

A practical guide to living with and after cancer

COPING WHEN SOMEONE CLOSE TO YOU HAS CANCER



About this booklet

Learning that someone close to you has cancer can be one of the most challenging times of your life. Whatever your relationship with that person, it's natural to feel a range of emotions.

We've written this booklet for anyone who is close to someone with cancer. It aims to help you understand some of the emotions you may have. It also gives suggestions for coping and getting the support you may need.

People react in different ways to the news that someone close to them has cancer. This booklet explores some common feelings that people experience, but everyone's situation is different.

We've included comments from people affected by cancer. Some are from people who've chosen to share their story with us. To share your story, visit **macmillan.org.uk/cancervoices** Other comments are from the website **healthtalk.org**

To help you find the information you need, we have divided this booklet into sections. It's fine to skip parts of the booklet that don't apply to you.

Additional resources

Supporting someone with cancer

Our booklet **Be there for someone facing cancer** has advice about how you can support your relative or friend with cancer and make sure they don't go through it alone.

If a child has cancer

This booklet is for adults with a partner, relative or friend with cancer. The Children's Cancer and Leukaemia Group (CCLG) has a booklet for the parents and carers of children with cancer. It's called **Children and young people with cancer: a parent's** guide. You can read it on our webstite – visit macmillan.org.uk/ cancerinformation/cancertypes/childrenscancers

Information for carers

We have several resources for people who are caring for someone with cancer. **Looking after someone with cancer** is a handbook for carers, written by carers. It covers issues such as relationships, employment and life after caring. **A guide for young people looking after someone with cancer** is our booklet for young people aged 12–18 who are caring for an adult with cancer.

You are not alone

Whatever your situation, you don't have to face it alone. We can answer any questions you have, offer support, or simply listen if you need a chat. Call us 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**

Turn to pages 51–59 for some more useful books, addresses and websites, and to pages 60–61 for some space to write down any notes or questions you have.

Contents 3

Contents

Your feelings

Talking about feelings

Your relationship

Further information



'Sometimes I feel so angry – not with anyone in particular, just with the situation we are in. I keep thinking, "Why me?"

Jázmin

YOUR FEELINGS

How you might feel

Coping with your feelings

10

6

How you might feel

Going through cancer can be an emotional roller coaster, with many ups and downs. This is often the case for the person who has cancer but it can also be true for the people who are close to them.

When you are supporting someone with cancer, you may have many different feelings. They may come and go and be stronger at some times than others. Some people believe they should ignore their feelings to focus on the needs of the person with cancer. But it's hard to try to block your feelings for a long time. You will need to take care of yourself during what can be a very stressful time in your life. Paying attention to your feelings is an important part of this and it will help you support the person with cancer better.

> 'When mum was diagnosed, she wanted me and my dad to be with her. It was the hardest moment of my life so far. I wanted to run away and not hear any more, but I knew that it was time for me to be strong, to offer them as much help as I could. After all, they've always been there for me.'

Melvin

Over the next pages we've listed some of the most common feelings people have when someone they care about has cancer. There are suggestions for what can help you cope with these feelings in the next chapter on pages 10–15.

Shock

When you first hear that someone close to you has cancer, you may find the news difficult to take in. Everything can seem unreal. You might think it can't be true. You may feel numb and unable to express any emotion. This is natural. It can take time to absorb unexpected information.

Fear

It can be an anxious time. There are many different triggers for fears and worries. These can include:

- diagnosis
- treatment
- test results
- making decisions.

You may worry about the future and feel uncertain.

Grief

You may feel sad for the loss of the life you, and the person you care about, had before cancer. You may feel you have lost the certainty that the people you love are okay. It's important to allow yourself to grieve for these losses. It takes time to come to terms with them.

Sadness

Sadness is a natural response when someone you care about has cancer. You're probably feeling sad for the person who is ill, and wishing it hadn't happened.

Everyone has good and bad days. It's not reasonable to expect yourself to feel positive or happy all of the time. But if you feel sad for weeks or more, without any relief, you may be depressed. Depression can affect your sleep pattern, and your ability to concentrate or make decisions.

If you think you may be depressed, talk to your GP. There are effective treatments. You can also contact some of the organisations listed at the back of this booklet for more information and support – see pages 51–57.

Anger

There are different reasons for anger. You may feel angry because:

- this has happened to the person you care about and to you
- you are trying to cope with too much
- your anger is covering other uncomfortable feelings, such as fear or anxiety.

Talking to someone about how you feel can help stop anger from building up.

If you find it difficult to control your anger, look out for warning signs that you're getting angry. When you notice them, try counting to ten, breathing deeply or walking away. The tool on pages 10–11 can help you record things that have made you angry and things that have had a positive impact on your day.

Guilt

Feelings of guilt are especially common in carers. You may feel guilty about:

- being well when the person you care about isn't
- whether you are doing enough for the person with cancer
- not doing a perfect job as a carer
- feeling resentful if your own needs aren't being met
- not being able to give as much time to other roles, such as being a parent, partner or employee.

Using words like 'should' and 'must' when thinking about what you need to do can make you feel more guilty. So try to notice when you use these words and see whether you can avoid them.

If you feel guilty, talk about it with someone you trust. They may help you see things differently.

Loneliness

When someone close to you has cancer, you may feel like you're on your own. You may feel that other people don't understand what you're going through. If you have caring responsibilities, people may not really understand what this involves. They may not realise how many extra responsibilities you have. It could be helpful to explain this to them.

If you are a carer, try to arrange for someone else to spend time with the person you are caring for. This will give you a break, even if it's only a few hours a week. If there isn't a relative or friend who can take over for a few hours, speak to your GP or social worker, or the cancer team at the hospital. They can help you get an assessment of your needs, which can lead to valuable support.

Coping with your feelings

The following tips can help you deal with the difficult feelings you may have.

Talk about your feelings

Whatever you're feeling, it can help to acknowledge it and talk about it with someone you trust. Sharing your feelings can help you come to terms with the situation, and help put things into perspective.

You may want to talk to someone you know well, or you may prefer to talk to someone outside of your family and friends. If your feelings are overwhelming, or they are affecting your everyday life, talking to a professional may give you the help you need. You can ask your GP about how to get counselling or see a psychologist. A counsellor or psychologist will help you talk about your feelings. They may also help you change the way you are thinking.

There's more information about talking about your feelings and talking to the person with cancer on pages 17–23.

Write your feelings down

Writing about your feelings can help you express yourself, especially if you find it difficult to talk about how you feel. If you have fears or anxieties, writing them down may help you let go of them or come back to them another time. You could try keeping a diary, blogging or using social media. You can also join our online community – visit **macmillan.org.uk/community**

You can use the tool opposite to write down how you feel and what makes it worse or better. We've written in an example.

How I'm feeling today	What makes this feeling worse	What makes this feeling better
I'm feeling angry	Sitting on my own and thinking	Going out for a long walk

Get information

Learning more about the cancer can help you have realistic expectations and help you understand what you can do to help. To read our cancer information, visit **macmillan.org**. **uk/cancerinformation**

Be active

Regular exercise – even just short walks – can help reduce stress. It can also help you keep fit and healthy. Exercising with other people is a good way of getting out and spending time with people. You may want to join a class or a club. Find something you enjoy so you continue with it.

Keep to your usual routines

Doing familiar things can be reassuring and help you feel more in control. Try to stick to your usual routines as much as possible.

Keeping up with hobbies, interests and social activities can also help you cope. This might be hard to do if you are the main carer for someone with cancer. If this is the case, it's important to get some help with your caring responsibilities. See pages 38–43 for information about how to get support if you're looking after someone with cancer.



Find ways to relax

Relaxation can help calm the body. You could try:

- deep breathing
- muscle relaxation exercises
- listening to relaxing music
- imagining yourself somewhere safe and calm
- physical activity, such as walking or swimming
- complementary therapies, such as massage.

Some Macmillan centres offer free complementary therapies to people with cancer and their carers. Find your nearest Macmillan centre at **macmillan.org.uk/informationcentres** Some charities offer complementary therapies for people affected by cancer. This can include family members and carers. See pages 51–53 for details.

If you need help learning how to relax, talk to your GP. They can tell you what resources are available locally. You can also buy relaxation books and CDs online.

'I lie awake at night panicking. I know she's often awake at night too, and I wonder what's going through her mind.'

Timéo

Be kind to yourself

Find time to do something you enjoy every day. This may be watching a favourite programme, reading a magazine or setting aside some time for a hobby.

Try to find time to talk with and meet friends or relatives on a regular basis. It's good to do this even if you don't feel like it. Spending time with other people can help lift your mood if you feel down.

Notice your successes – even the small ones. This will help build your confidence more than criticising yourself.



'I think if anything good has come out of this, it's made me a better person, because I now realise what – and who – is important.'

Lucas

TALKING ABOUT FEELINGS

Talking about your feelings	18	
Talking with the person who has cancer	22	

Talking about your feelings

One of the ways we cope with difficult life events is by talking about them and about our feelings. Talking about your thoughts and feelings can help you:

- relieve tension by stopping worries and fears from building up
- feel reassured that your feelings are normal
- understand how you're feeling and why
- put things into perspective
- find the answer to a problem
- build bonds with your family and friends.

It's a good idea to have someone you can talk to other than the person with cancer. This will take pressure off both of you. The person you talk to might be a partner, close friend, family member or spiritual advisor. Sometimes people find it easier to talk with someone they don't know – over the next pages are some suggestions.

Macmillan Support Line

You can contact the Macmillan Support Line Monday–Friday, 9am–8pm. You can call to ask questions about cancer, to discuss money worries, for advice about work or simply for someone to listen to you.

If you feel distressed or need emotional support when the Macmillan Support Line is closed, you can call Samaritans on **08457 90 90 90**. Its confidential helpline is open 24 hours a day.

Counselling

It can sometimes help to talk to a counsellor, especially if you feel very low. Counsellors are trained to listen and help people talk through their problems. They won't give advice or answers, but they will help you find your own answers. Talking one to one with a trained counsellor can help you sort out your feelings and find ways of coping with them.

This can be helpful if you aren't able to discuss your feelings with the people close to you. Some people find it easier to talk to people who aren't involved with their situation.

GP practices may have their own counsellors, or they can refer you to one. If your employer has an employee assistance programme (EAP), you can contact a counsellor that way.

You can call our cancer support specialists on **0808 808 00 00** for information on how to find a counsellor. Or you can contact an organisation such as the British Association for Counselling and Psychotherapy – see page 53.

'Some days I feel terrible. I can't even go into his room in case I break down in front of him. I feel I should be stronger for him, but I can't be.'

Thomas



Support groups

Most areas of the UK have cancer support groups for carers. These are usually led by people caring for someone with cancer, sometimes with support from a healthcare professional. Other members of the group may be in a similar position to you. A group usually includes people caring for people with different types and stages of cancer. You may find this wider experience helps you see your own problems from a different perspective.

Our cancer support specialists on **0808 808 00 00** can tell you about support groups in your area, or you can find them on our website at **macmillan.org.uk/supportgroups**

Online support

You may want to join an online support group or chat room. There are a number of these groups. Some are aimed at particular types of cancer, while others are more general. There are groups specifically for carers, relatives and friends.

You can exchange messages with other people or, if you prefer, you can just read other people's posts. These messages can be both uplifting and sad. They can help you feel less alone and more able to cope. And they are a good way to find other people who are in similar situations.

On our online community at **macmillan.org.uk/community** you can talk to people in our chat rooms, blog about your experiences, make friends and join support groups. You can share your own thoughts and feelings, and get support from others.

Talking with the person who has cancer

It's natural for someone with cancer to have a mix of emotions, including fear, anger and frustration. These feelings can come and go. But over time, the person will usually find ways to manage them and come to terms with what has happened. Talking can help them do this. So talking and especially listening are important ways you can support the person with cancer.

Our booklet **Talking with someone who has cancer** has more advice on how you can do this, but here are some tips:

- You don't need to rush into talking about the illness. Let your partner, relative or friend talk when they are ready. If they tell you something about their cancer, encourage them to tell you more.
- You don't need to have all the answers listening can be enough. When your partner, relative or friend is talking, don't get caught up thinking about what you're going to say next.
- You can encourage them to keep talking by making encouraging noises such as, 'Mmm,' or, 'Uh huh' or saying things like, 'What happened next?' You can also repeat back what you've heard. This helps you check you've got it right and shows you're listening. You might say things like, 'So you mean that...?'
- Respect your relative or friend's feelings. They might want to talk about things you find hard to hear, such as worries about whether treatment will work or fears about dying. Try not to say that everything will be fine. It can sound as if you're dismissing what they are facing. It's better to let them speak freely about their feelings. You can say something like, 'It's hard to look ahead when you're not sure what will happen'. This lets them keep talking about what's important to them.

Dealing with disagreements

When you're supporting someone who has cancer, there may be times when their frustration or anger with their situation is directed at you. They may be angry about the cancer, but this can be hard to put into words. So they may take out their feelings on the people close to them. This can feel hard to take, especially when you are doing your best and also coping with your own feelings.

Here are some practical tips to help you manage disagreements:

- It helps if you and the person with cancer can try to accept each other's feelings.
- If you can't agree on an issue, you can agree to disagree.
- Don't assume you know what the other person thinks or wants. Ask them.
- Give the other person a chance to talk about how they feel, even if you disagree.
- Avoid 'all or nothing' words such as 'always' and 'never', for example, 'You never listen to me,' or, 'I always call you'. These words make the other person defensive.
- Avoid criticising someone's character. Say how their actions made you feel instead. For example, instead of saying, 'You are thoughtless – I have to remember everything', try saying, 'I feel overwhelmed and stressed when I have a lot to remember'.
- Talk about the issue with someone else. This may make you feel better about it.
- Try to see the other person's side of the argument.
- Write down some of your feelings. This can help you put things into perspective.

'All of us now just enjoy every day, everything from having a cup of tea to talking on the phone to each other. Cancer has made us very close as a family.'

Maryanne

YOUR RELATIONSHIP

If your partner has cancer	26
If a family member has cancer	32
If your friend has cancer	36
Are you a carer?	38

If your partner has cancer

When your partner has cancer, it can feel like your world has been turned upside down.

You may be concerned about how cancer has affected your partner emotionally as well as physically. They might seem different. This could be because they are under a lot of stress or in pain, or simply tired. This can put strain on you and your relationship.

It's common to have many different feelings when a partner has cancer. You will both probably find your own ways of coping with your feelings. Even if you and your partner have very different ways of dealing with the illness, try to be understanding of each other's reactions. Try to work together to understand and support each other.

Often partners try to protect each other by not being completely honest about their fears and concerns. But being honest about your feelings may make it easier for your partner to be honest about theirs. Talking about these things may help you understand each other and feel closer.

> 'The news that Lauren had cancer was the single most horrible day in our entire lives to date. The only way to get through something like this is by taking one day at a time. You just do what needs to be done and then have to rely on the help of your family and friends.'

lan

Relationship changes

Some people will find their relationship changes because of cancer. This may not be immediate, but it can happen over time. Illness can add a lot of pressure to a relationship. It changes your lives and your plans.

Some couples start to understand each other more and have more love for each other. This can be because the cancer is a challenge to overcome together. Or it may be because you both realise the love and affection that you took for granted before.

Cancer doesn't always cause relationship problems, but it can make existing ones more difficult. For some people, a cancer diagnosis may show the relationship is less strong than they or their partner had thought. If you have found it hard to talk through problems together in the past, this may make it more difficult to support each other through cancer. If your relationship is hostile, or if you no longer have strong positive feelings for one another, the stress of a cancer diagnosis is likely to test your relationship further.

Our booklet **Cancer, you and your partner** has more information about how cancer can affect relationships. We also have a video on our website about the impact cancer can have on a relationship – watch it at **macmillan.org.uk/youyourpartner**

Changes in roles and responsibilities

When your partner is diagnosed with cancer, the roles you each have in the relationship may change.

Cancer can change the way people depend on each other. Some people may have to become very dependent on other people for the first time in a long while – perhaps since they were a child. This vulnerability can be difficult for both partners in the relationship. It can also cause anxiety or resentment.

You may have to take on tasks that your partner used to do, such as doing more work around the house or managing the finances. If your partner was the main earner and you now have to go out to work or increase your hours, this can be difficult for both of you.

Taking on more responsibilities may mean you have less time for other things, for example social activities, work or spending time with family. This can lead to resentment, or you may feel guilty that you are not doing enough.

Your sex life

Although you might not be thinking about sex at the moment, cancer and its treatment can have a big impact on your sex life. Sometimes people assume their partner won't want to be intimate if they are ill. Or they may be afraid of hurting their partner.

Treatments for some cancers, such as prostate and cervical cancer, can affect sexual function. Cancer treatments can also affect your partner's energy and mood, so they may not feel like having sex. Sometimes people feel frustrated about the effect cancer has on their relationship. But cancer doesn't have to mean an end to your sex life. We have two booklets called **Sexuality and cancer – information for men** and **Sexuality and cancer – information for women**. They have helpful information about talking about sex and coping with sexual difficulties.

If you or your partner are lesbian, gay, bisexual or transgender

If you are in a same-sex relationship, or if you or your partner are a minority sexuality or gender, you may have extra emotional and practical concerns when your partner is diagnosed with cancer.

It might be that your relationship becomes public for the first time when you're in hospital or dealing with healthcare professionals. Or if there are already difficult family relationships, there may be conflict with your partner's relatives over who is the main support or carer for the person with cancer. If your partner is transgender, their cancer might bring up issues about a gender they do not identify as.

You may feel the people you meet during treatment don't recognise you as a couple. Or you or your partner may find it harder to feel comfortable seeking and getting the help you need. It's important to remember that the law protects you and you shouldn't be treated any differently because of how you identify.

Sometimes talking about these issues can help you cope or resolve them. You can find a list of organisations offering support on pages 51–57. You can also call us on **0808 808 00 00**. Our cancer support specialists are experts in supporting anyone who is affected by cancer. Or you could talk to people in the group for lesbian, gay, bisexual and transgender people on our online community – **community.macmillan.org.uk/cancer_experiences/lgbt**

Facing problems

Keep talking to your partner and showing affection. Some couples find that if they face cancer together and support each other emotionally, it makes their relationship stronger.

This won't be the case for every relationship. The situation you are in might give you an opportunity to look again at your relationship. It may force you to change the situation, even if it means ending the relationship.

Some people will have to deal with the stress of conflicting feelings. For example, if your relationship was close to ending before your partner was diagnosed, you may feel too guilty to end it now. Or you may worry about how that would look to other people.

If the cancer can't be cured

If your partner's cancer is not curable, you may be emotionally preparing yourself for their death. This is incredibly difficult, but try not to withdraw from your partner or stop communicating with them. You will need each other now more than ever.

Sometimes, when a person with cancer isn't going to get better, it can bring up strong feelings about the relationship and make you both re-examine it.

'We find it difficult to talk to each other about our feelings. So we've approached a charity for marriage counselling. It's been really helpful having someone unbiased we can share our feelings with.'

Phillip

If you have children

If you have children, you may find it hard to know what to tell them. Children don't always show their feelings, but their behaviour may change at home or at school.

Teenagers may have to take on more responsibilities around the house – perhaps cooking meals or looking after younger siblings. This can be hard at a time when they're seeking more freedom and independence.

Our booklet **Talking to children and teenagers when an adult has cancer** gives support and helpful advice.



If a family member has cancer

When someone has cancer, it can affect the whole family. All families are different and each family will respond differently when someone is diagnosed with cancer.

All families have experience of dealing with stresses or tensions, but cancer may test the family in a new way. Everyone in the family may feel anxious, sad and tired. If there are relationship problems already, this can make them worse. But cancer can also bring families closer together as they deal with the challenge.

It's important to talk to each other honestly about how you feel. Not talking can cause tension. Family can be a strong source of emotional support. Talking to each other about what's happening can be an important way to help you all cope.

Changes in roles and responsibilities

During and after treatment, the person with cancer may not have the energy to do things they did before. Other family members may have to take on more responsibilities or adjust to new roles. This can affect people's social activities and work. It can also affect what the family can do together.

If life is becoming very busy, you can plan as a family what tasks need to take priority. Try to share the tasks out across the family so you can support each other.

It's important that the person with cancer has a role too. They may want to give support to other family members, as well as being given support.

If your parent has cancer

If your parent has cancer, you may find yourself having to look after them for the first time. You might have mixed feelings about having to care for them in ways you haven't before, for example if you're helping them wash or get dressed.

There might be arguments with your brothers, sisters or other family members about who does what or who makes certain decisions. It can help to divide up responsibilities clearly, so each person knows what to do. You could use a communication plan (see below).

If you are a teenager caring for a parent with cancer, you may be classed as a young carer and be entitled to support – see pages 38–43. We have a booklet for young people aged 12–18 called **A guide for young people looking after someone with cancer**. It talks about other young carers' experiences.

Communication plan

If there are different family members involved in caring for the person with cancer, it may help to use a communication plan. It could cover:

- what information everyone needs to know
- who will speak to healthcare professionals, when they will do it and what they will ask.

This will help prevent misunderstandings and confusion.

You could use the communication plan on the next pages. We've written in an example of the kinds of thing to include. You could photocopy the plan and use it for different weeks.

COMMUNICATION PLAN

	Monday	Tuesday	Wednesday
Example	8am: Saffiyah taking the kids to school	1pm: Pat driving to day unit for chemo (tel 01)	8am: Saffiyah taking the kids to school
Morning			
Afternoon			
Evening			

date _ / _ /

Friday	Saturday	Sunday
9am: Stu calling physio to ask about exercises (tel 01)	10am: Pat doing the ironing	4pm: Liz visiting
	physio to ask about exercises	9am: Stu calling physio to ask about exercises

If your friend has cancer

It's not only partners and families who are affected emotionally when someone has cancer. You can have a range of feelings when your friend is diagnosed and as they go through treatment.

If your friend has family support, you may still have an important role in supporting them. Talk to your friend and find out how you can help. Perhaps you can do practical things, such as going to the clinic with them or spending regular time with them each week. This will give their carer time to do other things.

Maybe your friend needs someone to talk to. Sometimes people find it easier to talk about certain things with a friend than with their family. Or they may welcome the chance to talk about normal things, like what's been happening at work or what you've been doing. Sometimes people worry about saying the wrong thing, so they avoid certain topics. Our booklet **Talking with someone who has cancer** can help you feel more confident about talking with your friend.

'Communicating with someone with cancer can be a real challenge if you find it difficult to talk about or express your emotions. Try other ways of expressing yourself, such as finding or making a special card to send, writing a letter or email, sending a text message, or using images, art or music.'

Isabel

In some cases, the person with cancer may not have a family supporting them, but they may have a group of very supportive friends. This can cause similar issues as when lots of family members are involved in someone's care. Friends may not agree on what needs to be done, and who will do it. It might be best if you all sit down with the person with cancer to talk about it and ask them what they want. You could use the communication plan on pages 33–35. This may be a time when you all appreciate the value of friendship and your relationships become stronger and closer.

If your friend has no one else to look after them, you may feel responsible for their care. It's not only partners or family members who become carers, so if you provide substantial support to someone with cancer, you may be classed as a carer. This means you could get some support to help you carry out your caring role. You can find out more about being a carer on pages 38–43.

If your friend starts to need more help, you might feel pressured to do more for them. You don't have to do anything you don't feel comfortable with. Local authorities and health and social care trusts have responsibilities to arrange services that people need. See page 39 for more information.

If you're a friend of someone with cancer, we are here for you. Call us on **0808 808 00 00** for information or support.

'I've got a wonderful web of very close friends around me. I think it has deepened those relationships. I can have conversations now that I wouldn't have probably had with them before.'

Aamina

Are you a carer?

You may not see yourself as a carer. You may just think you are doing the right thing. But if you provide unpaid support to a family member or friend who would not be able to manage without this help, you are a carer. Caring can mean many things, including:

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

Many partners, relatives and friends of people who have cancer become a carer for that person.

Getting practical support

Some carers feel they have to do everything themselves. But there is no shame in accepting help. This can help the person you're caring for too.

Help from family and friends

Getting practical help from your family and friends can really make things easier.

Keep a list of simple things people can help you with. Perhaps someone could do the shopping for you, take the children out for an afternoon or collect prescriptions. Stick the list on the fridge or carry it around with you. This will mean you're ready when people offer to help.

You may also find the communication tool on pages 33–35 a useful way of organising help.

Needs assessments

The person with cancer should receive a holistic needs assessment from a healthcare professional. This looks at all the types of support they may need for their cancer and any other issues it causes. You can help make sure the person with cancer has one of these assessments. They can ask their cancer team for one.

If you are the main carer for a person with cancer, you are entitled to an assessment of your needs. This is called a carer's assessment. This assessment may lead to you getting practical support. This could mean equipment to help with caring tasks, or help from a paid carer. To arrange an assessment, contact your local social services, social work department or health and social care trust. You can find them in your local phone book or online.

Breaks from caring

A carer's assessment could help you access services that allow you to have time away from caring. These breaks are sometimes called respite care. It's important to have this.

In some cases, the person with cancer may not understand your need for a break, but it will benefit both of you if you have some time apart. You'll have more energy when you return.

Some carers' organisations offer free respite care to give you a temporary break from caring. They can also offer other support. Call us on **0808 808 00 00** for more information about this. We can also help with other issues, such as work or financial matters. 'Caring for someone can be hard emotionally. One thing that's hard is you sometimes have to put your own feelings aside because you're dealing with someone else's.'

Linda

Your feelings

Caring for someone with cancer can be a strain, but it can also be very rewarding. Many carers value the time they spend with their partner, relative or friend who has cancer. Caring for someone can also strengthen your relationship. You may feel proud of the care and support you are giving. Caring may also make you think about what's important in life.

People have different beliefs about care and what it means to be a carer. Your feelings may also be affected by any past experiences you've had of caring. The relationship you have with the person you're caring for and the support available to you will also affect the experience. These things can all make a difference to how you feel about being a carer.

Try to talk about your feelings to your family or friends, or to one of the healthcare team. This can release some of the strain and help you feel better. If you're very tired or stressed, talk to your GP. They may be able to suggest some things that could help.

Our booklet **Looking after someone with cancer** is a handbook for carers written by carers. It includes examples of the challenges carers face and how they cope.

It may help to speak to other people in a similar situation. You could do this in the carers' group on our online community – visit **macmillan.org.uk/community** We can also tell you about support groups in your area – call us on **0808 808 00 00**.

Making time for yourself

Having some time for yourself can help you relax and feel more able to cope.

Try to have regular, complete breaks doing something you enjoy. Even if they're short breaks, this is likely to make you feel better. This could just be going to the shops for an hour, going to the cinema or taking your child to the park. Do something you want to do, and try not to think about cancer for a while.

Keep doing the little things you enjoy too. These will help you through the difficult times. For example, order your favourite magazine each week and give yourself time to read it, or make time to watch your favourite TV programme.

If you're finding it hard to cope, get help. Talk about how you're feeling with a family member or close friend and talk to your GP.

Make time to look after your own physical and mental health. Always go to see your doctor if you have any concerns about your health.

> 'I sometimes wonder if the world is still out there. People ring me and call in from time to time, but some days I feel so cut off.'

Zeinab

Work

If you are working while looking after someone with cancer, this can cause extra stress.

If you are a carer, you have a right to ask your employer to consider your situation and take your needs into account. For example, you can request flexible working arrangements. There's more information in our booklet **Working while caring for someone with cancer**.

Financial support

Money can be a big cause of stress for people affected by cancer. For help accessing benefits or for free financial advice, call us on **0808 808 00 00**. You could also order some of our free publications about financial support for people affected by cancer – visit **be.macmillan.org.uk**



FURTHER INFORMATION

About our information	46
Other ways we can help you	48
Other useful organisations	51
Helpful books	58
Your notes and questions	60

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:

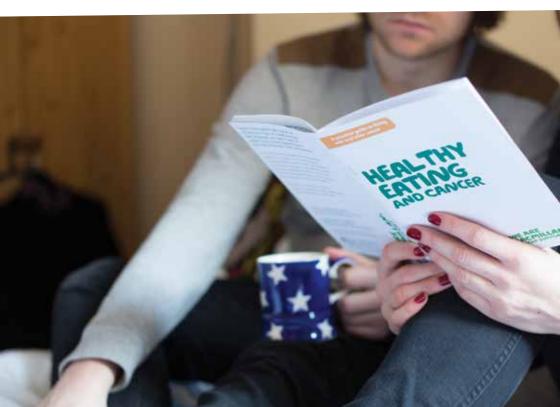
- audiobooks
- Braille
- British Sign Language
- Easy Read booklets
- ebooks
- large print
- translations.

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 guidance
- be there to listen if you need someone to talk to
- tell you about services that can help you in your area.

Call us on **0808 808 00 00** or email us via our website,

macmillan.org.uk/talktous

Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face. Visit one to get the information you need, or if you'd like a private chat, most centres have a room where you can speak with someone alone and in confidence. Find your nearest centre at macmillan.org.uk/ informationcentres or call us on 0808 808 00 00.

Talk to others

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

Support groups

Whether you are someone living with cancer or a carer, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting **macmillan.org.uk/** selfhelpandsupport

Online community

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

The Macmillan healthcare team

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

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

Mal

Help with money worries

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

Financial guidance

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

Help accessing benefits

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

Macmillan Grants

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing to a much-needed break. Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants. We can also tell you about benefits advisers in your area. Visit **macmillan.org.uk/ financialsupport** to find out more about how we can help you with your finances.

Help with work and cancer

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

> Macmillan's My Organiser app This free mobile app can help you manage your treatment, from appointment times and contact details, to reminders for when to take your medication. Search 'My Organiser' on the Apple App Store or Google Play on your phone.

Other useful organisations

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

General cancer support

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 various services to people affected by cancer and their family and friends, including a free helpline, counselling, a family support service, and links to local support groups. Offers classes in art therapy, journal writing, creative writing and singing.

Cancer Support Scotland

Calman Cancer Support Centre, 75 Shelley Road, Glasgow G12 0ZE **Tel** 0800 652 4531 **Email** info@ cancersupportscotland.org **www.cancersupport scotland.org**

Offers information and support to people with cancer and their family and friends. Runs a network of support groups across Scotland. Also provides counselling and complementary therapies.

Health and Social Care in Northern Ireland www.n-i.nhs.uk

The official gateway to health and social care services in Northern Ireland.

Healthtalk www.healthtalk.org www.youthhealthtalk.org

Have video and audio clips of people talking about their experiences of cancer and its treatments.

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. Download practical booklets from the website. Has a directory of local hospice services, including emotional support for you and the person with cancer.

Maggie's Centres

1st Floor, One Waterloo Street, Glasgow G2 6AY **Tel** 0300 123 1801 **Email** enquiries@ maggiescentres.org **www.maggiescentres.org** Provides information about cancer, benefits advice, and emotional support to anyone affected by cancer, including family and friends.

NHS Choices www.nhs.uk

The online 'front door' to the NHS. The country's biggest health website, it gives all the information you need to make decisions about your health.

NHS Direct Online www.nhsdirect.nhs.uk

NHS health information site for England.

NHS 24 in Scotland www.nhs24.com

NHS health information site for Scotland.

NHS Direct Wales www.nhsdirect.wales.nhs.uk NHS health information site

for Wales.

Patient UK www.patient.co.uk

Provides people in the UK with good-quality 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 healthand illness-related websites.

Tenovus

Head Office, Gleider House, Ty Glas Road, Cardiff CF14 5BD **Tel** 0808 808 1010 (Mon–Sun, 8am–8pm) **www.tenovus.org.uk** Offers support and information to people with cancer and their relatives and friends. Provides support such as mobile cancer support units, counselling, a free helpline and an 'Ask the nurse' service on the website.

Mental health support

Action on Depression

11 Alva Street, Edinburgh EH2 4PH Tel 0808 802 2020 (Wed, 2–4pm) Email info@ actionondepression.org www.actionon depression.org

Scotland's national charity for depression. Offers support by phone and email, and runs local support groups. Has an online community and online self-help courses based on cognitive behavioural therapy.

Breathing Space www.breathingspace scotland.co.uk

A free, confidential web and phone service aimed at young men in Scotland experiencing low mood or anxiety.

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 of

counselling and appropriate services. You can search for a qualified counsellor at **itsgoodtotalk.org.uk**

The British Psychological Society

St Andrew's House, 48 Princess Road East, Leicester LE1 7DR **Tel** 0116 254 9568 (Mon–Fri, 9am–5pm) **Email** enquiries@bps.org.uk www.bps.org.uk Has a directory of chartered psychologists.

Lifeline

Tel 0808 808 8000 (24 hours a day, 365 days a year) Textphone 18001 0808 808 8000 www.lifelinehelpline.info Crisis response service

for people in distress or despair in Northern Ireland. Trained counsellors operate the helpline.

Mental Health Foundation www.mentalhealth.org.uk/ help-information/podcasts

Provides free, downloadable podcasts through its website. These are designed to help people relax and improve overall well-being.

MIND

PO Box 277, Manchester M60 3XN Tel 0300 123 3393 Email info@mind.org.uk www.mind.org.uk (England, Scotland and Northern Ireland) www.mind.org.uk/ mind_cymru (Wales) Charity offering information, advice and support to anyone worried about their own or someone else's mental health.

Royal College of Psychiatrists

21 Prescot Street, London E1 8BB **Tel** 020 7235 2351

www.rcpsych.ac.uk

The professional and educational body for psychiatrists in the UK and the Republic of Ireland. Produces information leaflets for the public, which can be downloaded from the website.

Samaritans

Freepost RSRB-KKBY-CYJK, Chris, PO Box 9090, Stirling FK8 2SA **Tel** 08457 90 90 90 **Email** jo@samaritans.org **www.samaritans.org** Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

SANE

1st Floor, Cityside House, 40 Adler Street, London E1 1EE **Tel** 0845 767 8000

www.sane.org.uk

The helpline offers information and advice on all aspects of mental health for people with mental illness, or their family or friends. You can also get support by email (via the website) or join the online community.

Switchboard – the LGBT+ Helpline

Tel 0300 330 0630 (Mon–Sun, 10am–11pm) Email chris@switchboard.lgbt www.switchboard.lgbt Provides confidential information and support for lesbians, gay men, bisexual and transgender people and anyone considering issues around their sexuality and/or gender identity.

Walking groups

Walking for Health (England) Tel 020 7339 8541 www.walkingforhealth. org.uk

Macmillan and the Ramblers work together to run this network of health walks across England. You can phone or visit the website to find a guided walk near you.

Paths for All (Scotland) Tel 01259 218 888

www.pathsforall.org.uk A group of organisations that promote walking for health in Scotland. Use the website to find a health walk near you.

Let's Walk Cymru (Wales) Tel 029 2064 6890 www.ramblers.org.uk/ letswalkcymru

A country-wide walking programme designed to increase the number of people walking to improve their health and well-being. You can search for routes or walking groups on the website.

Walk NI (Northern Ireland) Tel 028 9030 393 www.walkni.com

A guide to walking in Northern Ireland, with route maps and information about events and accommodation.

Support for carers

Carers Direct (NHS Choices) Tel 0808 802 0202 Textphone 0800 988 8657 (Mon–Fri, 9am–8pm, Sat–Sun, 11am–4pm) www.nhs.uk/carersdirect A free, confidential advice service for anyone caring for someone in England. On the website there is information about many aspects of caring, including looking after your own well-being.

Carers Trust (Princess Royal Trust for Carers in Scotland)

32–36 Loman Street, London SE1 0EH **Email** support@carers.org www.carers.org and www.youngcarers.net

Provides support, information, advice and services for people caring at home for a family member or friend. Can tell you about support in your area, including respite care. Also has an online support forum. Carers UK Tel (England, Scotland, Wales) 0808 808 7777 Tel (Northern Ireland) 028 9043 9843 (Wed-Thu, 10am-12pm and 2-4pm) Email advice@carersuk.org www.carersuk.org Offers information and support to carers across the UK. Can put people in contact with support groups for carers in their area. Runs online courses for carers at carersuk.org/ for-professionals/training/ e-learning#aboutme

These courses aim to help you find resources and sources of support so that caring responsibilities don't become overwhelming.

Crossroads Caring for Carers Northern Ireland

7 Regent Street, Newtownards, Northern Ireland BT23 4AB **Tel** 028 9181 4455 **Email** mail@crossroadscare.co.uk **www.crossroadscare.co.uk** Provides respite care, giving people a break from their caring responsibilities.

Crossroads Caring Scotland

24 George Square, Glasgow G2 1EG Tel 0141 226 3793 www.crossroads-scotland. co.uk

Provides respite care, giving people a break from their caring responsibilities.

NI Direct www.nidirect.gov.uk/carers

Government website providing information for carers in Northern Ireland about where to get support, financial matters, employment, carers' rights and getting respite care.

You can search for more organisations on our website at macmillan.org.uk/organisations or call us on 0808 808 00 00.

Helpful books

As big as it gets: supporting a child when a parent is seriously ill

Stokes J, Crossley D, et al. 2007. Winston's Wish. £5.99. Provides a range of ideas for parents and carers, including suggestions on talking to children about cancer and how to offer support.

Cancer is a word, not a sentence

Dr Robert Buckman. 2011. Collins. £10.99. A practical guide to life after a cancer diagnosis. It focuses on day-to-day issues, such as how to talk to your partner, children, friends and healthcare team. Includes a section for people close to someone with cancer.

Carers – looking after yourself

The Brain Tumour Charity. 2015. Free. Fact sheet that gives suggestions to help carers manage their role practically and emotionally. **Cellmates: our lessons in cancer, life, love and loss** Clark R. 2013. Saraband. £9.99. Compiled from a collection of diary entries and letters that the author wrote while her husband had cancer.

Going into hospital? A guide for patients, carers and families

Warren O, Dean Franklin B, Vincent C. 2015. Eastdown Publishing. £14.99. Provides clear, practical information about how hospitals work, who the staff are and the investigations and treatments people may receive.

The guide to grants for individuals in need 2016/17

Cain R, Reynolds J. 2016. Directory of Social Change. £85. A directory of organisations that give financial support to people in need. A copy can be found in most public libraries.

In it together: for partners of people with breast cancer

Breast Cancer Care. 2014. Free. A booklet about ways to cope with breast cancer, including facing treatment together, communicating with each other, and dealing with family and friends. Includes details of support organisations.

Past caring: the beginning not the end

Jenkinson A. 2004. Polperro Heritage Press. £8.95. One person's experience of caring for both parents, including how she coped and advice from other former carers about life after caring.

The secret C

Stokes J. 2009. Winston's Wish. £4.99. Aims to help parents or carers explain cancer to children aged 7–10 years old, through pictures, captions and straightforward language.

The selfish pig's guide to caring

Marriott H. 2009. Piatkus. £9.99. Written by a former carer, this book talks about the feelings carers may have, including guilt and isolation. It also covers issues such as sex and dealing with friends and healthcare professionals.

Topic of cancer: a positive and supportive guide for patients, families and friends Castle F, Greenough J. 2012. Upfront Publishing. £4.99. Written by someone whose partner had cancer, this book offers practical advice and talks about emotional issues. It covers everything from hearing the diagnosis to getting

What can I do to help? 75 practical ideas for family and friends from cancer's frontline Hutton D. 2010. Short Books Ltd. £7.99.

support and living with cancer.

Written by a cancer survivor, this book gives practical examples of ways that family and friends can help someone close to them with cancer.

Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you and your health is collected in a cancer registry. This is used to plan and improve health and care services. Your hospital will usually give this information to the registry automatically. There are strict rules to make sure the information is kept safely and securely. It will only be used for your direct care or for health and social care planning and research.

Talk to your doctor or nurse if you have any questions. If you do not want your information included in the registry, you can contact the cancer registry in your country. You can find more information at **macmillan.org.uk/cancerregistry**

YOUR NOTES AND QUESTIONS

Disclaimer

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

Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by Dr Tim Iveson, Consultant Medical Oncologist and Macmillan Chief Medical Editor.

With thanks to: Dr Chris Hewitt, Consultant Clinical Psychologist; Dr Anne Johnson, Macmillan Consultant Clinical Psychologist; and Pauline McCulloch, Colorectal Lead Nurse. Thanks also to the people affected by cancer who reviewed this edition, and those who shared their stories.

Sources

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

Egan G. The skilled helper: a problem management and opportunity development approach to helping. Edition 10. 2014. Brooks/Cole. Macmillan Cancer Support. Identifying cancer carers and signposting them to support. 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

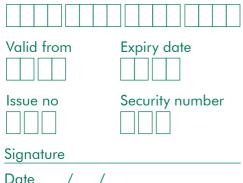
Email

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

Card number



Don't let the taxman keep your money

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

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

I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. I understand 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.

© Macmillan Cancer Support, April 2016. 2nd edition. MAC14292. Next planned review 2018. Macmillan Cancer Support, registered charity in England and Wales (261017), Scotland (SC039907) and the Isle of Man (604). Printed using sustainable material. Please recycle.



WE ARE MACMILLAN. CANCER SUPPORT