
- harassment
- victimisation
- indirect disability discrimination.

Protection from these types of discrimination may be different in England, Wales, Scotland and Northern Ireland. If you are not sure if you are protected, contact our Work Support team on **0808 808 00 00** for more advice.

Your employer does not have to make reasonable adjustments if you do not have a disability. This applies to carers too. However, other laws may give you the right to request flexible working, and to a reasonable amount of time off work for caring responsibilities. It is important to check whether your employer has a policy for carers. They may allow additional arrangements.

## **Direct disability discrimination**

This is when you are treated less favourably than somebody else whose circumstances are similar to yours because you are associated with someone who has a disability. If someone has or has had cancer, the law considers this as a disability.

This type of discrimination includes situations where, because you are a carer for someone with a disability, you are:

- not offered a job
- refused a promotion, for example because your employer is worried you will not be focused on the job
- given worse employment terms than your colleagues for example, lower pay.

#### **Harassment**

This is when you are treated in a way that makes you feel uncomfortable, insulted or intimidated, and this behaviour is related to your association with the person with cancer. This might include written or spoken comments or jokes.

### **Victimisation**

This is when you are treated badly because you have done, or intend to do, something that is protected by law. This is called a protected act. Protected acts include:

- making a complaint about discrimination or harassment under the Equality Act or the Disability Discrimination Act
- helping someone else make a complaint about discrimination or harassment.

## Indirect disability discrimination

Indirect disability discrimination is when a rule, policy or practice appears to treat all employees the same, but it actually puts some people at a disadvantage. For example, it is indirect disability discrimination if you have worked from home and then your employer makes a rule that everyone has to work from the office. As a carer this may put you at a disadvantage as you may not be able to do your caring duties anymore.

An employer may be able to justify their actions if they can show that there is a genuine business need. For example, they may be justified if the rule, policy or practice is necessary and there is not a non-discriminatory option available.

## If you feel your employer is not being reasonable

If you feel your employer is not behaving in a reasonable and fair way. and you have not been able to resolve the problem in a way that you are happy with, you may want to think about making a formal complaint. This is sometimes called a formal grievance.

If you feel your employer is being unreasonable and has not dealt with your grievance fairly, you may be able to complain to an employment tribunal or industrial tribunal. This is an independent body that makes decisions in legal disputes between employees and employers.

It is a good idea to contact your union representative if you have one, or contact:

- Acas if you live in England, Scotland or Wales
- the Labour Relations Agency (LRA) if you live in Northern Ireland.

We have more information about resolving problems at work in our booklet Your rights at work when you are affected by cancer. Advice NI and Citizens Advice also have information about this.

Many carers aren't given sufficient supportive leave arrangements to allow them to carry out the role of carer. I feel there is much to do in terms of working conditions to support the flexible needs of carers.

Patrick, who cared for his wife



# Looking after yourself

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## Taking care of yourself

Caring for someone can be physically and emotionally demanding. It is important to take care of yourself, as well as the person you are caring for. It can help to know the signs of feeling stressed, and try to recognise them. You can also plan how to deal with stress.

You may want to try the following:

- Contact your GP to talk about your situation and how you are feeling.
- Make a list of activities you like doing. Try to do 1 or 2 each week.
- Spend some time away from the person you are caring for. Friends and family may be able to help with your caring responsibilities to allow you to do this. Or you can search for local carers' services and respite services on the Carers Trust website.
- Talk to other carers at a local support group. Carers UK can help you find out if there is a group in your area.
- Ask the hospital or your GP surgery for information that can help you manage the emotional challenges of caring.
- Call the Macmillan support line on 0808 808 00 00 to talk to someone about your feelings, and get support. Or visit macmillan.org.uk/inyourarea to find local support.
- Join the Macmillan Online Community. There is a forum for carers where you can share worries and find people who understand.
- Find out about some of the organisations and websites that offer practical and emotional support for carers. These include Carers UK and Carers Trust.

## Time for yourself

You may need time to yourself to help you cope. This gives you the chance to relax and do things you enjoy. Remember that no one will expect you to do everything. Try to ask for help from your friends and family.

## Help from social services

A social worker is responsible for assessing what practical and social help you and the person you care for need. If you do not already have a social worker, the GP or nurse involved in the person's care can refer you.

You can also contact your local social services department. You can find their number online by searching for the name of your local authority, council, or health and social care trust. Your GP surgery can give you the number too.

The social worker will visit and do a community care assessment or needs assessment for the person you care for. Each local authority has different ways of deciding who can get support. The available services are different across the UK. If the person you care for is eligible for some help, the local authority has a duty to meet their needs. The services the person needs may be provided by social services, or by other organisations, such as charities.

#### These services include:

- home care
- the delivery of meals (sometimes called meals on wheels)
- laundry services for people with incontinence (problems controlling your bladder or bowel)
- home equipment and adaptations
- information and benefits advice.
- time off from caring so you can have a break (respite care)
- someone coming to spend time with the person you care for, to give you a break (sitting services).

I juggled a full-time job with caring for my terminally ill husband and young son. Being a carer is physically, mentally and emotionally exhausting, and I was permanently 'on duty'.

Kate who cared for her husband

Some services are paid for by the NHS. Sometimes, social services do a financial assessment to work out if the person you care for needs to pay something. This is usually called means-tested support.

Your social worker should stay in touch with you after the services have been put in place. They will check that the services are working and that the needs of the person you are looking after have not changed. Many social workers are also trained in counselling. They may be able to offer emotional support.

#### Carer's assessment

Trying to balance caring with your life, work and family commitments can be difficult. You can ask the social worker for an assessment of your needs. This is called a carer's assessment. You can talk about any help you need.

You can still ask for this assessment even if the person you care for:

- does not want an assessment of their needs
- is not eligible for support.

## **Questions about caring** for someone at home

This table shows questions you may have about caring for someone at home.

	Cancer team	GP services	Occupational health professionals
How do I apply for a carer's assessment? A carer's assessment is done by social services to decide what support you need to be able to care for someone.	<b>~</b>	<b>~</b>	
How can I organise extra support at home to help me manage my work and caring responsibilities? For example, can I get someone to be with them during the day or at night?	~	~	
How can I meet other working carers to share my experiences and learn from others?	<b>~</b>	<b>~</b>	



A tick in a circle shows the service or person most likely able to answer your question.



A simple tick shows a service or person who may also be able to help.

We explain these roles and services on page 18.

Line manager	HR manager	Advisory services	Charities and support groups	Unions	Social services
					•
		~	~		•
		<b>~</b>	•		<b>~</b>

## Financial support

Cancer can mean extra costs for you and the person you care for. This can include:

- paying for travel to hospital
- higher food costs
- more expensive heating bills.

If you stop working or reduce your hours, you may have less money coming in. You and the person you care for may be able to get benefits such as Carers Allowance or financial support.

You can call us for free on **0808 808 00 00** to speak to a:

- financial guide, who can assess your situation and give you personalised guidance
- welfare rights adviser, who can tell you what benefits you may be able to get and help you make a claim.

We also have more information in our booklet Help with the cost of cancer.

You can order our booklets and leaflets for free. Visit be.macmillan.org.uk or call us on 0808 808 00 00.



My employer agreed carer's leave and sick leave while Lucy was having treatment. The pay wasn't enough to cover the costs of travel and caring. I talked to my Macmillan adviser about applying for Disability Living Allowance (DLA). I don't think I would have been able to complete my application without their support. ,,

Helga, who cared for her daughter Lucy

## **Questions about** finances

The tables on the following pages show questions you may have about money and benefits.

	Cancer team	GP services	Occupational health professionals
What benefits can I get if I am self-employed?		<b>~</b>	
What benefits could I get if I continue working, stop working or go back to work?		<b>~</b>	
Does my employment status affect the benefits I can get? For example, what happens if I am on a short-term contract?			
If I am already getting benefits like Income Support, how will this affect the benefits I can get as a carer?			
The person I care for is getting benefits. Will this affect the benefits I can get as a carer?			
If I get benefits as a carer, will this affect the benefits the person I care for can get?			



A tick in a circle shows the service or person most likely able to answer your question.



A simple tick shows a service or person who may also be able to help.

We explain these roles and services on page 18.

Line manager	HR manager	Advisory services	Charities and support groups	Unions	Social services
		<b>②</b>	<b>✓</b>		<b>~</b>
		<b>②</b>	<b>②</b>		•
		•	<b>~</b>		
		•	<b>~</b>		
		•	<b>~</b>		
		<b>②</b>	<b>~</b>		

	Cancer team	GP services	Occupational health professionals
If I make adjustments such as working fewer hours, how will this affect my pay and benefits?			
I need evidence to support my claim for benefits as a carer. Who can help me get this?	<b>~</b>	<b>~</b>	
When will my benefits be confirmed?			
How long can I claim benefits for?			
How will my company pension or State Pension be affected if I cannot go back to work or work fewer hours to care for someone?			

Line manager	HR manager	Advisory services	Charities and support groups	Unions	Social services
•					
	<b>~</b>	<b>Ø</b>			<b>~</b>
		•	<b>~</b>		
			<b>~</b>		
	•	•	•	<b>~</b>	



## If the cancer is advanced

If the cancer is advanced, the needs of the person you care for are likely to change. There may be extra demands on you. This can be hard to cope with. Sometimes the person will not be able to stay at home to be looked after, but will be moved to a hospital, hospice or a care home.

You can talk to the person's GP, community or specialist nurse to find out more about extra support and help. You can also ask <u>social services</u> for a reassessment of your needs as a carer. Or for a reassessment of the needs of the person you are caring for.

You may need more time off work, especially if you are looking after the person at home at the end of their life. You may decide you want to stop working for a while.

Whatever you decide, this will be a difficult time for you. Try to talk to your manager about any changes, so they can keep supporting you.

We have more information about caring for someone with advanced cancer at <a href="macmillan.org.uk/caring-end-of-life">macmillan.org.uk/caring-end-of-life</a>



## If you are no longer a carer

You may no longer be a carer for different reasons. The person you cared for may have recovered and no longer need your support. Or they may be in hospital, hospice or a care home. If this happens, you might still be providing some care. For example, you may be visiting them regularly or helping them make decisions about their care.

You may no longer be a carer because the person you cared for has died. Even if you felt prepared for this, you may still feel shocked and numb. It is common to have many different feelings, and sometimes physical symptoms. You may be very upset, and at the same time feel relieved. These are all common feelings to have.

We have more information in our booklet After someone dies: coping with bereavement.

## Work and bereavement

Try to keep talking to your manager about how you are feeling. Tell them about any time away from work that you might need. This includes time off to make plans for or attend a funeral. You could tell them what you want your colleagues to know. Let them know if you are happy to be contacted while you are off work.

Your employer may have a leave policy. Check with them what type of leave you can take. This may include compassionate leave or parental bereavement leave. How much time off work you need depends on what is best for you. You may find that if you return to work too quickly, you need to take more time off later.

"When my dad died, I was given 2 weeks off work, but following a meeting with the doctor and the occupational therapist, they said I needed more time off to recover. I'm still suffering with anxiety and stress from being the only one who was there to help. ,,

Sara, who cared for her dad

You could ask to have regular contact with your manager while you are off work. This could be a chance to:

- maintain contact with your workplace community
- talk about any support or adjustments that will help you go back to work
- learn about changes or updates.

To start with, you may need a temporary change in your hours or responsibilities. Or you may be able to work from home. You may find working again hard when you are coping with a bereavement. But getting back into a routine can be a good thing.

You may worry about seeing or talking to the people you work with for the first time when you go back to work. Tell your manager if you would prefer people not to talk to you about the loss. They can tell your colleagues. People sometimes like to offer sympathy. But you might find it hard to be reminded of your loss. You do not have to share any more than you want to.

You may find it hard to concentrate. You might feel very tired and be easily distracted. There are some things you can do during this time. For example, you could talk to your manager about having someone check your work for a while.

Feelings of grief may come and go. Some last a short time, while others go on for longer. If your employer has an employee assistance programme (EAP), you might find this helpful for emotional support and counselling.

Tell your manager and colleagues when you are finding things difficult and if you need their help.

"My mum passed away, which is heartbreaking. I'm slowly going back to work, which is tricky, as I'm working from home and it is difficult trying to remember everything. Luckily work is really supportive. "

Lydia, who cared for her mum

## Getting back to work

If your caring role has changed or ended, you may want to go back to how you worked before. If you have been off work for a while, it might help to have a slow and flexible return. It is a good idea to have a meeting with your manager before going back to work. Try to have regular meetings with them.

It may take time to get used to full-time work, or to the responsibilities you had before. You may feel you have lost confidence. Talk to your manager if you need training or support to help you.

As a carer, you will have developed a lot of skills that employers value. For example, you may have improved your time management.

Getting back to regular work can give you routine. It can also give you the chance to make plans for the future.

If you stopped working and are looking for a new job, you can find advice on writing a CV, filling in application forms and doing well in job interviews. Your local library may have books on interview skills. There is also lots of advice online.

Your local Jobcentre or Jobs and Benefits office can offer support with your job search. There are different websites that give career advice. These include:

- National Careers Service, if you live in England
- Skills Development Scotland, if you live in Scotland
- Careers Wales, if you live in Wales
- JobApplyNI, if you live in Northern Ireland.

If you have gaps in your employment history because of your caring role, explain this on your CV or in person at an interview. Remember that you have developed many skills as a carer that may help you in your work.

Macmillan has a <u>Work Support team</u> that can help with getting back to work. Call **0808 808 00 00** to speak to an adviser.





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## **About our information**

We provide expert, up-to-date information about cancer. And all our information is free for everyone.

## Order what you need

You may want to order more booklets or leaflets like this one. Visit be.macmillan.org.uk or call us on 0808 808 00 00.

We have booklets about different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer treatment and information for carers, family and friends.

## Online information

All our information is also available online at macmillan.org.uk/ information-and-support You can also find videos featuring stories from people affected by cancer, and information from health and social care professionals.

## Other formats

We also provide information in different languages and formats, including:

- audiobooks
- Braille
- British Sign Language
- easy read booklets

- interactive PDFs
- large print
- translations.

Find out more at macmillan.org.uk/otherformats

If you would like us to produce information in a different format for you, email us at cancerinformationteam@macmillan.org.uk or call us on 0808 808 00 00.

## The language we use

We want everyone affected by cancer to feel our information is written for them.

We want our information to be as clear as possible. To do this, we try to:

- use plain English
- explain medical words
- use short sentences
- use illustrations to explain text
- structure the information clearly
- make sure important points are clear.

We use gender-inclusive language and talk to our readers as 'you' so that everyone feels included. Where clinically necessary we use the terms 'men' and 'women' or 'male' and 'female'. For example, we do so when talking about parts of the body or mentioning statistics or research about who is affected.

You can read more about how we produce our information at <a href="mailto:macmillan.org.uk/ourinfo">macmillan.org.uk/ourinfo</a>

## Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we are here to support you.

## Talk to us

If you or someone you know is affected by cancer, talking about how you feel and sharing your concerns can really help.

#### **Macmillan Support Line**

Our free, confidential phone line is open 7 days a week, 8am to 8pm. We can:

- help with any medical questions you have about cancer or your treatment
- help you access benefits and give you financial guidance
- be there to listen if you need someone to talk to
- tell you about services that can help you in your area.

Our trained cancer information advisers can listen and signpost you to further support. Call us on **0808 808 00 00**. We are open 7 days a week, 8am to 8pm.

You can also email us, or use the Macmillan Chat Service via our website. You can use the chat service to ask our advisers about anything that is worrying you. Tell them what you would like to talk about so they can direct your chat to the right person. Click on the 'Chat to us' button, which appears on pages across the website. Or go to macmillan. org.uk/talktous

If you would like to talk to someone in a language other than English, we also offer an interpreter service for our Macmillan Support Line. Call **0808 808 00 00** and say, in English, the language you want to use. Or send us a web chat message saying you would like an interpreter. Let us know the language you need and we'll arrange for an interpreter to contact you.

## **Macmillan Information and Support Centres**

Our Information and Support Centres are based in hospitals, libraries and mobile centres. Visit one to get the information you need and speak with someone face to face. If you would like a private chat, most centres have a room where you can speak with someone confidentially.

Find your nearest centre at <a href="macmillan.org.uk/informationcentres">macmillan.org.uk/informationcentres</a> or call us on **0808 808 00 00** 

## Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you have been affected in this way, we can help. Please note the opening times may vary by service.

## Financial guidance

Our financial team can give you guidance on mortgages, pensions, insurance, borrowing and savings.

## Help accessing benefits

Our welfare rights advisers can help you find out what benefits you might be entitled to, and help you complete forms and apply for benefits. They can also tell you more about other financial help that may be available to you. We can also tell you about benefits advisers in your area. Visit <a href="mailto:macmillan.org.uk/financialsupport">macmillan.org.uk/financialsupport</a> to find out more about how we can help you with your finances.

### Help with energy costs

Our energy advisers can help if you have difficulty paying your energy bills (gas, electricity and water). They can help you get access to schemes and charity grants to help with bills, advise you on boiler schemes and help you deal with water companies.

#### **Macmillan Grants**

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing, to changes needed to your home.

Call us on **0808 808 00 00** to find out more about Macmillan Grants.

## Help with work and cancer

Whether you are an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit macmillan.org.uk/work

## Work support

Our dedicated team of work support advisers can help you understand your rights at work. Call us on **0808 808 00 00** to speak to a work support adviser.

## Talk to others

No one knows more about the impact cancer can have on your life than those who have been through it themselves. That is why we help bring people together in their communities and online.

#### **Support groups**

Whether you are someone living with cancer or a carer, family member or friend, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting <a href="mailto:macmillan.org.uk/selfhelpandsupport">macmillan.org.uk/selfhelpandsupport</a>

#### **Online Community**

Thousands of people use our Online Community to make friends, blog about their experiences and join groups to meet other people going through the same things. You can access it any time of day or night. Share your experiences, ask questions, or just read through people's posts at macmillan.org.uk/community

You can also use our Ask an Expert service on the Online Community. You can ask a financial guide, cancer information nurse, work support adviser or an information and support adviser any questions you have.

## Macmillan healthcare professionals

Our nurses, doctors and other health and social care professionals give expert care and support to individuals and their families. Call us or ask your GP, consultant, district nurse or hospital ward sister if there are any Macmillan professionals near you.

## Other useful organisations

There are lots of other organisations that can give you information or support. Details correct at time of printing.

#### **Access to Work**

Tel **0800 121 7479** 

Textphone **0800 121 7579** 

www.gov.uk/access-to-work

Provides advice to people with long-term health conditions and their employers. Gives grants to pay for practical support to help you do your job.

#### Access to Work (NI)

www.nidirect.gov.uk/articles/access-work-practical-help-work

Gives support and advice to employees with disabilities and their employers. To apply for assistance through this programme, speak to an adviser at your local Jobs and Benefits Office.

## Advisory, Conciliation and Arbitration Service (Acas)

Helpline 0300 123 1100

www.acas.org.uk

Gives advice to employees and employers to help improve working life and relations. Offers information, advice and training.

#### **Careers Wales**

#### Tel 0800 028 4844

#### www.careerswales.gov.wales

Provides help to people in Wales planning their career, preparing to get a job, or looking for apprenticeships, courses and training.

### **Equality Commission for Northern Ireland (ECNI)**

#### Tel 0289 050 0600

#### www.equalityni.org

Aims to promote equality of opportunity, encourage good relations and challenge discrimination.

### **JobApplyNI**

#### Tel 0289 016 3473

## www.jobapplyni.com

Run by the Department for Communities. Lists thousands of job opportunities in Northern Ireland.

### **Labour Relations Agency**

#### Tel 0330 055 2220

#### www.lra.ora.uk

Responsible for promoting the improvement of employment relations in Northern Ireland. Provides advice and support to both employees and employers, and helps resolve disputes.

## **National Careers Service England**

#### Tel **0800 100 900**

### https://nationalcareers.service.gov.uk

Provides personalised careers advice and information for people living in England.

## **Skills Development Scotland**

#### Tel 0141 285 6000

### www.skillsdevelopmentscotland.co.uk

Supports people in Scotland to develop their skills, at all stages of their career journey.

## **Working Families**

### Helpline **0300 012 0312**

https://workingfamilies.org.uk

The UK's national charity for working parents and carers.

#### **WorkSmart**

#### www.worksmart.org.uk

Provides information on employment rights, health at work and financial matters. It is part of the Trades Union Congress (TUC).

## Financial support or legal advice and information

#### **Advice NI**

Helpline 0800 915 4604

www.adviceni.net

Provides advice on a variety of issues including financial, legal. housing and employment issues.

### **Benefit Enquiry Line Northern Ireland**

Helpline **0800 232 1271** 

Textphone **0289 031 1092** 

www.nidirect.gov.uk/money-tax-and-benefits

Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

#### Carer's Allowance Unit

Tel 0800 731 0297

Textphone 0800 731 0317

www.gov.uk/carers-allowance

Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

#### Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Use its online webchat or find details for your local office by contacting:

#### **England**

Helpline **0800 144 8848** www.citizensadvice.org.uk

#### Scotland

Helpline 0800 028 1456 www.cas.ora.uk

#### Wales

Helpline **0800 702 2020** www.citizensadvice.org.uk/wales

## **Civil Legal Advice**

Helpline **0345 345 4345** Textphone 0345 609 6677 www.gov.uk/civil-legal-advice

Has a list of legal advice centres in England and Wales and solicitors that take legal aid cases. Offers a free translation service if English is not your first language.

#### **Disability and Carers Service**

#### Tel 0800 587 0912

Textphone 0800 012 1574

nidirect.gov.uk/contacts/disability-and-carers-service

Manages Disability Living Allowance, Attendance Allowance, Carer's Allowance and Carer's Credit in Northern Ireland. You can apply for these benefits and find information online or through its helplines.

#### **GOV.UK**

#### www.aov.uk

Has information about social security benefits and public services in England, Scotland and Wales.

## Jobs and Benefits Office Enquiry Line Northern Ireland

Helpline 0800 022 4250

Textphone **0800 587 1297** 

www.nidirect.gov.uk/money-tax-and-benefits

Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

#### **Law Centres Network**

#### www.lawcentres.org.uk

Local law centres provide advice and legal assistance. They specialise in social welfare issues including disability and discrimination.

#### Macmillan Benefits Advice Service (Northern Ireland)

Tel 0300 123 3233

#### **Money Advice Scotland**

#### www.moneyadvicescotland.org.uk

Use the website to find qualified financial advisers in Scotland.

#### **NI Direct**

#### www.nidirect.aov.uk

Has information about benefits and public services in Northern Ireland.

## **Support for carers**

#### **Carers Trust**

#### Tel 0300 772 9600

#### www.carers.org

Provides support, information, advice and services for people caring at home for a family member or friend. You can find details for UK offices and search for local support on the website.

#### **Carers UK**

#### Helpline **0808 808 7777**

#### www.carersuk.org

Offers information and support to carers across the UK. Has an online forum and can put people in contact with local support groups for carers.

## Equipment and advice on living with a disability

#### **British Red Cross**

#### Tel 0344 871 11 11

#### www.redcross.ora.uk

Offers a range of health and social care services across the UK, such as care in the home, a medical equipment loan service and a transport service.

#### **Disability Rights UK**

Tel **0330 995 0400** (not an advice line)

#### www.disabilityrightsuk.org

Provides information on social security benefits and disability rights in the UK. Has a number of helplines for specific support, including information on going back to work, direct payments, human rights issues, and advice for disabled students.

## **Living Made Easy**

### Helpline 0300 123 3084

### www.livingmadeeasy.org.uk

Provides free, impartial advice about all types of disability equipment and mobility products.

## **General cancer support organisations**

## **Black Women Rising**

#### www.blackwomenrisinguk.org

Aims to educate, inspire and bring opportunities for women from the BAME community. Shares stories and supports Black cancer patients and survivors through treatment and remission.

#### **Cancer Black Care**

#### Tel **0208 961 4151**

#### www.cancerblackcare.org.uk

Offers UK-wide information and support for people from Black and minority ethnic communities who have cancer. Also supports their friends, carers and families.

#### **Cancer Focus Northern Ireland**

#### Helpline **0800 783 3339**

#### www.cancerfocusni.org

Offers a variety of services to people affected by cancer in Northern Ireland.

#### **Cancer Research UK**

#### Helpline 0808 800 4040

#### www.cancerresearchuk.org

A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

#### **Cancer Support Scotland**

#### Tel 0800 652 4531

#### www.cancersupportscotland.org

Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

#### **Macmillan Cancer Voices**

#### www.macmillan.org.uk/cancervoices

A UK-wide network that enables people who have or have had cancer. and those close to them such as family and carers, to speak out about their experience of cancer.

#### Maggie's

#### Tel **0300 123 1801**

#### www.maggies.org

Has a network of centres in many locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer. their family, and friends.

## **Penny Brohn UK**

#### Helpline **0303 3000 118**

## www.pennybrohn.org.uk

Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

### **Riprap**

#### www.riprap.org.uk

Developed especially for teenagers in the UK who have a parent with cancer. Has an online forum where teenagers going through similar experiences can talk to each other for support.

#### **Tenovus**

#### Helpline 0808 808 1010

#### www.tenovuscancercare.org.uk

Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online 'Ask the nurse' service.

## **LGBT-specific support**

#### **LGBT Foundation**

#### Tel **0345 330 3030**

#### www.labt.foundation

Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

## Your notes and questions

## Your notes and questions

#### Disclaimer

We make every effort to ensure that the information we provide is accurate and up to date but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. Some photos are of models.

#### **Thanks**

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by Chief Medical Editor Prof Tim Iveson, Consultant Medical Oncologist, and Michelle Rouse Griffiths, Professional Development and Knowledge Lead, Macmillan Cancer Support.

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Thanks also to the people affected by cancer who reviewed this edition, and those who shared their stories.

We welcome feedback on our information. If you have any, please contact cancerinformationteam@macmillan.org.uk

#### **Sources**

Below is a sample of the sources used in our work support information. If you would like more information about the sources we use, please contact us at cancerinformationteam@macmillan.org.uk

Citizens Advice www.citizensadvice.org.uk [accessed May 2022].

GOV.UK www.gov.uk [accessed May 2022].

NI Direct www.nidirect.gov.uk [accessed May 2022].

## Can you do something to help?

We hope this booklet has been useful to you. It is just one of our many publications that are available free to anyone affected by cancer. They are produced by our cancer information specialists who, along with our nurses, benefits advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we are here to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.

## 5 ways you can help someone with cancer

#### Share your cancer experience 1.

Support people living with cancer by telling your story, online, in the media or face to face.

#### 2. Campaign for change

We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

#### 3. Help someone in your community

A lift to an appointment. Help with the shopping. Or just a cup of tea and a chat. Could you lend a hand?

#### Raise money 4.

Whatever you like doing you can raise money to help. Take part in one of our events or create your own.

#### 5. Give money

Big or small, every penny helps. To make a one-off donation see over.

Please fill in your p	ersonal details	Do not let the taxman	
Mr/Mrs/Miss/Other	ſ	keep your money	
Name		Do you pay tax? If so, your gift will be worth 25% more to us -	
Surname		at no extra cost to you. All you	
Address		have to do is tick the box below,	
Postcode		and the tax office will give 25p for every pound you give.	
Phone		I am a UK tax payer and	
Email		I would like Macmillan Cancer	
Please accept my g		Support to treat all donations I make or have made to Macmillan Cancer Support in the	
I enclose a cheque Charity Voucher ma Macmillan Cancer S	ade payable to	last 4 years as Gift Aid donations, until I notify you otherwise.	
OR debit my: Visa / MasterCard / CAF Charity Card / Switch / Maestro		I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any	
Card number		difference. I understand Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.	
Valid from	Expiry date	Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, campaigning and services for people affected by cancer. If you would prefer us not to use	
Issue no	Security number	your details in this way please tick this box. In order to carry out our work we may need to pass your details to agents or partners who act on our behalf.	
Signature		If you would rather donate online go to <a href="mailto:macmillan.org.uk/donate">macmillan.org.uk/donate</a>	
Date / /		O Parish and with	







# This booklet is about working while caring for someone with cancer. It aims to help you cope with the effects that caring might have on your work life.

The booklet explains the support you could get at work, flexible working and your rights. It has tips on talking about cancer with your employer and the people you work with. There is also advice for people who are self-employed.

At Macmillan, we give people with cancer everything we've got. If you are diagnosed, your worries are our worries. We will help you live life as fully as you can.

For information, support or just someone to talk to, call **0808 808 00 00** or visit macmillan.org.uk

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using NGT (Text Relay) on 18001 0808 808 00 00, or use the NGT Lite app.

Need information in different languages or formats?
We produce information in audio, interactive PDFs, easy read, Braille, large print and translations. To order these, visit macmillan.org.uk/otherformats or call our support line.



Patient Information Forum