MACMILLAN CANCER SUPPORT

WORKING WHILE CARING FOR SOMEONE WITH CANCER

Work and cancer series - for carers





The Macmillan work and cancer series

Macmillan produces a range of information about work and cancer.

For people living with cancer:

- Work and cancer
- Questions to ask about work and cancer

For employers:

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

For people caring for someone with cancer:

- Working while caring for someone with cancer
- Questions for carers to ask about work and cancer

For self-employed people with cancer:

• Self-employment and cancer

More information:

Your rights at work when you are affected by cancer

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 if you 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 on page 5 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 62 to 67, there are details of other organisations that can help.

Quotes

In this booklet, we have included quotes from people affected by cancer in the workplace. Some are from our Online Community (macmillan.org.uk/community). The others are from people who have chosen to share their story with us. This includes MayMay, who is on the cover of this booklet. To share your experience, visit macmillan.org.uk/ shareyourstory

For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on 0808 808 00 00, 7 days a week, 8am to 8pm, or visit macmillan.org.uk

If you would prefer to speak to us in another language than English, interpreters are available. Please tell us, in English, the language you want to use. If you are deaf or hard of hearing, call us using NGT (Text Relay) on 18001 0808 808 00 00, or use the NGT Lite app.

We have some information in different languages and formats, including audio, eBooks, easy read, Braille, large print and translations. To order these visit macmillan.org.uk/ otherformats or call 0808 808 00 00.

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CARING FOR SOMEONE WITH CANCER

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If you are a carer			

If you are a carer

You may not see yourself as a carer. You may just think you are helping out.

You are a carer if you give any unpaid help and support to someone with cancer who could not manage without your help. Understanding that you are a carer is important to get the support you need. You may have a job or children who you look after too, as well as caring for someone.

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 is possible. In any UK workplace, about 3% of people will be working while caring for someone with cancer. 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 wellbeing and health needs (see pages 48 to 55).

Different ways of caring

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

- giving emotional support and being there to listen to them
- helping with everyday tasks, such as shopping, cooking, cleaning or collecting prescriptions
- driving them, or going with them, to appointments
- talking to or contacting others on their behalf, such as health and social care professionals
- helping them get advice and information, for example about the cancer, work or other support
- giving medication, changing dressings and helping with other healthcare tasks
- helping with personal care, such as washing, eating, dressing or using the toilet.

'I didn't really consider myself his carer. I just thought of myself as his fiancée. He wasn't well, so I looked after him.'

Lisa

Every caring situation is different. Your responsibilities will depend on what the person needs and what you are able to offer. You may be sharing caring responsibilities with family or friends, or you may be the main carer. How much care you provide can change over time. Remember that you do not have to do everything yourself. There is help and support available.



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 decide, you may need to:

- talk to your manager or employer about possible flexible working arrangements
- talk to other people in your life about the help they can offer you or the person you are caring for
- find out about practical or financial support that you or the person you are caring for may be able to get (see page 51).

It is important to make decisions with the person you are caring for. They may already feel as if they have lost control over their lives.

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 (consent). We have more information about the health and social care professionals who might be involved in care in our booklet Looking after someone who has cancer (see page 58).

You can ask their cancer doctor or specialist nurse about organising a carer's assessment. This is done by social services to find out what kind of support you might need. Carers Trust (see page 65) has information about local organisations that can help with practical support. You may also be able to get financial help, such as benefits or grants (see page 51).

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 guilty about 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. 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, social group or someone at work about how you are feeling.

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

You might find it easier to talk to people who are not involved with your situation. 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 listen if you just want to talk to someone. You can call them free on 0808 808 00 00.

We also have more information about coping with your feelings and getting the support you need in our booklet Looking after someone with cancer (see page 58).





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Working while caring

Balancing working and caring can be difficult. But if you decide to keep working, it can have some benefits. For example, working while caring 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
- mean you are less likely to have 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 havina 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, for example with flexible working, also has benefits for employers. It 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 about your situation as soon as possible. This means they can tell you about the support available in your workplace, and the ways they can help you.

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 effects 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 own situation. It may change from day to day.

We have detailed information on our website about different types of cancer and cancer treatments. We also have information about talking to someone with cancer in our booklet Talking with someone who has cancer (see page 58).

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 if you will need time off work to be with the person you are caring for.

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, and this could affect how you perform at work. You may need some time off work to deal with the diagnosis. It can take time to understand your feelings. Try 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, flexible working might be particularly helpful 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. This could affect how much time off work you need if you want to be near them and the hospital is far away.

They may also have treatment as an outpatient. This means having treatment at hospital without staying overnight. If this happens, you might not need to be with the person you are caring for at every appointment. You might just need to take them home from hospital, depending on the treatment and how they react to it.

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

You could talk to the person you are caring for about the times they most need you to be with them. This can help you to know if and when you do not need to be there. It is also important to think about the help you can get from others.

Surgery

If the person you are caring for has surgery, they may not need to stay in hospital overnight after the operation. This is called day surgery.

Or they might need to stay in hospital for a period of time. How long they need to stay for will depend on the type of operation they had and their recovery.

Regularly visiting the person you are caring for in hospital can be very tiring. This 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 x-rays to destroy cancer cells. Treatment usually happens between Monday and Friday. A course of treatment may take a few weeks.

Each treatment only takes a few minutes. But going to and from hospital and waiting in hospital for treatment to start, can take up most of the day.

It may sometimes be possible for the radiotherapy team to plan the person's treatment in the morning or late afternoon. This could mean you need less time off work. Ask the radiotherapy team whether this is possible.

We have more information about radiotherapy in our booklet Understanding radiotherapy (see page 58).

Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. It is usually given as an outpatient, but it can take most of the day. The person you are caring for may need to go into hospital overnight, or for a few days. They may have the drugs as an injection into a vein (intravenously), or as tablets.

Chemotherapy is usually given as several sessions of treatment, with rest periods in between the sessions. This gives their body time to recover. A course of chemotherapy may last for a few months. The chemotherapy nurse will explain how often the person you care for will have treatment. Knowing this can help you plan any time off work you might need.

The person you are caring for may need someone with them at home for the first few days after chemotherapy. It is hard to know how they will react until after a session. Their reactions might change as they keep having treatment. If they have certain side effects, for example 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 (see pages 40 to 42).

We have more information about chemotherapy in our booklet Understanding chemotherapy (see page 58).

Hormonal therapies

Hormonal therapies reduce the level of certain hormones or block their effects on the cancer cells. People usually have these drugs as tablets, for months or years. Some are given as injections every few weeks or months. Hormonal therapies can cause:

- tiredness
- weight gain
- hot flushes
- sweats
- muscle pain.

We have more information about hormonal therapies in our booklet Side effects of cancer treatment (see page 58).

Targeted therapies

Targeted therapy drugs affect the way cancer cells grow. People can have them in a chemotherapy unit every few weeks as a drip (intravenous infusion) or as tablets. Possible side effects include:

- flu-like symptoms
- chills
- headaches
- a raised temperature
- lowered resistance to infection
- tiredness.

Help from others

It is important to think about how other family members and friends 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.

People are often keen to help but may not know what to do. You could start by:

- making a list of day to day activities you may need help with
- asking people what they can do
- asking them how much they can help.

You can then ask people to do specific things. It might help to make a rota of who helping with what. Our booklet **Looking after someone with cancer** has more information about managing help from others.

We have more information that might be helpful in our booklet Coping when someone close to you has cancer (see page 58).

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 how easy it is to park. You could also find out whether parking is free, or if there are reduced parking fees. Some hospitals give people with cancer free car parking or discounts.
- Give yourself plenty of time, especially for treatments. Things can sometimes take longer than expected.
- If you need help with transport, speak to your GP or the hospital to see what support is available. Some areas have local voluntary groups, which are sometimes called good neighbour schemes. They provide practical help to people in need.

'I had a flexible employer who let me work around my husband's hospital appointments and chemotherapy. I had to switch off from the cancer when I was at work, so it gave me an "escape" as soon as I walked through the office doors.'

Jane

After treatment

When treatment finishes, 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 worried about the cancer coming back.

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

We have more information about what can happen after cancer treatment in our booklet called Life after cancer treatment. This booklet is about the emotional and practical issues people often face at this time. It gives advice that may help. You can order this for free at be.macmillan.org.uk

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 (see pages 37 to 38).

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

We use the terms 'manager' or 'employer' but there may be different people at your workplace who 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
- a human resources (HR) manager
- your trade union representative, if you are a member.

You can ask your employer to keep the information you give them confidential. This means they will not tell anyone else what you have told them. We have more information about this in our booklet Your rights at work when you are affected by cancer (see page 58).

'When I realised there was a decline in my sister's health, I called my work. I said I was terrified of losing my job, but that she needed 24/7 care so I couldn't work at that time. When they said there was no way I would lose my job, it was a massive relief. I felt like somebody cared.'

Claire

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.

If you feel nervous about talking to your manager, you can take someone with you. This could be a friend, family member, colleague or trade union representative. It is a good idea to meet in a private place where you will not be interrupted. Make sure 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 (see page 68). This will help you remember what was, said and can be used if anything unexpected happens later.

You will probably want to give a short explanation of your situation. For example, you could explain the treatment the person you are caring for will have and what care they will need. It may help to tell your manager that things might change while they are having treatment. And that this could mean you needing time off, sometimes 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 (statutory entitlements) and what other support is available.

At the meeting, your manager may ask how you are coping and what your concerns about work are, at the moment. They may also ask if you would like other managers or people you work with to know about your situation, and how much you want to tell them.

If you would prefer not to tell people yourself, your manager could do this. Or you could ask someone else at work to do this for you.

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
- your ability to do your job in the short and long term.

You and your manager can talk about ways of doing your job to suit you. They will need to think about 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, your manager may need to be flexible with how they are applied. A HR manager should also know about your legal rights as a carer (see page 36).

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 Your work and cancer toolkit. It contains information that you and your employer may find helpful. Access this by signing up to macmillan.org.uk/atwork

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

How your employer can support you

You may want to talk to your manager 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 may offer:

- 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 a 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
- any policies about sick leave, sick pay, absence and leave (including emergency leave), and how using any of these policies might affect your pay
- any relevant company benefits you could get, such as employee assistance programmes, occupational health and counselling services.

Not all companies 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 give you information about your legal rights.

Most workers have certain legal rights. This is regardless of the number of hours per week they 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. You may find our booklet Questions for carers to ask about work and cancer helpful (see page 58).

Some workers are not protected by the law. This could be someone who is not an employee, such as an agency or freelance worker. If you are in this situation, it is important to get advice from an experienced adviser, such as your local Citizens Advice (see page 64).

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 (see page 65)
- counselling services that may be available to you as an employee.

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 there are other employees who are carers. If so, it may be useful to share your experiences and have someone to talk to.

Talking to others at work can have the following benefits:

- You have someone to talk to and it gives them the chance to support you.
- You can tell them when you need help.
- They may suggest helpful ways of coping with your work.
- It may make you feel closer to the people you work with.

If you do not want to tell your colleagues

You may prefer not to tell your colleagues, or to only tell a few people. You might want to keep your work life as normal as possible. It is important that your wish to be private is respected. Do not feel under pressure to explain things if you are not comfortable doing this. 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 giving up 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 before deciding.

Giving up 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 (see pages 36 to 45). For more information about this, you can contact the Carers UK helpline (see page 65). You can also speak to a Macmillan work support adviser on **0808 808 00 00**.

'I arranged with the organisation that I work with that I would start working part time only – 3 days a week, devoting the rest of my time to caring for my mum.'

MayMay

Your finances

When you are making decisions about work, your finances may be an important thing to think about. We have more information about finances in our booklet Planning and managing your finances (see page 58).

Giving up 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 an advantage. But for others, it can leave them financially worse off. Our financial auides can discuss this with you.

We have more information about benefits you may be able to get if you are 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 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 a booklet called **Self-employment and cancer** which you may find helpful (see page 58).



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Your legal rights as a working carer

You have certain rights at work that may help make it easier for you 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 (see pages 37 to 38). This right only applies if you:

- are an employee
- have worked for your employer for at least 26 weeks before your request
- are not an agency worker (unless you are returning from parental leave).

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 or working part-time
- flexible holidays to fit in with alternative care arrangements.

Requesting flexible working

There is a process that you and your employer must follow when you make a flexible working request:

- you need to make your request in writing
- you can only make one request in a 12-month period
- your employer must consider your request in a fair way
- your employer must make a decision within 3 months (or longer if you agree to this)
- if your employer agrees, this will change the terms and conditions in your employment contract
- if your employer does not agree, they must write to you and explain their reasons – you may be able to appeal this decision or complain to an employment or industrial tribunal.

Your employer may have a specific flexible working request form you can use.

Acas (see page 62) and Carers UK (see page 65) have more information about your right to request flexible working and about making a request.

You can also make an informal request for flexible working arrangements. This means it is not requested under the law on flexible working. 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.

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
- a HR manager.

If you are not allowed to appeal, you could suggest involving Acas (see page 62), or the LRA in Northern Ireland (see page 63). They can help you and your employer discuss the possible options. Or you could raise a complaint (grievance) with your employer.

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 full-time.



Time off in an emergency

Carers who are employees have the legal right to take a reasonable amount of time off work to deal with an emergency that involves the person they care for. They have this right under the following laws:

- The Employment Rights Act 1996, for people who live in England, Scotland and Wales.
- The Employment Rights (Northern Ireland) Order 1996, for people who live in Northern Ireland.

The person they are caring for is called a dependant. This person could be:

- a mother, father, son, daughter, spouse or civil partner
- anyone who lives with the carer, but is not a tenant, lodger, boarder or employee
- someone who relies on the carer to help them if they become ill
- someone who needs the person to make care arrangements for them.

An emergency might include:

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

Carers do not need to have been in their job for a certain amount of time before they can take time off to help someone they look after in an emergency. But how much time off they can have depends on the situation. An employer may decide, by looking at what has happened, how close the person's relationship is to the dependant and whether someone else could help instead.

Someone who wants to use this type of time off must tell their employer about the emergency as soon as possible. If possible, they should tell their employer when they expect to return to work. The time off is usually unpaid, but this depends on the employer's policy.

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

As an employer, you may have a policy for other types of leave for carers. Or you could talk to the person about arranging time off. Some options could be:

- carers' leave (paid or unpaid)
- compassionate leave
- flexible working
- borrowing holiday days from next year or buying additional days
- career breaks and sabbaticals (usually unpaid).

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

These options aim to allow your employee to look after their own health, or the health of the person they care for, while reducing the impact on your organisation. They also protect the employee as much as possible from financial problems.

Carers UK offers advice on employment issues and rights for carers, including time off.

How carers are protected from discrimination

If you are a carer, there are laws that protect you from being discriminated against at work because of your connection with a disabled person (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 one of these types of discrimination (see pages 44 to 45):

- direct discrimination
- harassment
- victimisation.

Your employer does not have to make reasonable adjustments if you are not disabled. This applies to carers too. However, other laws may give you the right to request flexible working, and the right to a reasonable amount of time off work for caring responsibilities.

Direct disability discrimination

This is when you are treated less favourably than somebody else because you are connected to someone who has cancer.

Direct disability discrimination includes situations where, because you are a carer for someone with a disability, you are:

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

Harassment

This is when a person is treated in a way that makes them 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.

Protection from harassment applies in England, Scotland, Wales and Northern Ireland.

Victimisation

This is when you are treated badly because you have done, or intend to do, something that is protected by law (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.

Protection from harassment applies in England, Scotland, Wales and partly in Northern Ireland.

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 can complain to an employment tribunal. This is an independent body that makes decisions in legal disputes between employees and employers.

It is a good idea to talk to your staff or union representative if you have one, or contact Acas (see page 62), or the Labour Relations Agency in Northern Ireland (see page 63).

We have more information about resolving problems at work in our booklet Your rights at work when you are affected by cancer (see page 58).



LOOKING AFTER YOURSELF

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Taking care of yourself

Caring for someone can be physically and emotionally demanding. It is important to look after yourself, as well as the person you are caring for. It can help to recognise the first signs that you are stressed, and look out for them. You can also plan how to deal with stress. You may want to:

- see your GP to talk about your situation and how you are feeling
- make a list of activities you like doing and schedule in some time each week to enjoy one or two of them
- spend some time away from the person you are caring for you can search for local carers' services and respite services on the Carers Trust website (see page 65)
- talk to other carers at a local support group Carers UK (see page 65) can help you see if there is a group in your area
- ask the hospital or GP surgery for information that can help you manage the emotional challenges of caring
- look at some of the organisations and websites that offer practical and emotional support for carers, such as Carers UK and Carers Trust.

Time for yourself

You may need time for yourself to help you cope with the demands of being a carer and working. This gives you the chance to relax and do things you enjoy. Try to do this as much as you can.

Remember that no one will expect you to do everything. Try to ask for help from your friends and family. Or you could talk to organisations that can offer respite breaks. Our booklet Looking after someone with cancer has more information about services that might be available (see page 58).

Help from social services

A social worker is responsible for assessing what practical and social help you and the person you are caring 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 the local social services department. You can find their number in the phone book or online by searching for the name of your local authority, council, or health and social care trust.

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 services available 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
- meals (sometimes called meals on wheels)
- laundry services for people with incontinence
- equipment and adaptations for their home
- information and benefits advice
- respite care
- sitting services.

Some services are paid for by the NHS, so they are free. Sometimes, social services do a financial assessment to work out if the person you care for needs to pay something.

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 your needs have not changed. Many social workers are also trained in counselling and can offer emotional support.

Carer's assessment

It is important to keep healthy, and to balance caring with your life, work and family commitments. 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 get more information about a carer's assessment at macmillan.org.uk/carers

You can still ask for this assessment even if the person you care for does not want an assessment of their needs. Or if they are not eligible for support.

Financial support

Cancer can mean extra costs for you and the person you care for. This can include paying for travel to hospital, or higher food or heating bills.

If you give up work or reduce your hours, you may have less money coming in. You and the person you care for may be able to get benefits 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.

Our booklet **Help with the cost of cancer** has more information about financial help and benefits (see page 58).

If the cancer is advanced

If the cancer gets worse, the needs of the person you care for are likely to change. You can talk to the person's GP, community or specialist nurse, or social services staff about this.

Sometimes you may not be able to keep looking after the person at home. They may need a different type of care than you can provide for them. The extra demands of you as a carer can also affect you.

Talk to the person's GP or nurses to find out more about extra support and help. You can also ask social services 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 give up work for a while.

Whatever you decide, this will be a difficult time for you and will affect your work. Try to talk your manager about the changes in your circumstances, so they can keep supporting you.

We have got more information about caring for someone with advanced cancer on our website.

If you are no longer a carer

You may no longer be a carer for a number of different reasons. The person you cared for may have recovered and no longer need your support. Or they may be in hospital or a care home. If this happens, you might still be providing some care. For example, you may be visiting them regularly or be involved in 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 normal feelings to have.

We have got more information in our booklet After someone dies: coping with bereavement (see page 58).

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, including funeral arrangements. You could tell them what you want the people you work with to know. Let them know if you are happy to be contacted while you are off work. Your employer may provide compassionate leave.

How much time off work you need depends on what is best for you. You may not take much time off, or you might need longer. You may find that if you return to work quite quickly, you need to take more time off later.

You could ask to have regular contact with your manager while you are off work. This could be to talk about any changes or support you need to help you go back to work.

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 the people you work with for the first time when you go back to work. If they offer sympathy, you might find it hard to be reminded of your loss. But you do not have to share any more than you want to. You can just say thank you.

You may find it hard to concentrate. You might feel very tired and be easily distracted. Talk to your manager if you think it would be helpful to have someone else check your work.

Feelings of grief may come and go. Some may 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.

Getting back to work

If your caring role has changed or ended, you may want to go back to how your 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.

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

If you gave up work and are looking for a new job, there is lots of advice on writing a CV, filling in application forms and performing well in job interviews. Your local library will have books on interview skills.

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 visit nationalcareerservice.direct.gov.uk
- Skills Development Scotland, if you live in Scotland visit skillsdvelopmentscotland.co.uk
- Careers Wales, if you live in Wales visit careerswales.com/en
- JobCentreOnline, if you live in Northern Ireland visit jobcentreonline.com/JCOL/welcome

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.



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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-andsupport 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
- eBooks
- 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.

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. Our cancer support specialists 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.

Call us on **0808 808 00 00** or email us via our website, macmillan.org.uk/talktous

Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face.

Visit one to get the information you need, or if you'd like a private chat, most centres have a room where you can speak with someone alone and in confidence.

Find your nearest centre at macmillan.org.uk/ informationcentres or call us on **0808 808 00 00**.

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's why we help to bring people together in their communities and online.

Support groups

Whether you are someone living with cancer or a carer, 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 macmillan.org.uk/ selfhelpandsupport

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

The Macmillan healthcare team

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.

Book reviews

Our volunteers review many books about cancer. These include people's stories of living with cancer, and books for children. Visit publications. macmillan.org.uk and search 'book reviews'.

'Everyone is so supportive on the Online Community, they know exactly what you're going through. It can be fun too. It's not all just chats about cancer.'

Mal

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you've been affected in this way, we can help.

Financial guidance

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

Help accessing benefits

Our benefits advisers can offer advice and information on benefits, tax credits, grants and loans. They can help you work out what financial help you could be entitled to. They can also help you complete your forms and apply for benefits.

Macmillan Grants

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing to a much-needed break.

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants.

We can also tell you about benefits advisers in your area. Visit macmillan.org.uk/ **financialsupport** to find out more about how we can help you with your finances.

Help with work and cancer

Whether you're 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 (Monday to Friday, 8am to 6pm).

Macmillan Organiser

This includes a records book to write down information such as appointments, medications and contact details. You can also download the app on IOS or Android.

Other useful organisations

There are lots of other organisations that can give you information or support.

Work and employment

Access to Work **Tel** 0800 121 7479 **Textphone** 0800 121 7579 (Mon to Fri, 8am to 7.30pm) www.gov.uk/access-to-work Provides advice and practical support to people with long-term health conditions and their employers. This helps pay for practical support, so you can do your job.

Access to Work (NI) www.nidirect.gov.uk/ articles/access-workpractical-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 (Mon to Fri, 8am to 6pm) www.acas.org.uk Gives advice to employees and employers to help improve working life and relations. Offers information, advice and training.

Equality Advisory Support Service (EASS) **Tel** 0808 800 0082 **Textphone** 0808 800 0084 (Mon to Fri, 9am to 7pm, and Sat, 10am to 2pm) www. equalityadvisoryservice.com

Promotes equality and provides information to people about their rights in England, Scotland and Wales

Equality Commission Northern Ireland (ECNI) Tel 0289 050 0600 **Email** information@equalityni. org

www.equalityni.org

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

Labour Relations Agency

Tel 0330 055 5300 (Mon to Fri, 9am to 5pm) Email info@lra.org.uk www.lra.org.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.

WorkSmart www.worksmart.org.uk

This website 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

Benefit Enquiry Line Northern Ireland Helpline 0800 022 4250 (Mon, Tues, Wed and Fri, 9am to 5pm, and Thu, 10am to 5pm) **Textphone** 0289 031 1092 www.nidirects.gov.uk/ money-tax-and-benefits Provides information and advice about disability benefits and carers' benefits in Northern Ireland. You can also call the Make the Call helpline on 0800 232 1271 to check you are getting all the benefits you

Carer's Allowance Unit **Tel** 0800 731 0297 **Textphone** 0800 731 0317 (Mon to Fri, 8am to 6pm) www.gov.uk/carersallowance

are eligible for.

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 their online webchat or find details for your local office in the phone book or by contacting:

England Helpline 0344 411 1444 www.citizensadvice.org.uk

Wales Helpline 0344 477 2020 www.citizensadvice.org.uk/ wales

Scotland Helpline 0808 800 9060 www.cas.org.uk

Disability and Carers Service Tel 0800 587 0912 **Textphone** 028 9031 109 (Mon to Fri, 8am to 5pm) www.nidirect.gov.uk/ contacts/disability-andcarers-service

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

GOV.UK www.gov.uk

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

Law Centres Network www.lawcentres.org.uk Local Law Centres provide advice and legal assistance. They specialise in social welfare issues including

Macmillan Benefits Advice Service (Northern Ireland) **Tel** 0300 123 3233

disability and discrimination.

NiDirect www.nidirect.gov.uk

Has information about benefits and public services in Northern Ireland.

Support for carers

Carers Direct Tel 0300 123 1053 (Mon to Fri, 9am to 8pm, and weekends, 11am to 4pm) www.nhs.uk/carersdirect Provides information and support for carers, including financial help, practical tips and home adaptations.

Carers Trust Tel 0300 772 9600 (Mon to Fri, 9am to 5pm) Email info@carers.org www.carers.org Provides information and support 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 (England, Scotland, Wales) 0808 808 7777 (Mon and Tue, 10am to 4pm) **Helpline** (Northern Ireland) 0289 043 9843

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.

Crossroads Care **Northern Ireland** Tel 0289 181 4455 **Email** info@crossroadscare. co.uk

www.crossroadscare.co.uk Provides care to help people live independently at home, and respite care so that carers can have a break.

Crossroads Caring Scotland Tel 0141 226 3793

Email info@crossroadscotland. co.uk

www.crossroads-scotland. co.uk

Provides care to help people live independently at home, and respite care so that carers can have a break.

Equipment and advice on living with a disability

Disabled Living Foundation (DLF) Helpline 0300 999 0004 (Mon to Fri, 10am to 4pm) Email helpline@dlf.org.uk www.dlf.org.uk Provides free, impartial advice about all types of disability equipment and mobility products.

Disability Rights UK Tel 0330 995 0400 **Equality Advisory Support Service** Helpline 0808 800 0082 (Mon to Fri, 9am to 7pm, and Sat, 10am to 2pm) Email enquiries@ disabilityrightsuk.org www.disabilityrightsuk.org Provides information on social security benefits and disability rights in the UK. Has a number of helplines for specific support, including personal budgeting help, equality and human rights issues, and advice for disabled students.

General cancer support organisations

Cancer Black Care **Tel** 0208 961 4151 www.cancerblackcare.org.uk Offers UK-wide information and support for people from Black and ethnic minority communities who have cancer. Also supports their friends, carers and families.

Cancer Focus Northern Ireland Helpline 0800 783 3339 (Mon to Fri, 9am to 1pm) Email nurseline@ cancerfocusni.org www.cancerfocusni.org Offers a variety of services to people affected by cancer in Northern Ireland.

Cancer Research UK Helpline 0808 800 4040 (Mon to Fri, 9am to 5pm) 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 (Mon to Fri, 9am to 5pm) **Email** info@ cancersupportscotland.org 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 Centres Tel 0300 123 1801 Email enquiries@ maggiescentres.org

www.maggiescentres.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 300 0118 (Mon to Fri, 9.30am to 5pm) **Email** helpline@pennybrohn. org.uk

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

Tenovus Helpline 0808 808 1010 (Daily, 8am to 8pm) Email info@tenovuscancercare. org.uk

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.

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 the Working Through Cancer Programme team at Macmillan.

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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

We have listed a sample of the sources used in the booklet below. If you would like more information about the sources we use, please contact us at cancerinformationteam@macmillan.org.uk

gov.uk (accessed September, 2018) nidirect.gov.uk (accessed September, 2018) equalityhumanrights.com (accessed September, 2018)

Can you do something to help?

We hope this booklet has been useful to you. It's just one of our many publications that are available free to anyone affected by cancer. They're 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're there 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.



Share your cancer experience

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

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.

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

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

Give money

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

Call us to find out more 0300 1000 200 macmillan.org.uk/getinvolved

This booklet is about working and caring for someone with cancer. It aims to help you cope with the effects of caring on your work life.

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

We're here to help everyone with cancer live life as fully as they can, providing physical, financial and emotional support. So whatever cancer throws your way, we're right there with you. For information, support or just someone to talk to, call **0808 808 00 00**, 7 days a week, 8am to 8pm, 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, eBooks, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call our support line.



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The Information Standard This organisation has been certified as a producer of reliable health and social care information.

www.theinformationstandard.org

Please fill in your personal details Mr/Mrs/Miss/Other Name Surname Address Postcode Phone Email Please accept my gift of £ (Please delete as appropriate) I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support OR debit my: Visa / MasterCard / CAF Charity Card / Switch / Maestro Card number Valid from Expiry date Security number

Issue no

Signature

Date

Don't let the taxman keep your money

Do you pay tax? If so, your gift will be worth 25% more to us – at no extra cost to you. All you have to do is tick the box below, and the tax office will give 25p for every pound you give.

I am a UK tax payer and I would like Macmillan Cancer Support to treat all donations I make or have made to Macmillan Cancer Support in the last 4 years as Gift Aid donations, until I notify you otherwise.

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 difference. Lunderstand Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

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 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. UNDRAISING

If you'd rather donate online go to macmillan.org.uk/donate

Please cut out this form and return it in an envelope (no stamp required) to: Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851, 89 Albert Embankment, London SE1 7UQ

REGULATOR