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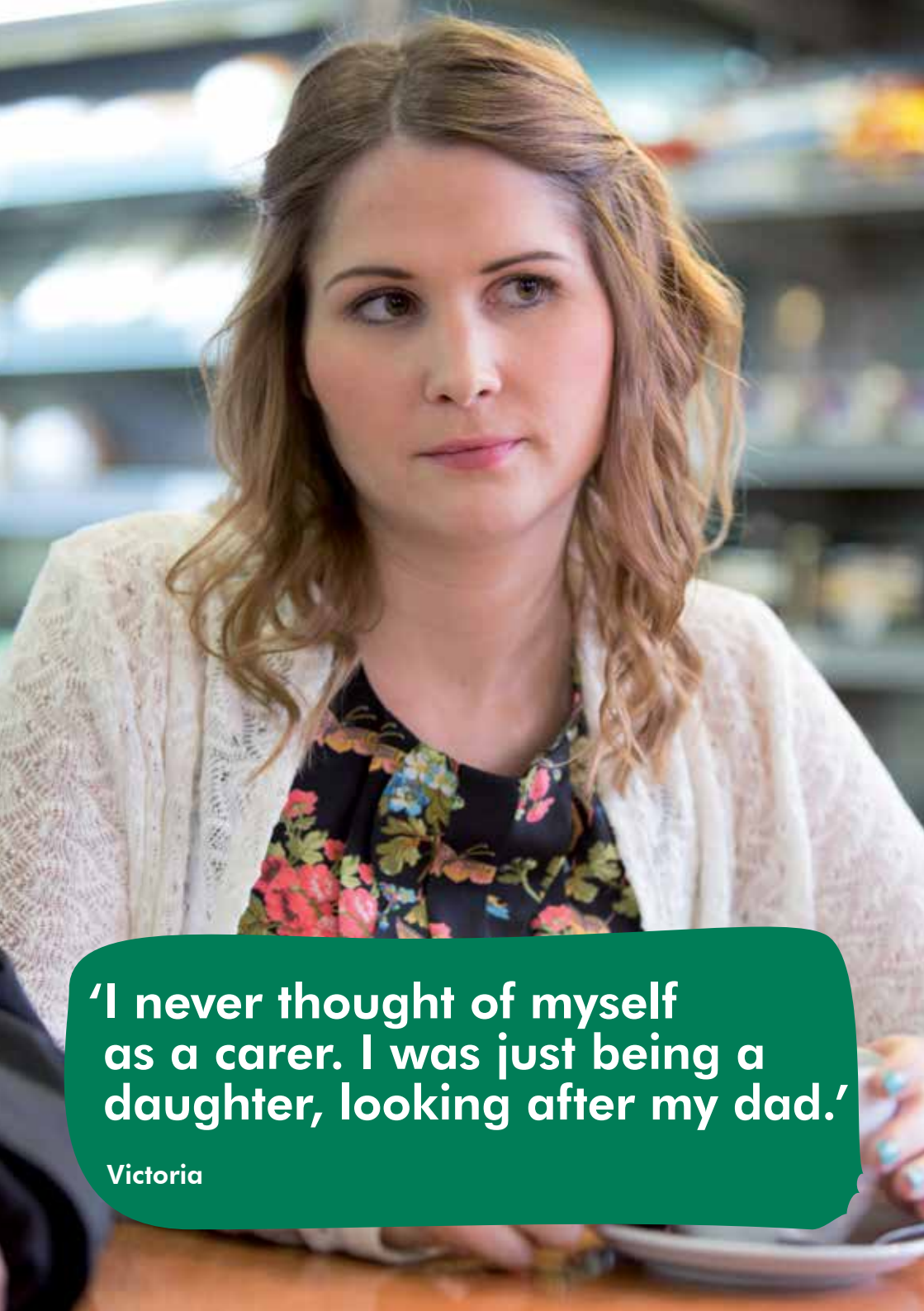
A practical guide for carers, by carers

LOOKING AFTER SOMEONE WITH CANCER



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'I never thought of myself as a carer. I was just being a daughter, looking after my dad.'

Victoria

About this booklet

This booklet is a practical guide for anyone looking after someone with cancer. It has tips about taking care of yourself, as well as the person you care for.

A carer is someone who provides unpaid support to a family member or friend who could not manage without this help. They don't always live with the person they care for, and may have a job or children to look after as well.

Not everyone identifies with the term **carer**. You may think of yourself as a partner, family member or friend who is just doing their bit to help. But recognising that you are a carer can be a first step in getting the support you might need.

Caring can mean many things, including:

- providing transport
- helping with everyday chores
- being a good listener
- helping with personal care.

The person who spends the most time looking after someone with cancer is usually referred to as their **main carer**. But some people have more than one carer. If you are not the main carer, this information is still for you. You may also want to pass this booklet on to your family and friends. Knowing more about what you're going through can help them support you.

Lots of young people are carers too. If you're aged 12–18 and looking after someone with cancer, you may want to read our booklet *Let's talk about you*. It's written by young carers, for young carers. You can order a free copy online at be.macmillan.org.uk or by calling us on **0808 808 00 00**.

This booklet has been created and updated with the help of a group of experienced carers. These carers volunteer their time with Macmillan and have used their experiences to create this useful guide to support other people looking after someone with cancer. Some members of the group have shared their particular experiences to help you. You'll see their advice in green boxes like the one below.



A message from the experienced carers' group

'We really wanted to use our experiences of caring to help others in the same position. So we've worked with Macmillan to produce this booklet. You'll see photos and quotes from some of us as you read through.

This booklet used to be called *Hello, and how are you?* but we decided to change the title for this edition. We hope the new title makes it more obvious that it's written for people like you.

During our time caring for a loved one, we realised that a carer can often be overlooked. We're sometimes just not provided with the information and support we need. Like us, you may find yourself in a variety of situations, some of which may be difficult and challenging. But many of us found that being a carer can be a very rewarding experience. We hope you find this booklet useful.'

How to use this booklet

No two experiences of caring are the same. That's why this booklet is not meant to be a list of instructions on how to be a carer. Instead, it includes lots of practical things that we hope you can relate to and find useful.



We have used this icon throughout the booklet for practical tips. We hope you find the tips helpful.

Don't feel that you need to read everything. Use the contents on page 1 to get to the information that is most relevant to you. Your needs, skills and knowledge may change over time as you're a carer, so you may find that different sections are relevant at different times.

It's important to remember that if you have medical questions, you should speak to a healthcare professional for advice. They may not always realise you are a carer, so it's a good idea to let them know straight away.

We've also included some useful addresses and websites on pages 109–117.

If you'd like to discuss this information, call the Macmillan Support Line free on **0808 808 00 00**, Monday–Friday, 9am–8pm. If you're hard of hearing you can use textphone 0808 808 0121, or Text Relay. For non-English speakers, interpreters are available. Alternatively, visit **[macmillan.org.uk/carers](https://www.macmillan.org.uk/carers)**



WORKING WITH PROFESSIONALS

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From the beginning of your caring experience, you may be in contact with a number of health and social care professionals.

These could include:

- a GP
- an oncologist (a doctor who specialises in cancer)
- a clinical nurse specialist (who specialises in a particular area of health, such as cancer, or in a specific cancer type)
- a district nurse (who visits people at home)
- social workers (who support vulnerable people in society and direct them to services to help improve their welfare)
- physiotherapists (who help people become more mobile after an illness or injury)
- occupational therapists (who help people to work or do daily tasks).

There will be often be one person who is the main point of contact for you and the person you care for. Professionals may call this person a key worker. This is usually a clinical nurse specialist.

Communicating and organising

Your relationship with the professionals should work as a partnership. Sometimes you may have to take the initiative to make this happen. By working together, you and the person you care for will get the best from their knowledge and skills.

Health and social care professionals, including the key worker, are there for you too. You can ask them questions about the cancer and your caring role. But there may be times when they can't share information with you about the person you care for, particularly if the person has asked them not to. This also applies to sharing information about you with the person you care for. See page 15 for more information about sharing information and confidentiality.

Remember that they don't always have all the answers. It may help to try to find out as much as you can about each professional's role and how they work together. Then you can ask the right person straight away when you have a question or problem.

It's good to have realistic expectations about what they can do for you and the person you're caring for. If you give them as much information as you can about the person you care for and how their situation is affecting you, they will be able to help you both.

It may also help to recognise that professionals can get emotionally involved. This can happen if they work with the person you care for and you, for a long time.



Practical tips to help you work with professionals

- Make sure you have phone numbers for the GP, key worker, district nurse, cancer ward and local hospice. Save these into your home and mobile phones, and note down the name of receptionists.
- Before going to any appointments, ask the person you are caring for if they have any questions for the healthcare professional. And think about what you want to ask. Write these down so you don't forget.
- Keep a notebook with details of every visit to the hospital or from a professional. Try using a file to keep all leaflets, information sheets and appointment details together in one place.
- Keep a record of blood tests or x-rays and their results. This will make it easier to question any mistakes and may help if you need medical assistance out of hours (see pages 12–13).
- Make sure your GP knows you are caring for someone. Even if you and the person you care for are registered at the same practice, they may not know you are a carer.
- Be prepared if the person you are caring for is coming home from hospital. Make sure you have all the information you need to cope at home.



Out-of-hours services

It can be very worrying if you need to contact professionals when services are closed in the evenings or at weekends. Sometimes carers find they have to do healthcare tasks themselves during these periods.

The out-of-hours period generally runs from 5pm–8am on weekdays, and all day at the weekends and on bank holidays. But under recent UK government plans, some services may begin to open for longer and on more days in certain areas.

There are different services across the UK that can help you during out-of-hours periods:

- In England, you can call the NHS 111 service out of hours for a telephone health assessment. Just call **111** free of charge from any phone. You could also use the NHS Choices free symptom checker online at **[nhs.uk/symptomcheckers](https://www.nhs.uk/symptomcheckers)**
- In Scotland, call NHS 24 on **08454 24 24 24**.
- In Wales, call NHS Direct on **0845 46 47**.
- In Northern Ireland, contact numbers vary but are listed at **[nidirect.gov.uk/out-of-hours-service](https://www.nidirect.gov.uk/out-of-hours-service)**.

You may not be sure about what signs, symptoms or situations to look out for. You could ask your GP or key worker in advance about what kinds of things should cause concern. Check what the out-of-hours services are in your area and save any useful phone numbers.

If the condition of the person you care for, their symptoms or needs change, contact the hospital or your key worker immediately. If it's left until near the weekend, it will be more difficult to sort out and their condition may get worse.



Practical tips to help out of hours

- Try to think of any problems that may come up out of hours. Discuss these with professionals during the working day and plan what you should do in each situation.
- Have a plan prepared in case you can't look after the person you care for at short notice, for example if you're ill. It's a good idea to discuss this with social services and a local carers' centre if you have one.

If the person you care for needs urgent medical help

If the situation is urgent, call your key worker or the hospital where they were last looked after for immediate advice. If you need to go to accident and emergency (A&E), bring any information you think may help. This might be a patient diary or treatment summary record.

Care plans

Everyone with a long-term condition should have a care plan if they want one. A care plan is an agreement between the person who is ill and the health or social care professionals. It describes how professionals plan to care for them and what they can do to manage their day-to-day health themselves.

Ask the key worker or oncologist if a care plan has been organised for the person you care for. The plan should include details about support they will get following treatment or after leaving hospital. Make sure you are clear about what support is available, and ask to have the details explained to you.

If you are offered help with personal care (see pages 42–47), ask whether you have to pay. These services are not always free.

Being assertive

As a carer, being assertive is really important. Being assertive means giving your point of view and being confident about asking for help.

It's important to be assertive with family and friends. Try to tell people when it's not a good time to visit. Seeing the wrong person at the wrong time could make the person you care for feel worse.

You can also be assertive with the professionals you meet. Try to learn as much as you can about cancer care. If you don't understand something, ask for it to be described in more basic terms. You can't be expected to understand medical jargon.

If you're unhappy with the treatment the person you care for is receiving, tell your key worker or a relevant health professional. Our leaflet *Getting the best from your cancer services* contains questions people can ask professionals at any time during their cancer experience. Each question is followed by a description of what should happen according to national guidelines.

Patients are given copies of any medical notes and letters about their health and care. You could ask for copies of these but you'll need the person's permission first.

Sharing information and confidentiality

Professionals may prefer to only share information with relatives or someone nominated by the person you care for. The Data Protection Act 1998 requires any organisation, corporation or governmental body that collects personal information to handle it safely. If the person you care for would like professionals to share information with you, they should let them know as early as possible. You should also let their healthcare team know that you are the carer.



'He's still my dad, but the family dynamic has changed. The relationship between father and son has changed.'

Mike

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Looking after someone when they have cancer can have a big effect on your relationship with them. Your relationships with other family members and friends may also change.

These relationships may come under extra strain. They can also change and develop, sometimes in very positive ways.

You and the people around you will face many situations you are unlikely to have been in before. People have their own ways of coping under stress and they might not always act as they usually would. If you are worried about someone or concerned about changes in their behaviour, mental health charities may be able to help. You can find contact details for these on pages 111–112. You can also discuss these issues with any health or social care professional, who will be able to arrange appropriate help or tell you how to get it.

There are lots of ways that caring for someone can affect other relationships. For example, if you are caring for a friend, you may experience tensions with their family members. Or if you are one of several family members caring for someone, you may argue with each other more. But it may also bring you closer together.

Try to tackle any issues in your relationships rather than ignoring them. If your relationships are difficult, it can make the caring role even harder. Relationships that are working well can be a great source of strength, both to the person you are caring for and to you as a carer.

We've included the contact details of useful organisations such as Relate and Relationships Scotland on page 112. They may be able to offer you relationships counselling.

You and the person you care for

You may feel in partnership with the person you care for. When something affects them, it usually has an impact on you because you're both in this together.

Try to be prepared for the ups and downs. This isn't going to be easy for either of you. You may both be trying to protect one another and find it hard to show emotion. You may be coping with your own illness or health condition too.

It's important to still nurture the relationship you had with one another before the cancer. Try to be understanding and supportive. Just spending time together or talking with them can make a huge difference to their well-being.

Try to maintain a routine and sense of normality in day-to-day life. Patience and humour are really important so don't be afraid to laugh.



Practical tips for your relationship

- Try to be yourself and live as normally as possible. Behaving differently can make the person you care for feel more aware of their condition.
- Let them know that although you are there to help, they are still in control. Make a point of asking whether they need you to do something. Be careful not to make all the decisions – make sure they always have a choice.

Family

Every family is different and has a certain way of doing things. But when a family member is seriously ill, things may change. If there are already strains and tensions, these can get worse in stressful situations. Spending time together and talking openly can help. It can even bring you closer together.

'Caring for my dad brought me and my step mum closer together. Now we have a kind of bond that wasn't there before.'

Victoria

Don't be surprised by difficult and emotional situations. Be honest with your family about how you feel and make sure you give each other space when needed.

You may feel pressured to act as a counsellor for the rest of the family, and possibly others as well. While it is good to talk, try not to take on other people's problems. You won't be able to please everyone, so try not to worry about it too much.

If you're finding family relationships difficult, you may find counselling, support from a health professional, or talking to someone outside the family helpful. You will have a lot to cope with and it may help to write down a list of priorities.

Young people

Young people can be more accepting and realistic than adults. They are also likely to ask more questions.

Our booklet *Let's talk about you* is written for young carers aged 12–18. It has lots of useful tips and advice for young people who have caring responsibilities.

You may also like to read our booklet *Talking to children and teenagers when an adult has cancer*.

Friends

Your friends, colleagues and neighbours may be able to provide practical and emotional support too.

Sometimes, friends may avoid you and the person you care for altogether. This can be upsetting, but remember it's likely that they just don't know how to open up. You could try starting the conversation by asking them a question.

There are online courses available that may improve the way you communicate with the person you care for, and your family and friends. Visit [learnzone.org.uk/public](https://www.learnzone.org.uk/public) to find out more.

Juggling responsibilities

Sharing responsibilities can help you cope. Discuss how you can do this with family members, friends and other carers.

You may need to share some of the everyday responsibilities that you no longer have time to take care of. Think about using a rota to show each family members' responsibilities and needs.

You may feel unsure about asking for help. Having a list of things people can help you with may make it easier to accept support. For example, someone could do some shopping for you, take the kids out for an afternoon or collect prescriptions. You could stick the list to your fridge or note it in your mobile phone.

Make sure the person you care for feels involved. Allow them to take some responsibility for certain decisions if they are able to. Try to be sensitive to feelings and upsets. Take each day and its problems one step at a time, and try to keep family life as normal as possible.

If you live on your own

Not everyone will have the support of family or friends when they are caring for someone with cancer. If you don't have this kind of support, there are services and organisations there to help (see pages 106–117). If you feel isolated, they can be someone to talk to about any difficulties you are facing.

You could join a self-help and support group and speak to other people affected by cancer. You can search for groups in your area online by visiting [macmillan.org.uk/supportgroups](https://www.macmillan.org.uk/supportgroups) or by asking a member of your healthcare team about what support is available locally.

You can also talk to other people affected by cancer online. Our online community at [macmillan.org.uk/community](https://www.macmillan.org.uk/community) is a social networking site where you can talk to people in chat rooms, blog your experiences, make friends and join support groups. There's also a specific group for people who are caring for someone. Here you can share your thoughts and feelings, and get support from other carers.

If you prefer talking to someone over the phone, you can call our cancer support specialists on **0808 808 00 00**. They will try to answer your questions but are also there if you just want a chat. Or you can get confidential information and advice from Carers UK by calling **0808 808 7777**. The Carers Trust also provides support and advice across the UK – see page 110.

Time for yourself

You may feel that you want to be there for the person you're looking after all the time. It's up to you to decide what's best for you both. You will need time for yourself, so don't be afraid to ask for help from friends and family or accept help when it's offered.

Make sure people who offer to help know what's involved and be clear about how you would like them to help. Some offers of help may come from people who can't offer the support you need, or who you or the person you care for don't necessarily want to help you at the time. It's okay to turn down offers of help.

Even short periods of time to yourself can make a huge difference. Having a hobby such as gardening, writing or sports can be a good break away from caring for a few hours.

Your sex life

If you are caring for your partner, it's normal for your sex life and the way you both feel about your sexuality to be affected. However, sex may be one of the things that brings normality to your lives.

Talking openly with your partner about sex can help you cope with any problems. Our booklet *Cancer, you and your partner* has useful advice about how cancer can affect your emotions, sexuality and ability to communicate in a relationship.

Speak to your partner about whether or not they need time and space to recover from treatment. You may feel that you want to be more attentive to each other and that you have a more active sex life following the person's diagnosis.



'We found that touching, kissing and massaging can be a comforting and relaxing way to be intimate with each other. It can also be soothing to touch and stroke the person's scars from surgery.'

If your partner has had chemotherapy, you may need to use condoms for a few days afterwards. Talk to a doctor or nurse about this.

Remember that doctors and nurses will have experience of talking to other carers and people with cancer about sensitive issues like sex. If you feel comfortable, talk to them about any concerns. They can give you advice on how your sex life may be affected and things that may help you.

We also have booklets specifically about how cancer can affect a person's sex life. There is separate information for men and women. You can order this by calling **0808 808 00 00**. You might also find the video at [macmillan.org.uk/cancerandsexuality](https://www.macmillan.org.uk/cancerandsexuality) helpful.



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It's important to realise that your moods and emotions matter too.

You are likely to be very aware of how the person you care for is feeling. Family and friends will be thinking about this too. But it isn't only the person you care for who has feelings. People may forget to ask how you are feeling, but your feelings are important and you should try not to put them to one side. However you feel is okay and natural.

There's no need to apologise or feel guilty for having strong emotions or moods yourself. It's important that you find ways to express them, and to find the support and space that you need for yourself.

Our booklet *When someone close to you has cancer* goes into more detail about how you may feel while looking after someone with cancer. It suggests ways to help you cope with these feelings.

'Be kind to yourself. The way you're feeling is normal, we've all felt like that from time to time.'

Caroline

Anxiety

When someone close to you has been diagnosed with cancer, it's normal to worry about what will happen in the months or years ahead. Fear and anxiety are natural reactions to this situation.

Depression

Looking after someone with cancer is difficult and it is natural that you may feel very low sometimes. For some people, their low mood may get worse and this may mean they have depression.

Depression is a common condition that affects around 1 in 10 people. It can be triggered by difficult events, such as a cancer diagnosis or having treatment. But it can also happen by chance or be related to other events that have nothing to do with cancer. If you're having these kinds of feelings, there are things you can do to help yourself.



Practical tips to help you cope with anxiety and depression

- Ask for support whenever you need it and don't be afraid of your own emotions. This is a very difficult time, so strong and confusing feelings are natural.
- Take some time out from caring. There may be help available so the person you care for isn't left alone while you have a break. Some carer organisations offer free respite care (see pages 109–110). Or you can contact your local social services to find out what's available.
- Chat with a good friend about your worries. And talk to the person you're caring for about how you are feeling. They may be able to offer you support and may be glad you asked.
- Gentle exercise, like a 10-minute walk, can help.
- Avoid drinking too much alcohol.
- Spend some time alone relaxing. You could have a candle-lit bath, listen to music or treat yourself to some of your favourite foods.

You could also speak to your GP or a counsellor. They can help you manage depression or anxiety. Or if you prefer talking on the phone, you can call us on **0808 808 00 00**, or the Samaritans on **08457 90 90 90**. See pages 111–112 for more contact details.

If the person you care for is anxious or depressed

If the person you care for is very unwell, they may become preoccupied and have low moods. You may also notice that they have less empathy if they are taking strong painkillers.

There are things that can help to lift their spirits. They could try relaxation techniques, mood music, books or audiobooks, or having a television in their bedroom. Or they could try downloading relaxing MP3s (audio files) and podcasts from the internet. The website **learnzone.org.uk** has a section called Relaxation Corner where you can download these.

Many people find complementary therapies such as reflexology, massage or aromatherapy can also help with relaxation.

Visitors can also help. Or you could encourage them to talk to other people in a similar situation. Page 107 has some more information on support groups and online support.

Take time to sit together with family or friends and talk about your favourite memories. Remember that you're not the cause of the depression or anxiety.

If the person you care for has panic attacks, it can be helpful to keep paper bags nearby. Breathing into a paper bag can slow down their breathing and help them feel better.

If you think that the person you care for is depressed, talk to a health or social care professional. You can read more about depression and watch a video about it by visiting **macmillan.org.uk/depression**

Being positive

As a carer you may feel like you should 'be positive' for the sake of the person you look after. Your family or friends may say you should keep being positive to help you through this difficult time. But it's not always easy – a lot of people have periods of feeling low at some time in their lives, and this is quite natural. Sometimes being told to be positive when you feel low can be frustrating. It can feel as though the person isn't accepting how you really feel, even if they are just trying to help.

Being positive can mean different things to different people. It's generally about dealing with whatever situation you're in, being optimistic and finding ways of coping. People do this in different ways. What works for one person may not work for another.

No one can be positive all the time. It's important that you don't feel you must always stay on top of things. Being positive doesn't mean having to feel happy and cheerful all the time. It's a positive thing to acknowledge and talk about it if you're feeling tired, worried, depressed or angry.



Practical tips about keeping positive

- Don't forget that you are only human and that your best is good enough. Trying to get the most out of your day personally can help you stay positive. If you have any spare time to yourself, think about what will give you a boost. This may just be reading a newspaper or having a cup of tea.
- Try some activities that distract you from the situation. Keep doing your hobbies and interests where possible.
- If you can keep working, it may be a good distraction and give you routine in your life. There's more about working whilst caring on pages 60–67.
- Talking about good times with the person you care for and not worrying about your current situation can help to lift your spirits, and theirs.
- Feel good about the fact that you have made a difference to the person you are caring for. Remember that you're doing something positive by helping with their stress and pain.
- At the end of each day, try to remember something good you both did that day, or something that made you both laugh.

Be Good to Yourself is a workshop that may help you manage negative thinking and plan ways to live a healthier life. To find out more call **0808 808 00 00** or email **learning@macmillan.org.uk**

Guilt

You may sometimes feel guilty. This could be because you feel like you should be doing more for the person you care for. You may feel guilty about an argument you had with them or because you sometimes resent the support you have to give them. Feelings like these are common. It's important to accept that having negative thoughts does not make you a bad person. Talking about guilt will also help. If you can, try to share your feelings with your family and friends.

Remember, whatever you feel able to do is enough. Try not to feel guilty about having time to yourself – it's very important and can help you be a better carer.

Feeling isolated

You may feel isolated by your role as a carer. It may feel as though you are struggling alone. Remember that support is available. Pages 22–23 have more information to help you find this support.

Try to share your worries with the person you are caring for. Touch and cuddle them – a loving touch can make a big difference. They may feel isolated by the cancer too.

Some carers have trouble communicating with the person they care for, but talking to a professional can help.

Anger and frustration

When someone close to you is diagnosed with cancer, it's natural to feel angry. You might question why this has happened to them, and to you.

You may find you feel worried, anxious or hopeless, but you express it through anger or being irritable.

You might be looking for someone to blame, and get angry with the doctors and nurses. Or you might aim your anger at the people closest to you, even the person who has cancer. Not everyone feels this way but it's okay if you do.

It's really important to express your feelings as they happen, because they may become stronger if you try to hold them in. A hobby or sport where you can release your anger and frustrations may help. It may also help to write things down.

Even with members of your family and close friends, it can be difficult to say how you feel. You may find it helpful to talk about your anger with a counsellor or someone in a support group.

People being cared for can sometimes take their anger out on the people closest to them. Try not to feel responsible for their emotions. Some cancers can affect a person's behaviour, for example they might have sudden fits of anger. Speak to a healthcare professional about whether the person you are caring for may be affected in this way.

Fear

Try to understand what you are afraid of. It's natural to fear the unknown more than anything else, so the more you can learn about what frightens you, the easier it will be to deal with your situation.

Don't be afraid to ask questions. Knowing the facts will often help alleviate fear. If you are religious or have spiritual beliefs, religious and spiritual leaders may be a good source of support and comfort to you.

Tiredness and exhaustion

You will probably feel tired and even exhausted sometimes. Spending time looking after someone can be physically and emotionally draining. It's important to take care of yourself and make sure you don't become overwhelmed.



Practical tips to help with tiredness

- Rest whenever you can – short naps can help to revive you. Try a relaxation CD or MP3 (audio file). An hour or so in a state of deep relaxation can make you feel as if you've had a long sleep.
- Eat healthily and be active.
- Think about having a flu jab – carers are automatically entitled to one for free, so ask your GP. It's important to take care of your health too. If you get ill, see your doctor as soon as you can.

Denial

Denying that someone close to you has cancer after their diagnosis is a normal reaction. If you feel in denial, don't blame yourself or feel that you must hurry to overcome it.

Denial can be a useful way of coping with the news, both for you and the person with cancer. But if it lasts for weeks or months, it can become a problem.

If the person you care for is diagnosed with advanced cancer, denial may be a way of coping for you both. There is more information about these feelings on pages 85–86.



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There are various practical issues you will find yourself having to deal with as a carer.

Day-to-day activities such as housework, managing finances and personal care are all important parts of caring for someone with cancer. If these are things you haven't had to do before, you may find the practical advice in this section useful.

The practical help you give the person you care for can help you feel more confident and helpful as a carer. This could just be something small like bringing them a cushion to help them feel more comfortable.

Carer's assessment

A carer's assessment could help you manage with these practical issues. This is a meeting to discuss what help you need as a carer. You have a right to a carer's assessment if you provide care for someone aged over 18. You don't have to be living with or related to them.

The assessment is carried out by social services at your local council if you live in England, Scotland or Wales. You should be able to find the relevant number in your local phone book or online. In Northern Ireland, they are carried out by your local Health and Social Care Trust – visit [nidirect.gov.uk/assessments-for-carers](https://www.nidirect.gov.uk/assessments-for-carers) for more information.

The person you care for can also have their social care needs assessed. This is called a **community care assessment**.

At the meeting, social services will give you information and agree with you about the services they will provide. They should respect your wishes and the wishes of the person you're caring for.

After the carer's assessment, social services may provide you with things such as breaks from caring or help with cleaning your house. Your financial situation will not affect the help you are offered. But after the assessment, your local council will look at your savings and property to decide whether you will be charged for any services.

Even though your needs may be recognised, it doesn't necessarily mean you will get the help you need. You will need to meet your local council or Health and Social Care Trust's eligibility criteria. These are rules about what level of needs social services will meet – some currently only meet 'critical' or 'substantial' needs.

If you aren't happy with how the assessment was carried out or don't think you are getting the support you need, you can contact your local council or Health and Social Care Trust to complain.

If your situation changes at any time, contact social services to have your needs reassessed. For more information about carer's assessments, contact your local council or Carers Direct (see page 109).

Personal care

Food and eating

The person you care for is likely to have changes in their appetite, so try giving them smaller meals more often. Try using high-calorie drinks or adding milk powder to mashed potato. You could also add food supplements. Ask your doctor or nurse about getting more specific advice from a dietitian.

Cancer treatment can also change the sense of taste. You could try giving the person you're caring for foods with a variety of textures, as otherwise they may all taste the same.

Try not to make a big issue of food and mealtimes. Always try to include the person you care for and ask them what they'd like to eat. Some people with eating problems find that watching TV at the same time can help and be distracting. If they really don't want to eat anything, that's fine. But keep track of their mood and diet, and get help from a dietitian if you need it.

Our booklet *Eating problems and cancer* has more information about the difficulties people with cancer have when they eat and what may help.

Moving and handling

The person you care for may need your help to move around. This might be because their balance isn't good. Learning to move and handle them safely can benefit both of you. But be careful about injuring yourself. Many carers have back injuries from lifting and this can affect your ability to look after someone. Make sure you do it carefully and ask the person you care for what help they want from you. You may need a second person to help.

Your local Carers Trust carers' centre may offer training in areas such as first aid, and moving and handling (visit [carers.org/find-your-local-carers-centre](https://www.carers.org/find-your-local-carers-centre)). You could also contact the Age UK helpline on **0800 169 6565** or speak to your GP or district nurse. The British Red Cross also offers free courses on handling and can supply equipment (see page 111).

It's a good idea to find out in advance what emergency services offer locally, if the person you care for falls or has a similar accident.

Making them more comfortable

There are a number of things you can do to make the person you care for more comfortable. The ideas below have been suggested by the carers who helped us write this booklet. Please remember these are personal examples, some involving homemade equipment. They may not always work for you and it's usually best to check with a health or social care professional first to check what they would recommend.



Practical tips to help the person you're caring for more comfortable

- In the bath, you could put a towel under the person's arms. Or if there are more sensitive parts of their body, make a bath cushion for them to rest on out of foam and tied plastic bags. You could also put a towel on the edge of the toilet seat so that they can sit down more comfortably.
- If they have problems leaving their bed, you could get a plastic urinal, commode or bowl for the bedroom. You could also help them shave or wash their face with a bowl and mirror.

- Carry a thin, foam cushion in a bag that you can discreetly put down to make them more comfortable when they are out.
- Consider buying a sofa bed for the living room so they can lie down and watch TV, talk to friends and be part of family life. This also means you don't have to run up and down the stairs when they need you. You'll need to think about things like getting them on and off the sofa bed safely and whether you'll need help. It might be best to speak to a health or social care professional about these issues first.
- A high-quality, adjustable bed can make them more comfortable too. You could try applying for a Macmillan Grant to help with the cost. Call us on **0808 808 00 00** to find out more or go online at **[macmillan.org.uk/grants](https://www.macmillan.org.uk/grants)**

Equipment and transport

There are aids that can help the person you care for cope at home. Ask the hospital or your local social services about household aids and wheelchairs.

You may be able to get some equipment through a community equipment loan service, which is run locally by the NHS. Your district nurse, community nurse or physiotherapist will be able to arrange this for you. This equipment must be returned when you don't need it anymore.

Carers UK has put together a list of room-by-room equipment and adaptations that you may find helpful. Look at the full list of home improvement ideas at **[carersuk.org/equipment](https://www.carersuk.org/equipment)**

Homemade aids can be very useful. For example, a plastic carrier bag on the car seat will help someone swivel in and out of the car if you don't have a special cushion.

It's important to plan ahead. If you don't need any equipment now, your needs may change over time. Get advice from health and social care professionals in advance, so the equipment is ready when you need it. You can also ask them about getting free transport to and from hospital appointments. If you don't ask, you may not be offered the help you need.

If you think you are being supplied with equipment you won't use, make it clear to the appropriate person that you do not need it. Unnecessary equipment can clutter a house and be an inconvenience.

If you're worried about paying for travel and parking, you may find our booklet *Help with the cost of cancer* helpful. It has more information about how to reduce these kinds of costs.

Your local authority or Health and Social Care Trust can arrange for you to have a carer's assessment if you provide a regular and substantial amount of care. The assessment could help you get the equipment or training you need. See pages 40–41 to find out more about carer's assessments.

Using technology

You could think about using something called **telecare**. This is when sensors are positioned around your home to detect serious problems. These sensors can detect a gas leak, fire or if the front door has been left open.

You can use technology to alert health or social care professionals if there are problems with a person's health. This is sometimes called **telehealth**. The information is sent to an expert monitoring centre, through either the internet or telephone connection. Telehealth can monitor conditions such as asthma, heart failure, diabetes and hypertension. For example, a small heart monitor attached to the body can send this type of alert.

To find out more about telehealth and telecare, go to **carersuk.org/telecare**

There are also mobile phone apps designed to help carers. **Jointly** is an app that helps you to be organised and feel supported as a carer. Visit **carersuk.org/jointly** to find out more.

These new technologies can help people living with cancer to be more independent. They can also help the people looking after them feel more supported and secure.

Household chores

Help with household chores may be available to you. A local Carers Trust scheme may be able to provide you with practical help around the house. In some parts of the country these are known as Crossroads schemes or Princess Royal Trust for Carers schemes. At a national level, these charities have merged to become Carers Trust. See page 110 for contact details.

You can also search on our website for support services (including volunteering services in some areas) that might be able to offer practical support – visit [macmillan.org.uk/in-your-area](https://www.macmillan.org.uk/in-your-area)



Practical tip for household chores

- Try to prioritise – do what has to be done to keep the house hygienic and don't worry too much about the rest.
- If you don't usually do the housework and cooking, ask a person who does to teach you.

Medical issues

Prescriptions

Prescriptions are free for everyone in Scotland, Wales and Northern Ireland. People with cancer in England are eligible for free prescriptions. Ask your GP surgery or oncology clinic for an exemption certificate.

In England, you may be able to get free prescriptions for other reasons. This could be because you are 60 or over, or if you are receiving certain benefits. Our booklet *Help with the cost of cancer* has more information about this.

Availability of drugs

It's good to be aware that not all pharmacies will stock the drugs the person you care for needs. Speak to a pharmacist about ordering drugs.

Most pharmacists now deliver drugs and may deliver on Saturdays. Your local pharmacist should be able to give you more information about this.

Pain control

Pain can be a real issue for people with cancer. People are often advised to take regular doses of medication so the pain relief is always in their system. Make sure any pain relief is taken as advised by the doctor.

If you have been asked to give pain relief to the person you're caring for, ask for clear guidance. It can be a frightening situation and it will help to know exactly what is expected of you.

Tumours will sometimes put pressure on nerves, which can be very painful. Let the person's doctor or nurse know if the pain isn't well controlled.

You may worry if the person you're caring for is taking high doses of strong painkillers. It's important to remember that the right dose is the one that controls the pain, and this can vary.



Practical tip for keeping track of medication

- Try using a tablet box so you can separate all the pills the person needs to take that day. There's a photo of one on page 38. Some pharmacists can help with using a tablet box, for example by filling it with medication for you.
- Using a medication planner like the one on pages 51–52 can also help.

If the person you're caring for has difficulty swallowing tablets, which is not uncommon, ask their key worker about other methods of pain control. It may be possible to use a syringe driver instead, which can be attached to the person and give automatic controlled doses of painkillers and other drugs such as anti-sickness medications, avoiding the need for tablets.

Using a medication planner

If the person you care for is having treatment, you could use a planner to keep track of what medication they need to have, and when. If you need to help them take medications at home, this can be a good way to plan when the next treatment is due.

We've included a medication planner on the opposite page. You can fill it in with notes about what the medication looks like, when it needs to be given and when you need to reorder it. As well as making a note of any tablets, you can use the planner as a reminder for things like inhalers and creams too.

You'll probably need more space, so feel free to pull the planner out and photocopy it. Or you could try creating your own version by copying the layout.

This medication planner was developed with help from Boots Macmillan Information Pharmacists. These specially trained pharmacists are available in some Boots stores and can help you with questions about medications. Other local pharmacists can also give you support and guidance about medications too.

To find your nearest Boots Macmillan Information Pharmacist, visit [boots.com/macmillan](https://www.boots.com/macmillan)

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CANCER SUPPORT

MEDICATION PLANNER



	TIME	MON	TUES	WEDS	THURS
Medication: <i>Lansoprazole</i>	<i>Morning</i>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		
Dosage: <i>Take one in the morning</i>					
What's it for? <i>Stomach</i>					
Shape/colour: <i>White capsule</i>					
Instructions: <i>Take with food. Remember cream and inhaler too.</i>					
	TIME	MON	TUES	WEDS	THURS
Medication:					
Dosage:					
What's it for?					
Shape/colour:					
Instructions:					
	TIME	MON	TUES	WEDS	THURS
Medication:					
Dosage:					
What's it for?					
Shape/colour:					
Instructions:					
	TIME	MON	TUES	WEDS	THURS
Medication:					
Dosage:					
What's it for?					
Shape/colour:					
Instructions:					

	TIME	MON	TUES	WEDS	THURS	FRI	SAT	SUN
Medication:								
Dosage:								
What's it for?								
Shape/colour:	Instructions:					Reorder date:		

	TIME	MON	TUES	WEDS	THURS	FRI	SAT	SUN
Medication:								
Dosage:								
What's it for?								
Shape/colour:	Instructions:					Reorder date:		

	TIME	MON	TUES	WEDS	THURS	FRI	SAT	SUN
Medication:								
Dosage:								
What's it for?								
Shape/colour:	Instructions:					Reorder date:		

	TIME	MON	TUES	WEDS	THURS	FRI	SAT	SUN
Medication:								
Dosage:								
What's it for?								
Shape/colour:	Instructions:					Reorder date:		

Cancer research trials (clinical trials)

Clinical trials are medical research trials involving patients. They are carried out to try to find new and better treatments, including those for cancer.

Sometimes health professionals let people who are having treatment for cancer know about clinical trials that might be relevant for them. The person with cancer always has the chance to think about their options and decide what they want to do.

If the person you care for has been given the option of taking part in a clinical trial and you want to help them find out more, you could read our booklet *Understanding cancer research trials (clinical trials)*. Call **0808 808 00 00** or order a copy from **be.macmillan.org.uk**

Side effects of treatment

Treatments for cancer can have some unexpected and uncomfortable side effects. Ask the doctor or key worker about what kind of side effects the person you're caring for might have and how these can be managed.

If you have an idea of what to expect, it will help you tell the difference between a normal side effect and something more serious. This can reduce unnecessary trips to hospital and save you a lot of worry. But remember, side effects vary from person to person, and they're not always possible to predict.

Being prepared for the effects of treatment means you can learn ways to handle any problems. Side effects may include a dry mouth, nausea or constipation. Being able to reduce some of these side effects can help you feel like you're doing something positive to help the person you're caring for.



'Not all of us knew what side effects to expect or ways we could handle them. We urge you to find out as much as you can. Here are some of the common side effects the people we were caring for had. Remember it's not a complete list. The practical tips for managing these side effects are things that worked for us.'



Practical tips for a dry and sore mouth

- Ideally, the person you care for needs to see their dentist before they start any treatment. They should tell the dentist that they have cancer. It's possible that dental work may be done on the NHS, either at the hospital or a local dental practice.
- Hygiene is very important – they should use mouthwashes and regularly replace their toothbrush.
- Eating pineapple before a meal can enhance taste buds and increase saliva production. Drinking pineapple juice may also help.
- Sucking on pineapple or frozen grapes can soothe the mouth. Or they could try gargling with water and a few drops of tea tree oil.
- Make sure they always have a drink to hand.

A sore and dry mouth is a symptom that can continue after the person is better.





Practical tips to help with indigestion, nausea and vomiting

- Frequent, small amounts of food can often help, even if they don't feel hungry.
- Try peppermint or ginger tea, or crystallised ginger.
- If they have indigestion, discuss it with their doctor.



Practical tips for coping with constipation

- Try to learn what you can about what causes constipation and how it's treated.
- Talk to the person about what you can do to help them deal with this side effect.
- They may need to use suppositories or enemas – the district nurse can administer these.
- Prunes and liquorice can help, as well as other high-fibre foods. Ask the nurse for specific advice to suit you.



Practical tips to help with hair loss

- Tea tree oil shampoos can help relieve an itchy scalp.
- If they prefer to wear a hat when they are outside, make sure you have one to hand.

Other side effects of treatment

- Cancer treatment can seriously reduce a person's natural immunity. So anyone with an infection shouldn't visit the person having treatment. If someone has recently been immunised, check with your GP whether it's safe for them to visit.
- Thrush can be a side effect of cancer treatment but is easily treated by the doctor.
- Breathlessness can also be a problem with certain types of cancer. Our booklet *Managing breathlessness* has some useful tips to help with this.
- Some treatments can affect your sex life. Seek medical advice about sex during treatment.

We have more detailed information about coping with individual symptoms and side effects. You can order this information by calling **0808 808 00 00** or by visiting **be.macmillan.org.uk**



'I was just a wife, not a carer. I didn't give up work because people who give up work are carers and I didn't think that was me!'

Sue

WORK AND FINANCES

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Finding a balance between work and caring can be difficult, but it is definitely not impossible. Whether you work or not, there may be financial support available if you're worried about money.

If you work for an employer, you don't have to tell them that you are caring for someone, although it may help avoid problems in the future if you do.

Ask them for a private meeting. Speak to your manager or someone in the human resources (HR) department about your situation and ask them what options are available to you. Remember though, their interests may not be the same as yours.

If you feel comfortable, tell colleagues about your situation. They may provide some invaluable support to you.



'Many of us found work a welcome distraction. It took our minds off some of the problems we were facing at home and gave us that social contact.'

At work, you may feel worried or guilty about leaving the person you care for at home. If you feel very upset about this, ask your employer if you can go home for the day. You may also be worrying about needing time off. The following pages have information about what you're entitled to if you need time off or want flexible working hours.

Your rights at work

It's a good idea to find out as much information as possible about your rights before speaking to an employer about your caring role. This also applies if your situation changes.

Cancer is considered a disability under the Equality Act 2010 (England, Scotland and Wales) and the Disability Discrimination Act 1995 (Northern Ireland). As a carer, you are also protected from harassment and discrimination under these acts.

You can get advice from Carers UK, Citizens Advice or the Equality Commission for Northern Ireland. Contact details for lots of useful organisations are on pages 109–117.

Time off in an emergency

As a carer, you have the right to take unpaid time off work to look after dependants in cases of emergency. This right is covered by the Employment Rights Act 1996, as amended by the Employment Relations Act 1999 (in England, Scotland and Wales). In Northern Ireland, these laws are called the Employment Rights (Northern Ireland) Order 1996 and the Employment Relations (Northern Ireland) Order 1999.

Possible emergencies may mean a breakdown in care arrangements, the person you care for becoming ill or having an accident, or you needing to make longer-term care arrangements. Your employer may also have a policy for taking time off work, such as carers' leave or compassionate leave.

Flexible working

You also have the right to ask your employer for flexible working hours. The Work and Families Act 2006, the Employment Rights Act 1996 and the Employment Rights (Northern Ireland) Order 1996 give employed carers the right to request flexible working, such as changing hours or working from home.

Resolving issues

Once you know more about your rights, speak to your employer about what options are available to you and be clear about what you need. For example, you might be able to work flexible hours, do a job share or work from home.

If you find it difficult to resolve any work issues, you can contact ACAS (Advisory, Conciliation and Arbitration Service), an independent organisation that works with employees and employers to solve problems. Call their helpline on **08457 47 47 47** or visit **acas.org.uk**

If you are a member of a trade union, speak to your trade union official. They will be able to help you with any problems or legal issues you have at work. Our booklet *Your rights at work* has more information about legal rights at work for people affected by cancer.

If your situation changes, think about contacting us or Citizens Advice (see pages 116–117) about your rights. Then speak to your manager or HR department.

'My manager was amazing. You need to tell them what's going on.'

Victoria

Leaving work

Think carefully before you resign. Resigning is a permanent step, and the way you leave can have an impact on your finances. Think about whether giving up work is something you can afford to do.

Get expert advice before you decide, to find out whether your pensions, insurance and benefits could be affected. Our financial guides could help you – call them on **0808 808 00 00**. There are organisations on pages 116–117 you can also call for more advice.

Make sure you don't feel pressured to give up your job. If you do feel like this, you can speak to someone in your HR department or call us for more advice.

You could also think about taking a career break and see whether you can come back once your caring role ends.

If early retirement is an option, discuss it with your employer. Remember that for some people it's an advantage, but for others it can leave them financially worse off. Get expert advice to see whether you would benefit from early retirement.

Returning to work

Before returning to work, it may be worth seeking advice from an independent organisation about your rights and how your pensions, insurance and benefits could be affected. You can call our financial guides to discuss this or contact the financial support organisations on pages 116–117.

If you've had weeks, months or years off work, it may be helpful to have a gradual, flexible return. If you're going back to somewhere you used to work, have a catch-up meeting with your manager first.

If you are still caring for someone after going back to work, think about asking your manager for regular reviews so you can discuss any changes in your situation.

Once you have returned to work, your situation may change again. It's helpful to know in advance what options you have if changes do happen. Speak to your manager or HR department about this.

Employers appreciate having all the facts in front of them when considering potential employees. If you have gaps in your employment history because of your caring role, explain this on your CV or in person at an interview.

Your local Jobcentre or Jobs and Benefits Office should offer you job search support. Consider your skills and interests before applying for a job. Make sure it's the right one for you.



Practical tips on applying for a new job

- You can get practical advice on writing your CV, filling in application forms and performing well in interviews from books in your local library.
- Visit useful websites for more advice. These include **nationalcareersservice.direct.gov.uk** (England), **skillsdevelopmentscotland.co.uk** (Scotland), **careerswales.com** (Wales) and **jobcentreonline.com** (Northern Ireland)
- Don't forget that you have developed many skills as a carer. This is something you could mention in your CV if appropriate.

Self-employment

If you are self-employed, you may be wondering whether you can run a business and be a carer. You will have much more control over your working life than someone who is employed. But you won't have the same rights and protection.

It will help to be prepared. Talk to your bank manager and your accountant as soon as possible, and be ready to answer questions about your situation. Try to pay your tax on time too.

Applying for any benefits can be more complicated if you're self-employed. It's a good idea to speak to an experienced benefits adviser before you do this. You can speak to our advisers for free on **0808 808 00 00**.

You'll need to decide whether or not to tell your clients about your situation. It can be helpful to think this through first and try to imagine what their reactions might be. You can then be ready with information and suggestions to help with any concerns they may have. If you belong to a professional association, they may be able to give you some guidance.

You may want to take some time off work. Think about someone who could cover for you. Family and friends may be able to help, or you could hire temporary staff. If you have colleagues or associates, they may be able to take on some of your work, but bear in mind the risk of losing clients.



'We found it helpful to discuss our business commitments openly with the person we cared for. Together we were able to decide when they needed our support most and to keep these times free, for example for important hospital appointments.'



Practical tips to help you find out more about working while caring

- Read our information booklets about working whilst caring. These include *Working while caring for someone with cancer* and *Work it out for carers*.
- Find out about services to support small businesses and self-employed people. You can find details of these in our booklet *Self-employment and cancer*.
- Watch our DVD *Cancer in the workplace*, which has videos of carers talking about their experiences of working while caring. You can also see these videos online at macmillan.org.uk/work
- Remember you can ask your local social services for a carer's assessment. This is a chance to discuss any support that would help you balance work and caring, as well as other issues. See pages 40–41 for more about this.

You can order any of our booklets or the DVD by going to be.macmillan.org.uk or by calling our cancer support specialists on **0808 808 00 00**.

Benefits and financial support

Whether you are a full-time carer or still working, you may be entitled to benefits.

Carer's Allowance

Carer's Allowance is the main benefit for carers.

You may be eligible if you care for someone who is receiving one of the following disability benefits:

- Attendance Allowance.
- The care component of Disability Living Allowance at the middle or higher rate.
- The daily living component of Personal Independence Payment at either rate.

To qualify for Carer's Allowance you need to care for someone for more than 35 hours a week. It's handy to keep a diary of all the time you spend caring, as this can help with your application. If you qualify, you may become eligible for other benefits.

You can find out whether you are entitled to Carer's Allowance and make an application online. Visit [gov.uk/carers-allowance](https://www.gov.uk/carers-allowance) if you live in England, Scotland or Wales, or [nidirect.gov.uk/carersallowance](https://www.nidirect.gov.uk/carersallowance) if you live in Northern Ireland.

Carer's Credit

There is also a national insurance credit called Carer's Credit. You may be able to get this if you are not eligible for Carer's Allowance. Anyone who gets Carer's Allowance automatically receives Carer's Credit too.

Carer's Credit enables carers to build up qualifying years for the basic State Pension, the additional State Pension, and Bereavement benefits.

If your caring role ends, it's important to let the relevant benefits offices know. If you live in England, Scotland or Wales, contact the Carer's Allowance Unit, and if you live in Northern Ireland, contact the Disability and Carers service. This will help you to avoid problems later. If you have a low income once your carers' benefits stop, you may be able to claim other benefits.

For more information, visit [gov.uk/carers-credit](https://www.gov.uk/carers-credit) if you live in England, Scotland or Wales, or nidirect.gov.uk/carers-credit if you live in Northern Ireland.

Disabled parking badge and free tax disc

The person you care for may be entitled to a disabled parking badge for your car, which you can use when you are taking them out. Contact your local social services for more information.

You may also be entitled to a free tax disc (vehicle tax exemption). If you live in England, Scotland or Wales, you can find out by calling the Driver and Vehicle Licensing Agency (DVLA) on **0300 790 6801**. If you live in Northern Ireland, call the Driver and Vehicle Agency on **0120 477 0768**.

Tax refund

If you, or the person you care for, has to give up work and your income falls, you may be eligible for a tax refund. To find out, contact your local HM Revenue & Customs Enquiry Centre. If your circumstances change, it's also worth asking whether you are paying the right amount of tax. Look in the phone book or visit [hmrc.gov.uk](https://www.hmrc.gov.uk)


Insurance

Some life insurance policies pay out on diagnosis. Have a look through your policies, and those of the person you care for. You may find that you are covered for loss of income, medical treatment, credit cards, mortgage payments or other expenses.



Practical tips to help you find out more about financial support

- Contact our welfare rights advisers for advice or help accessing benefits and other kinds of financial support. Speak to an adviser by calling the Macmillan Support Line free on **0808 808 00 00**.
- Find out more about Macmillan Grants. Grants are available to help people living with cancer meet some of the extra costs it can bring. The application needs to come through a health or social care professional. Call our support line for more detail.
- Order our booklet *Help with the cost of cancer*, which has more information about benefits and financial help.
- Health and social care professionals may also be able give you advice and information on benefits and filling in forms, or put you in contact with someone else who can help.



'Richard's disease progressed quickly. Knowing the things that might happen with an illness is important because it enables you to plan ahead.'

Alison

MAKING DECISIONS AND LEGAL ISSUES

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The person you are caring for may want to discuss what they would like to happen if their illness gets worse, particularly if they have advanced cancer.

This section looks at some of the legal issues you may need to think about if you are helping the person you care for to plan ahead. It's important to think about who will make certain decisions if they become unable to.

We have a booklet called *Caring for someone with advanced cancer*, which you may also want to read.

Making difficult decisions

There may come a time when the person you care for can no longer make decisions for themselves. As a carer, you may need to make decisions on their behalf or you may be asked about decisions that affect them. For example, the doctor or nurse may ask you about stopping treatment or whether the person you care for should be resuscitated or not. You may be wondering when these kinds of difficult decisions need to be made, and who should make them.

Sometimes it can be difficult to make decisions because other people, perhaps family members, want to be involved. Or you may not want to be involved in making decisions at all. Every person and relationship is different. Use your own judgement and rely on the trust between you and the person you are caring for. If you talk about the options in advance, it can help if the time comes to make such decisions.

It can also help to have an open and honest discussion with the professionals involved. It's important that you know what the procedures involve and how they will affect the person you're caring for. It can be helpful to speak to their doctor to get expert medical information and advice.



'We found that having honest conversations helped during difficult times. Have these with the person you care for, and their healthcare team. We found it helpful to talk about these things early on in their illness, and to talk about it regularly. The earlier you discuss these issues, the more prepared you will be for them if they happen and you will know what to do in different situations. It can help to put their mind at ease too.'

When decisions have to be made, talk to the family and friends involved and make sure you all agree. The professionals can be a source of support as well.

If you find it difficult to start these conversations off, you may find our booklet *Lost for words* helpful. It looks at some of the difficulties people may have when talking about cancer and suggests ways of overcoming them. You can order it by calling **0808 808 00 00**.



Legal issues

Mental capacity

In England and Wales, the Mental Capacity Act 2005 aims to protect people who are unable to make decisions for themselves. This means that a person can plan ahead for when they may not be able to make decisions on their own. This includes decisions about financial matters and their health and social care. For carers, this means that there is guidance in place for you to make decisions on behalf of the person you care for.

If you live in Scotland, you are covered by the Adults with Incapacity (Scotland) Act 2000. Northern Ireland does not have a similar law at the moment. Although the Mental Capacity Act 2005 does not apply in Northern Ireland, much of the guidance in the Act is still followed when decisions are made about a person's mental capacity.

Power of Attorney

If the person you're caring for wants you to make their decisions, you will need to be given **Power of Attorney**. Power of Attorney is only used if the person who made it cannot make decisions for themselves.

There are different types of Power of Attorney. They can be temporary or long-term arrangements. In England, Scotland and Wales, they may cover either financial issues, health and care, or both. In Northern Ireland, you can appoint someone to make legal and financial decisions on your behalf, but not health and care decisions.

If you're unsure, ask the person you're caring for exactly which decisions they would like you to be involved in.

Power of Attorney can take a couple of months to organise. The process can be complicated, so it may be helpful to get legal advice from a solicitor. There is a charge for registering the Power of Attorney, but you may not have to pay the full amount.

If you live in England or Wales, the Office of the Public Guardian has information about making decisions on behalf of people, or for people would like to plan their future. Visit **justice.gov.uk/about/opg** or call **0300 456 0300**. If you live in Scotland, visit **publicguardian-scotland.gov.uk** or call **01324 678 300**. If you live in Northern Ireland, visit **courtsni.gov.uk** or call the Office of Care and Protection on **028 9072 4733**.

Planning ahead

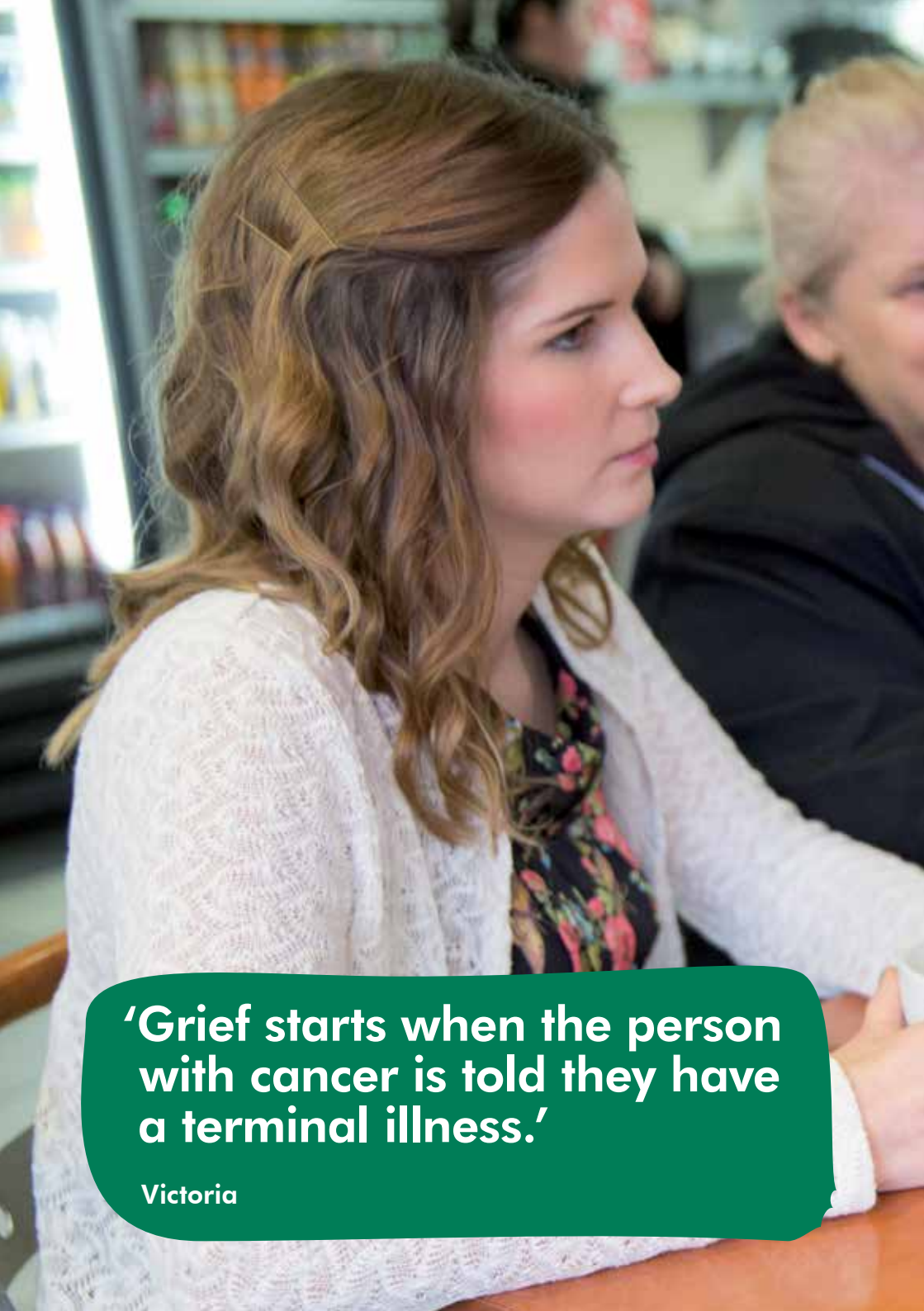
Advance care planning helps identify a person's wishes and choices for their care towards the end of their life. Making an advance care plan can help the person you're caring for think about the future. It can be a way of communicating what they want, to professionals and others involved. As their carer, it may help you to feel less uncertain about making decisions. It can also make things easier for the person's family.

The person you're caring for can also refuse specific treatments in advance by making an **Advance Decision to Refuse Treatment** (also known as Advance Directives or living wills). It's a good idea to talk about these decisions with the healthcare team around you.

There may be times when their wishes cannot be met, such as their choice of dying at home. There may be a good reason for this. If they need to be in hospital, the professionals caring for them should explain why. There may also be times when you can't cope and it has become too difficult to care for the person at home.

We produce a booklet called *Your life and your choices: plan ahead*. It has clear and detailed information about planning ahead for the end of life. There are versions available for people living in England and Wales, Scotland and Northern Ireland.

The National Council for Palliative Care has more information on advance care planning. Visit **[ncpc.org.uk](https://www.ncpc.org.uk)** or call **020 7697 1520**.



'Grief starts when the person with cancer is told they have a terminal illness.'

Victoria

END OF LIFE AND BEREAVEMENT

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While many people with cancer get better, others sadly will not. If you are caring for someone who is dying, this may be very difficult to come to terms with.

It can be even harder if the person hasn't accepted that they are going to die. Talking openly with them could make the situation less frightening for you both.

You may want to know what to expect if you are going to be with someone when they die. Remember that you can talk to one of the health or social care professionals involved. They may be able to help with any questions you have.

We produce a booklet called *End of life: a guide* with Marie Curie Cancer Care to help people plan for this time. You and the person you care for may want to read this. You can order it by calling the support line on **0808 808 00 00** or from **be.macmillan.org.uk**

The person you are caring for may make decisions about where they would prefer to die and what sort of funeral they'd like to have. If you have the opportunity to plan ahead, it may be helpful to choose a funeral director and talk to them about arrangements.

Their wishes may not always be possible, but talking about them may make them more likely. It can be comforting to know you've tried to help them achieve their wishes in their last days.

Caring at home

If you are caring for someone who is dying at home, there are services and support available. Speak to the district nurse, GP or social worker about the help you need and what is available in your area. You should request an assessment of your needs as a carer, which can help you to access support. This is done by your local social services (see pages 40–41).

'The district nurses provided superb support at end of life, which meant Richard could stay at home.'

Alison

If you need to take a break from caring, your local hospice may be able to care for them for a period of time. Or if you prefer, you can ask if they could attend the hospice's day care centre. Hospices offer a range of services when someone is diagnosed with a terminal illness. The charity Help the Hospices has more information (see page 112).

Marie Curie nurses can also give you a break by providing free nursing care to people with cancer in their own homes. Contact Marie Curie Cancer Care for more information on how to get a Marie Curie nurse (see pages 112–113).

You may also find support and information from the Dying Matters website at **dyingmatters.org** The 'find me help' section is aimed at people living with an illness and their carers.

Guidelines from the government

There are different government strategies across the UK that aim to make sure people get the best end-of-life care possible.

In England and Wales, The End of Life Care Strategy aims to promote high-quality care and greater choice for all people reaching the end of their lives. This means that you have the right to discuss the person's needs and preferences with the people supporting you. It also means that the person's care should be well-planned and coordinated by professionals, and that their choices will be respected. For a summary of the strategy, visit [gov.uk/government/publications](https://www.gov.uk/government/publications)

Scotland has a similar strategy called Living and Dying Well, available at [scotland.gov.uk/publications](https://www.scotland.gov.uk/publications)

Northern Ireland's strategy is called Living Matters: Dying Matters, and you can read this at [dhsspsni.gov.uk/8555_palliative_final.pdf](https://www.dhsspsni.gov.uk/8555_palliative_final.pdf)

If you look at these documents, or speak to professionals, you will probably read or hear the term **palliative care**. This means care for someone when their condition can't be cured. Palliative care is about relieving pain and other symptoms. But can also be about providing emotional and spiritual support for the person and those close to them.

Denial and acceptance

It can be difficult to accept a terminal illness, both for the person who is ill and those close to them. This can be an especially difficult issue in some cultures and age groups.



'We think that any solutions to these feelings are individual and personal. It's important to remember that denial is not an unusual reaction – you're not alone. It can be very difficult if you and the person you care for have different ways of thinking. One of you may accept the situation, while the other may deny it's happening. This can cause conflicting emotions.'

Sometimes the person you care for may not actually be in denial about dying. They may just be trying to protect family and friends by not admitting how serious the situation is. As a carer, you may or may not recognise that this is the case.

Trying to accept the situation can help you and the person you care for to look at all the practicalities that need to be taken care of, such as the person's will or other financial arrangements.

Some things can be organised or talked about without it being obvious that you're doing this because the person you care for is dying. For example, you may talk generally about finances, or suggest that you both update your wills. It may also help you to simply relive old times together.

If you are worried that the person you care for is not accepting the reality of the situation, you can ask a healthcare professional to talk to them. Specialist palliative care nurses are trained in listening and counselling skills. Spiritual support may be available in the hospital too.

If the person is in denial about dying, it's okay to try to get them to talk about it. But if things don't change, you may have to accept that this is the way they want to deal with it. Denial can be a very strong coping mechanism and should be respected.

If at any time you need help and support to cope with the fact that the person you're caring for is in denial, just ask. There are professionals ready to help you.

But feelings can change. If the person you care for begins to feel more ill, they may start to accept that they are going to die. And you could start to have feelings of denial if they have lived longer than originally expected.

Healthcare professionals can make incorrect assumptions about whether you, or the person you care for, accept the illness. It can be helpful to let them know how you really feel.

Physical changes before death

As the carer, the moment of death may not always be obvious to you. There are some physical changes or actions that may suggest the person you're caring for is near the end of life. In the last few hours, their hands, feet and skin may feel very cold and possibly moist. Their breathing pattern will also probably change as they get closer to death.

Knowing what to expect can help prepare you, but you need to decide for yourself how much you want to know about the process of dying.

Our booklet *End of life: a guide* has more information about physical changes at the end of life. And you could try contacting your local hospice. This may be a good place to get information about what to expect, or to ask questions about any particular worries you have.



'We found it important to know that when someone is dying, they're often still able to hear. Even if they don't respond, keep talking to them.'

Asking someone to be with you

You may be frightened to be alone with the person you care for in their final hours. There will usually be people around you at this time, but if there isn't, you could ask someone you're close to. This could be a family member, friend or even a professional.

Practicalities after death

You'll need to phone your GP or out-of-hours service (see pages 12–13) if the person you are caring for dies at home. You should leave the person and any medical equipment, such as syringe drivers, untouched until the GP arrives.

Be aware that funeral directors may charge you more if you use their night service. If you feel comfortable waiting, you can wait until the morning before speaking to the funeral director. The GP will have to finish all the necessary paperwork too.

A post-mortem is occasionally necessary. This might happen if the death was sudden. This is a medical examination of the body to find out more about the cause of death. The doctor or coroner may talk to you about this.

The funeral

Your chosen funeral director will guide you through all the formalities and practical issues relating to the funeral.

If the funeral is going to be far away from where the person you care for dies, it could be helpful to get a funeral director from the area where you want the funeral to be held. You don't need to have their body removed immediately if you don't want to.

Think about whether or not you want to be involved in the washing and dressing of their body before they go to the undertaker. You can talk to your funeral director about this.

Funeral arrangements are personal and individual. You may want to take photos and you don't have to wear black. The person you care for may have talked to you about the arrangements.

Remember to consider any religious or spiritual beliefs when it comes to arranging the funeral. And be aware that your plans can be affected by practicalities such as the availability of funeral services.

If you want people to make a donation to charity instead of giving flowers, you may need to speak to that chosen charity first. They may be able to help you by providing things like collection envelopes.

Bereavement

The grief doesn't necessarily start when the person you're caring for dies. You may have felt a sense of loss already. You may miss the way your relationship used to be and all the things you used to do together.

Try to share your feelings with the person you're caring for and grieve together with them and the family before they die. Comfort each other and talk about the good things that you've done together.

Be prepared for other people's reactions to death and respect each other's ways of grieving. However you react, feel and behave is okay. Allow yourself to grieve in your own way and take your time. Let yourself cry whenever you need to.

Be aware that grief can affect you physically too. You could lose your appetite or have difficulty sleeping. So it's important to look after yourself.



'Some of us felt numb, others felt relief; some of us went on holiday, others went to the funeral home every day. Some of us felt guilty – guilty that we were alive and the person we were caring for wasn't, guilty for feeling relief, or guilty about looking to the future.'

Try to take opportunities to talk about your loved one. Some of us found that having photos of them around the house, and even talking to them, could be comforting.'



Practical tips to help with bereavement

- Use the Tell Us Once service ([gov.uk/tell-us-once](https://www.gov.uk/tell-us-once)) in England, Scotland and Wales, which allows you to tell central and local government services about a death once only. It saves you the trouble of contacting different government services and departments individually, as they do that on your behalf. There are plans to introduce the service in Northern Ireland.
- You can find advice on registering a death at [gov.uk/register-a-death](https://www.gov.uk/register-a-death) It's a good idea to get five or six copies of the death certificate from the registrar. You may need them to sort out financial affairs, such as insurance policies.
- Read the helpful guide *When caring comes to an end*. Contact Carers UK (see page 109) or Help the Hospices (see page 112) for a copy.
- Read the booklet *What to do after a death in England and Wales* or *What to do after a death in Scotland*. You can get these from libraries, hospitals or healthcare professionals. You can also download them at [gov.uk](https://www.gov.uk) and [scotland.gov.uk](https://www.scotland.gov.uk) For information about what to do after a death in Northern Ireland, visit nidirect.gov.uk/death-and-bereavement

Your future

Think carefully before making any major life decisions just after the person you were caring for has died. You could think about putting some decisions on hold at this time.

If you need more support or someone to talk to, your local hospice may have a bereavement group you can join. You could also think about having some bereavement counselling. Cruse Bereavement Care may be able to offer you the support you need – see page 114 for contact details.



Practical tips to help you move on

- Think about how you want to deal with the person's clothes and personal items. Don't feel pressured to do this before you are ready – you can do this how and when you want to. You may want to ask for help from family and friends.
- You or family and friends may want to organise something to celebrate the person's life. Or you may find comfort in writing them letters or keeping photos of them in a special place.
- Sometimes changing things around in the home to make it look a little different can also help the process of moving on.



'Some of us found that sorting out personal items can cause conflict in the wider family network, so it's good to be prepared for this possibility. Something that helped us cope at this time was to make plans for days in the future that may be particularly difficult, like birthdays, anniversaries, Father's Day or Mother's Day.'



'What about caring for the carers? You're not looking after yourself when you're caring for someone. You don't make time for yourself – you can't.'

Mike

LIFE AFTER CARING

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It's a natural reaction to want to do something positive straight away, but give yourself some time. You'll need to adjust to no longer being a carer.



'For many of us, it took some time to adjust to the end of our caring role, whether that was because the person we cared for had recovered and no longer needed care, had moved into residential or nursing care, or because they had died.

Some of us also found that when we stopped being a carer, exhaustion – both physical and emotional – caught up with us and that we were more at risk of getting ill. Having spent a lot of time caring for someone else and putting their needs first, it's important that you take care of yourself. And where possible, try to let other people look after you too.'

You can have a lot of time to fill, which can make you feel a bit lost – without purpose or direction. It's not uncommon to walk around the house talking to yourself.

If you don't return to work, this may be a good time to learn something new. You could volunteer or campaign to improve current information and support for carers. Pages 100–101 have more information about how to do this.

You will have to deal with some practical matters fairly quickly, such as benefits. But you don't have to rush into decisions about what you will do next. Take your time and remember there are lots of people and organisations out there to support you.

Practical tips to help you after caring ends

- Write down what you need to do in the short and long term.
- If you're claiming Carer's Allowance, it's important that you let the Carer's Allowance Unit know you have stopped being a carer. There may also be a change in any other benefits you are entitled to. It's best to find out as quickly as possible what you need to do about benefits, as this will help to avoid problems later on.
- Try to accept help that's offered to you. After putting the needs of someone else first for so long, you shouldn't feel guilty about accepting support.
- Look after your health. It's not unusual to be affected physically and mentally by your experience. This may happen weeks, months, or even years after you stop being a carer.
- Get advice and support. You could call us on **0808 808 00 00** or visit the Carers UK website at **[carersuk.org/help-and-advice](https://www.carersuk.org/help-and-advice)**



'Many of us found it difficult to pick up the pieces and start again with regards to work, friendships and outside interests once we stopped being a carer. Don't force yourself to go back to the life you had before you were a carer. You may have changed a lot because of your experience.'

Your feelings

It's not unusual to feel guilty about returning to a 'normal' life free of caring responsibilities. It can feel strange when your caring role ends. You may want to take time out or try to continue with life as if nothing has changed. Do whatever feels right for you.

People are likely to rally around you for the first few days or weeks if the person you were caring for has died. Sometimes this might mean it takes months or years for the loss to sink in.

If you are finding it difficult to express your emotions, you could think about writing them down in a diary. It may help to talk to someone. You could call us on **0808 808 00 00** or visit **[macmillan.org.uk/selfhelpandsupport](https://www.macmillan.org.uk/selfhelpandsupport)** to find your nearest support group.



'Some of us felt very lonely, especially when going to social engagements that we would have normally attended with the person we cared for. Remember that there are still many support services out there to help you. Many of us are still benefitting emotionally from attending support groups even though our caring role has ended.'

Despite the fact that you have stopped caring for the person, you may find it hard to step back from that role. You may constantly feel an overwhelming need to help others or you may want to keep in contact with the hospital or hospice that provided support to the person you cared for. This is normal and something you can use positively. Pages 100–111 have more information about finding new challenges.

If the person you were caring for has recovered, you may find that you constantly worry about the cancer coming back. This may mean you're more protective than usual. Try to live life without this worry hanging over you. Our booklet *Worrying about cancer coming back* may help.

As cancer treatments get better, many people are now living with cancer as a long-term condition. This may mean you need to continue being a carer, due to the long-term effects of cancer treatment. We have more information about the long-term effects of different treatment types. You can also read more about living with or beyond cancer at [macmillan.org.uk/survivorship](https://www.macmillan.org.uk/survivorship)

New challenges

You may have to go back to work after caring ends, but it may also be something you want to do to bring some routine back into your life. There's more information about going back to work on pages 64–65.

You may want to refresh certain skills that you have not used for a while, or just learn something new. Your local library or some adult education centres can find suitable courses in your area. There are some useful websites you could look at for more information about courses, for example **learnirect.com** and **nationalcareersservice.direct.gov.uk/advice/courses**

Volunteering can be a great way to make a difference, meet new people and develop new skills. You could help out at the hospital where the person you cared for received treatment or your local carers' centre, or volunteer for a charity.

If you are interested in volunteering for Macmillan, contact your local volunteering adviser. You can find details at **macmillan.org.uk/volunteer** or by calling **0808 808 00 00**.

It's good to be aware that organisations and charities may have restrictions on who they accept as volunteers, especially if someone has recently been bereaved. Speak to the organisation or charity about any restrictions they may have.



'Many of us have gone on to use our experiences to help provide better support and information for carers. This booklet is an example of that work. You can do similar work by joining a local user group, working with a charity or speaking directly to your local council about carer services in your area.'

Macmillan Cancer Voices is a UK-wide network for people to use their experiences of cancer to improve cancer care. You can find out more about this by visiting [macmillan.org.uk/cancervoices](https://www.macmillan.org.uk/cancervoices) or by calling **0808 808 00 00**.

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A practical guide to
understanding cancer

UNDERSTANDING
BREAST
CANCER

A practical guide to
understanding cancer

UNDERSTANDING
OESOPHAGEAL
CANCER
(CANCER OF THE
GULLET)

A practical guide to
understanding cancer

UNDERSTANDING
STOMACH
CANCER

A practical guide to
understanding cancer

UNDERSTANDING
LUNG
CANCER

A practical guide to
understanding cancer

UNDERSTANDING
TESTICULAR
CANCER

A practical guide to
understanding cancer

UNDERSTANDING
CERVICAL
CANCER

A practical guide to
understanding cancer

UNDERSTANDING
WOMB
(ENDOMETRIAL)
CANCER

A practical guide to
understanding cancer

UNDERSTANDING
CANCER
OF THE OVARY

A practical guide to
understanding cancer

UNDERSTANDING
CANCER OF
THE PANCREAS

A practical guide to
understanding cancer

UNDERSTANDING
COLON
CANCER

A practical guide to
understanding cancer

UNDERSTANDING
THYROID
CANCER

A practical guide to
understanding cancer

UNDERSTANDING
ADVANCED
MELANOMA

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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 leaflets or booklets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

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

All of our information is also available online at **macmillan.org.uk/cancerinformation**

There you'll also find videos featuring real-life 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
- large print
- translations.

Find out more at **macmillan.org.uk/otherformats**

If you'd 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**.

Help us improve our information

We know that the people who use our information are the real experts. That's why we always involve them in our work. If you've been affected by cancer, you can help us improve our information.

We give you the chance to comment on a variety of information including booklets, leaflets and fact sheets.

If you'd like to hear more about becoming a reviewer, email reviewing@macmillan.org.uk You can get involved from home whenever you like, and we don't ask for any special skills – just an interest in our cancer information.



Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we're here to support you. No one should face cancer alone.

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 Monday–Friday, 9am–8pm. Our cancer support specialists can:

- help with any medical questions you have about your cancer or treatment
- help you access benefits and give you financial advice
- 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](https://www.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](https://www.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.

'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 advice

Our financial guidance team can give you advice 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](https://www.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](https://www.macmillan.org.uk/work)

Other useful organisations

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

Support for carers

Carers Direct

PO Box 4338,
Manchester M61 0BY
Tel 0300 123 1053
(Mon–Fri, 9am–8pm,
Sat–Sun, 11am–4pm)

www.nhs.uk/carersdirect

Confidential information and advice for carers. Offers advice on financial support, getting a break from caring, going to work and much more.

Carers UK

20 Great Dover Street,
London SE1 4LX
Tel 0808 808 7777
(Mon–Fri, 10am–4pm)

Email info@carersuk.org

www.carersuk.org

Offers information and support to carers. Can put people in touch with local support groups. Has national offices for Scotland, Wales and Northern Ireland:

Carers Scotland

The Cottage,
21 Pearce Street,
Glasgow G51 3UT

Tel 0141 445 3070

Email info@carerscotland.org

www.carersuk.org/scotland

Carers Wales

River House,
Ynsbridge Court,
Cardiff CF15 9SS

Tel 029 2081 1370

Email info@carerswales.org

www.carersuk.org/wales

Carers Northern Ireland

58 Howard Street,
Belfast BT1 6PJ

Tel 028 9043 9843

Email info@carersni.org

www.carersuk.org/northernireland

Carers Trust

32–36 Loman Street,
London SE1 0EH

Tel 0844 800 4361

Email info@carers.org

www.carers.org

A charity formed by the merger of The Princess Royal Trust for Carers and Crossroads Care.

Works to improve support, services and recognition for anyone living with the challenges of caring. Has offices in Scotland and Wales:

Glasgow office

Skypark 3, Suite 1/2,
14/18 Elliott Place,
Glasgow G3 8EP

Tel 0300 123 2008

In Scotland, Carers Trust is known as The Princess Royal Trust for Carers.

Cardiff office

3rd Floor,
33–35 Cathedral Road,
Cardiff CF11 9HB

Tel 0292 009 0087

Equipment and advice on living with disability

Assist UK

Redbank House,
4 St Chad's Street,
Manchester M8 8QA

Tel 0161 850 9757

Email

general.info@assist-uk.org

www.assist-uk.org

An independent voluntary organisation with a network of disabled living centres throughout the UK. Centres offer advice and a range of products and equipment for people who have difficulty with daily activities.

The Blue Badge Scheme

Tel 0844 463 0213 (England)

0844 463 0214 (Scotland)

0844 463 0215 (Wales)

0300 200 7818 (NI)

www.gov.uk/blue-badge-scheme-information-council

(England, Scotland and Wales)

www.nidirect.gov.uk/the-blue-badge-parking-scheme

(Northern Ireland)

Provides a national arrangement of parking concessions for people with severe walking difficulties

who travel either as drivers or passengers. It allows badge holders parking concessions so they can park close to their destination. The scheme operates throughout the UK.

British Red Cross

44 Moorfields,
London EC2Y 9AL

Tel 0844 871 11 11

Email

information@redcross.org.uk

www.redcross.org.uk

Offers a number of services for people with a disability, including a medical equipment loan service and a transport service, across the UK.

Disabled Living Foundation (DLF)

Ground Floor, Landmark House, Hammersmith Bridge Road, London W6 9EJ

Tel 0300 999 0004

(Mon–Fri, 10am–4pm)

Email helpline@dlf.org.uk

www.dlf.org.uk

A national charity that provides free, impartial advice about disability equipment and mobility products through its helpline, website and demonstration centre.

Mental health support

Beacon (Northern Ireland)

80 University Street,
Belfast BT7 1HE

Tel 028 9032 8474

Email

info@beaconwellbeing.org

www.beaconwellbeing.org

A network of support services throughout Northern Ireland.

Breathing Space (Scotland)

Tel 0800 83 85 87

(Mon–Thu, 6pm–2am,
Fri, 6pm–Mon 6am)

www.breathingspace.scotland.co.uk

A free, confidential phone and web service for people in Scotland experiencing low mood, depression or anxiety.

Rethink Mental Illness

(England and Wales)

89 Albert Embankment,
London, SE1 7TP

Tel 0300 5000 927

(Mon–Fri, 10am–1pm)

Email advice@rethink.org

Provides mental health advice and information, and campaigns for more support for people with mental health problems.

Samaritans

Chris, PO Box 9090,
Stirling FK8 2SA

Tel 08457 90 90 90

Email jo@samaritans.org

www.samaritans.org

Provides 24-hour confidential, non-judgemental and emotional support for people experiencing feelings of distress or despair, including those that could lead to suicide. Service provided by phone, email or letter.

Relationships

Relate

Premier House,
Carolina Court, Lakeside,
Doncaster DN4 5RA

Tel 0300 100 1234

www.relate.org.uk

Offers advice, relationship counselling, sex therapy, workshops, mediation, consultations and face-to-face support, by phone and through its website.

Relationships Scotland

18 York Place,
Edinburgh EH1 3EP

Tel 0845 119 2020

Email enquiries@

relationships-scotland.org.uk
www.relationships-scotland.org.uk

A network of local services for individuals, couples and families experiencing relationship difficulties in Scotland.

Advanced cancer and end of life care

Help the Hospices

Hospice House,
34–44 Britannia Street,
London WC1X 9JG

Tel 020 7520 8200

Email info@

helpthehospices.org.uk

www.helpthehospices.org.uk

Provides information about living with advanced illness. Compiles a directory of hospice services, as well as practical booklets. These are all available free on the website.

Marie Curie Cancer Care

89 Albert Embankment,
London SE1 7TP

Freephone 0800 716 146

Tel 020 7599 7777 (England)

0131 561 3900 (Scotland)

01495 740 888 (Wales)

028 9088 2060 (NI)

Email info@mariecurie.org.uk

www.mariecurie.org.uk

Marie Curie nurses provide free end-of-life care to people with cancer in their own homes, 24 hours a day, 365 days a year. There are also Marie Curie hospices across the UK.

Counselling, bereavement and emotional support

British Association for Counselling and Psychotherapy (BACP)

BACP House,
15 St John's Business Park,
Lutterworth LE17 4HB

Tel 01455 883 300

Email bacp@bacp.co.uk

www.bacp.co.uk

Promotes awareness and availability of counselling and signposts people to appropriate services. You can search for a qualified counsellor on the website.

Child Bereavement UK

Clare Charity Centre, Wycombe Road, Saunderton HP14 4BF

Tel 01494 568 900

Email support@childbereavement.org.uk

www.childbereavement.org.uk

Offers information, support and resources to families when a child dies, and when a child is bereaved of someone important in their life.

Childhood Bereavement Network

8 Wakley Street,
London EC1V 7QE

Tel 020 7843 6309

Email cbn@ncb.org.uk

www.childhoodbereavementnetwork.org.uk

A national, multi-professional group of organisations and individuals working with bereaved children and young people. Has an online directory, which you can search for local services.

Compassionate Friends

14 New King Street,
Deptford, London SE8 3HS

Tel 0845 123 2304

(daily, 10am–4pm
and 7–10pm)

Email helpline@tcf.org.uk

www.tcf.org.uk

A befriending service for the families of children who have died.

The helpline is always answered by a bereaved parent who is there to listen when you need someone to talk to.

Cruse Bereavement Care

PO Box 800,

Richmond TW9 1RG

Tel 0844 477 9400

(Mon–Fri, 9.30am–5pm)

Email helpline@cruse.org.uk

Young person's freephone

helpline 0808 808 1677

Young person's helpline

email info@rd4u.org.uk

www.crusebereavementcare.org.uk

Provides bereavement counselling, information and support to anyone who has been bereaved. Has a network of branches across the UK.

Also runs **rd4u.org.uk** – a website designed by young people to support other young people after the death of someone close.

Winston's Wish

3rd Floor, Cheltenham

House, Clarence Street,

Cheltenham GL50 3PR

Helpline 08452 03 04 05

Email

info@winstonswish.org.uk

www.winstonswish.org.uk

Helps bereaved children and young people rebuild their lives after a family death. Offers practical support and guidance to families, professionals and anyone concerned about a grieving child.

Cancer information and support

Cancer Black Care

79 Acton Lane,

London NW10 8UT

Tel 020 8961 4151

Email

info@cancerblackcare.org.uk

www.cancerblackcare.org.uk

Offers information and support for people with cancer from ethnic communities, and their friends, carers and families.

Cancer Focus Northern Ireland

40–44 Eglantine Avenue,
Belfast BT9 6DX

Tel 0800 783 3339

(Mon–Fri, 9am–1pm)

Email hello@cancerfocusni.org

www.cancerfocusni.org

Offers a variety of services to people affected by cancer, including a free helpline, counselling and links to local support groups.

Cancer Research UK www.cancerhelp.org.uk

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

Cancer Support Scotland

Calman Cancer Support
Centre, 75 Shelley Road,
Glasgow G12 0ZE

Tel 0800 652 4531

Email [info@](mailto:info@cancersupportscotland.org)

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

1st Floor, One Waterloo Street,
Glasgow G2 6AY

Tel 0300 123 1801

Email

enquiries@maggiescentres.org

www.maggiescentres.org

Provide information about cancer, benefits advice, and emotional or psychological support.

Tenovus

Head Office,
Gleider House, Ty Glas Road,
Cardiff CF14 5BD

Tel 0808 808 1010

(Mon–Sun, 8am–8pm)

www.tenovus.org.uk

Aims to help everyone get equal access to cancer treatment and support.

General health information

Health and Social Care in Northern Ireland

www.hscni.net

Provides information about health and social care services in Northern Ireland.

Healthtalkonline

www.healthtalkonline.org

www.youthhealthtalk.org

(site for young people)

Has information about cancer, and videos and audio clips of people's experiences.

NHS Choices

www.nhs.uk

The UK's biggest health information website.

Also has service information for England.

NHS Direct Wales

www.nhsdirect.wales.nhs.uk

NHS health information site for Wales.

NHS Inform

www.nhsinform.co.uk

NHS health information site for Scotland.

Patient UK

www.patient.co.uk

Provides people in the UK with information about health and disease. Includes evidence-based information leaflets on a wide variety of medical and health topics. Also reviews and links to many health- and illness-related websites.

Financial or legal information

Citizens Advice

Provides advice on financial, legal, housing and employment issues. Find details for your local office in the phone book or on one of the following websites:

England and Wales

www.citizensadvice.org.uk

Scotland

www.cas.org.uk

Northern Ireland

www.citizensadvice.co.uk

You can also find advice online in a range of languages at **adviceguide.org.uk**

Community Legal Advice

Tel 0845 345 43 45

(Mon–Fri, 9am–8pm,
Sat, 9am–12.30pm)

Minicom 0845 609 6677

www.gov.uk/

[community-legal-advice](http://community-legal-advice.org)

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 isn't your first language.

Equality Commission Northern Ireland

Equality House,
7–9 Shaftesbury Square,
Belfast BT2 7DP

Tel 028 90 500 600

Textphone 028 90 500 589

www.equalityni.org

Aims to advance equality, promote equality of opportunity, encourage good relations and challenge discrimination through promotion, advice and enforcement.

Pensions Advisory Service

11 Belgrave Road,
London SW1V 1RB

Tel 0845 601 2923

www.pensionsadvisoryservice.org.uk

An independent, non-profit organisation that provides free information, advice and guidance on pensions.

Unbiased.co.uk

Email contact@unbiased.co.uk

www.unbiased.co.uk

On the website you can search for qualified advisers who specialise in giving financial advice, mortgage, accounting or legal advice.

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. Quotes are sourced from the experienced carers' group.

Thanks

This booklet has been written and revised by carers, all of whom have experience of caring for someone close to them with cancer. It has been edited by Macmillan's Cancer Information Development team and approved by Charlotte Argyle, Carers Support Manager.

With thanks to: Richard Black and Lorraine Murphy, Macmillan Carers Support Coordinators; Julie Cunneen, Macmillan Lymphoedema Clinical Lead; Lisa Dadswell and Katy Herbert, Boots Macmillan Information Pharmacists; Pauline McCulloch, Colorectal Lead Nurse, Homerton University Hospital; Heather Nicklin, Macmillan Palliative Care Specialist Social Worker; and the people affected by cancer who reviewed this edition.

Sources

We've listed a sample of the sources used in the publication below. If you'd like further information about the sources we use, please contact us at **bookletfeedback@macmillan.org.uk**

Carers Direct. www.nhs.uk/carersdirect/guide/assessments/pages/carersassessments.aspx (accessed April 2014).

Carers UK. www.carers.org/what-carer (accessed April 2014).

GOV.UK www.gov.uk (accessed April 2014).

Macmillan and Ipsos MORI. *More than a million: understanding the UK's carers of people with cancer*. 2012.

National Council for Palliative Care. *Advance care planning and the Mental Capacity Act*. www.ncpc.org.uk/planning-and-capacity (accessed April 2014).

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

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

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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 taxpayer and I would like Macmillan Cancer Support to treat all donations I have made for the four years prior to this year, and all donations I make in the future, as Gift Aid donations, until I notify you otherwise.

I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax in each tax year, that is at least equal to the tax that Charities & CASCs I donate to will reclaim on my gifts. I understand that other taxes such as VAT and Council Tax do not qualify and that 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.



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

More than one in three of us will get cancer. For most of us it will be the toughest fight we ever face. And the feelings of isolation and loneliness that so many people experience make it even harder. But you don't have to go through it alone. The Macmillan team is with you every step of the way.

We are the nurses and therapists helping you through treatment. The experts on the end of the phone. The advisers telling you which benefits you're entitled to. The volunteers giving you a hand with the everyday things. The campaigners improving cancer care. The community there for you online, any time. The supporters who make it all possible.

Together, we are all Macmillan Cancer Support.

For cancer support every step of the way, call Macmillan on 0808 808 00 00 (Mon–Fri, 9am–8pm) or visit macmillan.org.uk

Hard of hearing? Use textphone 0808 808 0121, or Text Relay.
Non-English speaker? Interpreters available.
Braille and large print versions on request.

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