

## Cancer and relationships

## Support for partners, families and friends





I know my family were really informed thanks to a lot of the information Macmillan offers online and in booklets. That was priceless to us and still is, really.

Tarsim, mother of Amrik who was diagnosed with Hodgkin lymphoma

### About this booklet

This booklet is about coping with your feelings when someone you care about has cancer. It is for anyone who cares about someone with cancer, including partners, family members and friends.

We hope it helps you deal with some of the questions or feelings you may have. It also gives suggestions for helping yourself and getting the support you need.

#### How to use this booklet

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

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

At the <u>end of the booklet</u>, there are details of other organisations that can help.

There is an <u>example of a communication plan</u> you may wish to use.

#### Quotes

In this booklet, we have included quotes from people affected by cancer. These are from people who have chosen to share their story with us, including Tarsim and her son Amrik, who are on the cover of this booklet. To share your experience, visit <u>macmillan.org.uk/shareyourstory</u>

#### For more information

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

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

If you are deaf or hard of hearing, call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

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

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## Your feelings

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We tried to be strong, to show him that we were going to deal with it and get him well. But I have to say I think I was the worst in the family. I'm a strong person – but when it's your own child, it's extremely hard.

Tarsim, Amrik's mother

## How you might feel

Having cancer can be very emotional, with many ups and downs. This is often true for the person who has cancer, and their family and friends.

When someone you know has cancer, you may have many different feelings. These feelings may come and go. You may each have good days when you feel positive, and difficult days when you struggle more with how you are feeling. Everyone is different. There is no right or wrong way to feel.

You may want to focus on supporting the person with cancer. But it is important to pay attention to your feelings and take care of yourself as well during this stressful time. Taking care of yourself can help you support the person with cancer better.

Here are some common feelings people have when someone they care about has cancer. We have tips for what can help you cope with these feelings.

#### Shock

You may find it hard to believe that the person you care about has cancer. It is common to feel shocked and numb. You may not be able to understand all the information you get. At first, it can be hard to talk about the cancer. Or you might find it hard to think or talk about anything else. Both reactions are normal. Your mind is trying to process what is happening. These feelings usually get easier over time.

#### Fear and anxiety

You may be anxious or frightened about whether treatments will work. If you are caring for someone, you may worry about how a cancer diagnosis will affect your family life and work. We have more information in our booklets <u>Looking after</u> <u>someone with cancer</u> and <u>Working while caring for someone with cancer</u>.

It can help to recognise when you feel anxious. You may notice some physical symptoms such as:

- having tense muscles
- feeling short of breath
- feeling dizzy
- sweating
- having a dry mouth
- being unable to sleep
- feeling tired
- having digestive problems
- a pounding heart.

Anxiety can change the way we think. You may worry about

the future more. This is a normal response. But it can be one of the hardest things to cope with. It can help to try and focus on things you can control. It can also help to talk about your feelings. Try to keep doing things that are important to you and that you enjoy.

#### Denial

You might try to deny what is happening because you just want to continue as normal. You might find it hard to accept that someone you care about has cancer. This is a normal reaction.

Denial is a way of coping and may give you some time to adjust to the changes that are happening. But if it lasts for weeks or months, it can become a problem. Your partner, family members or friends may try to talk to you about this if they are worried about you. Denial can stop you from getting the help you need.

If you are struggling, take some time to think about your needs. Talking to someone can sometimes help you realise that support might help. This might be support you would like from other people, such as a counsellor or a support group.

If the person you care about is diagnosed with advanced cancer, you may both find it hard to accept. By talking things through, you may be able to support each other.

#### **Grief and loss**

You may feel grief and loss for the life you both had before cancer. You may also grieve because you have lost a sense of certainty about the future. It is important to allow yourself time to be sad and to grieve for these losses. It can take time to come to terms with them.

#### **Sadness**

Sadness is a natural feeling when someone has cancer. You will probably feel sad for the person who is ill, and wish it was not happening.

Everyone has good and bad days. Do not expect to feel positive or happy all the time. Sadness can come and go. You may feel sad even at times when you would usually enjoy yourself.

But if you feel sad for a few weeks or more, and it starts to affect your everyday life, you may be depressed. Symptoms of depression can include:

- feeling sad or numb for a few weeks or more
- struggling to enjoy things that you usually would
- sleeping problems
- difficulty concentrating or making decisions
- feeling helpless or hopeless
- changes in appetite (eating more or less).

If you think you or the person with cancer may be depressed, talk to your GP. There are treatments that can help. You can also contact a <u>support organisation</u>.

#### Anger

Many people feel angry. This is a normal reaction. You may be angry at people you know well. There are different reasons for being angry. It may be because:

- this has happened to a person you care about, and to you
- the cancer has changed your lives
- you are trying to cope with too much
- it is covering other feelings, such as sadness, fear or anxiety.

Talking to someone about how you feel can stop anger building up. If you find it difficult to control your anger, look out for signs that you are getting angry, such as feeling tense. There are some things you can do to help deal with these feelings, such as:

- taking deep breaths and focussing on your breathing
- doing some exercise, such as brisk walking
- writing down or talking about how you are feeling with someone you trust.

#### Resentment

You may sometimes resent the person who is unwell. It is natural to feel like this. You may not have much time to do the things you enjoy, or to see your friends. The person with cancer may be emotional or withdrawn at times. They may not notice the things you are doing for them. Or they may be irritable, especially if they are in pain.

Sometimes, people take out their fear or anxiety on the people they know best. This can be difficult to deal with. If this happens to you, you may feel unwanted and resentful.

Try to talk to them and explain how you feel. You could choose a time when you are both having a good day. Or you may find it easier to <u>talk</u> about your feelings with someone else.

Try not to let any feelings of anger and resentment build up. Try to understand how the other person feels. This may stop your anger and irritation developing into an argument.

#### Guilt

Feeling guilty is common. You may feel guilty about:

- being well when the person you care about has cancer
- finding it hard to cope
- whether you are doing enough to help
- not having a good relationship with the person in the past
- feeling resentful if your own needs are not being met
- not being able to give as much time to other roles, such as being a parent, partner or employee.

When you feel guilty, it is normal to hide your feelings. This can make it difficult for people to understand what you are going through. If you feel guilty, talk about it with someone you trust. They may help you see things differently.

My biggest feeling was guilt. Because you're expected to look after your child – that's what mothers do. But his cancer was out of my control. I was powerless.

Tarsim, Amrik's mother

#### Loneliness

When someone has cancer, you may feel like you are on your own. You may feel that other people do not understand what you are going through. People may not know about all the things you have to do. It may help to explain this to them.

If you are caring for or supporting the person with cancer, you may find it more difficult to go out or enjoy your usual activities. If you have stopped working, you may not see the people you used to. You could ask someone else to spend time with the person with cancer, so you can have a break.

You can also speak to:

- your GP
- a social worker
- the cancer team at the hospital.

They can help you get an assessment of your needs, which could lead to you getting support. We have more <u>information for carers</u>. You may also find our booklet <u>Looking after someone with cancer</u> helpful.

#### **Tiredness and exhaustion**

You will probably feel tired or even exhausted at times. Supporting someone can be physically and emotionally tiring. Feeling tired all the time can be a <u>sign of feeling depressed</u>. If you can, try to do some things you enjoy. This could be a hobby or spending time outside. It is also important to have someone to talk to. Try to share your feelings and take care of yourself.

# Coping with your feelings

There are things you can do to help cope with any difficult feelings you have.

#### Showing your feelings

Everyone reacts differently and has different ways of showing their feelings when someone they care about has cancer. Some people find it easy to talk about their feelings. But not everyone is comfortable with this. You may show your feelings in other ways such as:

- doing helpful things for example, cooking a meal or doing household tasks
- bringing gifts
- sitting quietly with the person who has cancer.

Whatever you are feeling, it can help to talk about it with someone you trust. Sharing your feelings can help you accept the situation. It can help you work through your thoughts and remember what is important to you.

There may be times when you want to be left alone to sort out your thoughts and feelings. Tell others if there are times when you find it hard to talk.

We have more information about <u>talking about your feelings</u> and ways you can get support.

#### Writing your feelings down

If you find it difficult to talk, writing about your feelings can help you express how you feel. If you are worried, writing down what you are worried about can help you see things more clearly. It may also help with reducing stress levels. You could try:

- keeping a diary
- writing a blog
- using social media
- joining our **Online Community**.

You may want to write down how you are feeling, and what makes it worse or better. Some people find using a tool useful. Here is an example.

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

## Taking care of yourself

If you feel your emotions are building up, it is important to focus on your well-being. Doing things you enjoy can help release tension.

#### Be active

Regular exercise can help reduce stress. Even short walks are good. Physical activity can also help you keep fit. Exercising with others 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 doing it.

#### Keep to your usual routines

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

Maintaining hobbies, interests and social activities can also help you cope. If you are the main carer for someone with cancer, this might be hard to do. So it is important to get some help. We have more information about getting support if you are caring for someone with cancer. You may find our booklet Looking after someone with cancer helpful.

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



#### Find ways to relax

Learning how to relax can help you cope with your feelings. 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 therapy.

Some Macmillan Information and Support Centres offer free complementary therapies to people with cancer and their carers. Some charities offer complementary therapies for people affected by cancer. We also have more information in our booklet <u>Cancer and complementary therapies</u>.

If you need help learning how to relax, talk to your GP. They can tell you what help is available locally. You can also buy relaxation books or download an app. <u>Some organisations</u> have relaxation exercises online that you can download.

#### Get enough sleep

If worry and anxiety are keeping you awake, talking to someone may help. Writing down your worries before going to bed can help clear your mind. Breathing and relaxation exercises may also help reduce anxiety and stress.

There are things you can do to try and improve your sleep:

- Go to bed and get up at the same times every day.
- Be physically active during the day.
- Make sure your bedroom is not too hot, cold, light or noisy.
- Have a snack, such as fruit, before going to bed.
- In the evening, avoid drinks that contain caffeine or alcohol.
- In the hour before bed, try not to watch television or use a mobile phone, tablet or computer.

#### Be kind to yourself

Find time every day to do something you enjoy. This may be:

- watching your favourite TV show
- reading a magazine
- doing a hobby.

Try to find time to see friends or family members regularly. It is good to do this even if you do not feel like it. Spending time with other people can help improve your mood if you feel down.

Recognise your successes. This will help build your confidence as you get back into your usual routine.



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## Talking about your feelings

When someone you care about has cancer, it may help to talk about what is happening and how you are feeling. Talking to someone about how you feel can help you cope with your emotions. It is often the first step in helping you feel better.

Talking about your thoughts and feelings can:

- make you feel more supported and less anxious
- help you understand your feelings and make your thoughts clearer
- ease the pressure and make you feel better
- help you work out what is important to you
- help you make important decisions
- allow you to feel closer to your family, friends or partner.

It is a good idea to talk to someone other than the person with cancer. This will take some pressure off both of you. The person you talk to could be a partner, good friend or family member. Or you may find it easier to talk to someone you do not know, such as a religious or spiritual leader. Most hospitals have a spiritual care team or can give advice on how to find someone. If your feelings are affecting your everyday life, talking to a professional may help. You can ask your GP how to get counselling or see a psychologist. A counsellor or psychologist helps you talk about your feelings. They can help you recognise how the way you are thinking may affect your feelings.

We have more information you may find useful in our booklet Talking with someone who has cancer.

#### **Macmillan Support Line**

Our free confidential phone line is open 7 days a week, 8am to 8pm. Call us on <u>0808 808 00 00</u>. Our cancer support specialists can:

- answer questions about cancer or its treatment
- help you access benefits
- 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.

#### Counselling

Counselling can help you talk about your feelings. It is a type of talking therapy. At your appointment, you can talk to a trained counsellor who will listen and support you without judging you. Counsellors do not usually give advice or tell you what to do. The counsellor can help you:

- cope with changes in your relationships
- think about what is important to you
- deal with practical problems
- find new ways of coping.

You may be offered a:

- single session of counselling
- short course of sessions over a few weeks or months
- longer course that lasts for several months or years.

It can take a number of sessions, but you should slowly start to feel better with the help and support of your counsellor. Counselling can happen:

- face to face
- in a group
- over the phone
- by email
- online, by video call or through live chat services.

Some GPs, hospitals and cancer treatment centres have their own counsellors, or they can refer you to one. If your employer has an employee assistance programme (EAP), you can often contact a counsellor that way. Ask your employer for more information.

Counselling may be free, or you may need to pay for it. This is more likely if you see a counsellor long term. We have more information about talking therapies at <u>macmillan.org.uk/talking-therapies</u>

You can call our support line on <u>0808 808 00 00</u> for more information about finding a counsellor. You can also find information about private therapists or counselling on the <u>British Association for Counselling</u> <u>and Psychotherapy</u> website.



#### Support groups

Most areas of the UK have cancer support groups for carers, partners, family members and friends. These are usually led by people who may be in a similar position to you, sometimes with support from a healthcare professional.

Joining a support group can have many benefits, such as:

- gaining a sense of community and knowing that you are not alone
- listening to and learning from the experience of others
- doing things that make you feel better.

A group usually includes people who have experience of different types and stages of cancer. You may find this helps you see your own problems from a different point of view.

Our cancer support specialists on <u>0808 808 00 00</u> can tell you about support groups in your area. Or you can find support groups on our website at <u>macmillan.org.uk/supportgroups</u>

Some people find groups very helpful and get support from other members. But others find it uncomfortable to talk about personal issues with strangers. If support groups are not right for you, do not worry. There are other ways to get support.

We have more information about the different types of help available in our booklet <u>How are you feeling? The emotional effects of cancer</u>.

### **Online support**

If you use the internet, you can join an online support group or chat room. There are groups for:

- different types of cancer
- people to chat more generally about practical and emotional issues
- carers, family members and friends.

You can share your own thoughts and feelings by posting messages for others to read and reply to. Or you can just read other people's comments or posts. These messages can sometimes be helpful. They can also be sad and difficult to read. It may help to know that other people feel like you do. You may feel less alone and learn how other people cope.

This might be helpful for you if you find it difficult to talk face to face. Online groups are also easy to leave. You do not need to say why you are leaving.

Our Online Community offers this type of support. It is quick and easy to join. You can message people in our chat rooms, blog about your experiences, make friends and join specific support groups. Visit macmillan.org.uk/community

## Spiritual and religious support

Some people find that they have more spiritual or religious feelings during stressful times. This may be because they have questions about their faith and beliefs. Or it may be because they get comfort from their faith.

It might help you to talk to someone, such as a hospital chaplain or a religious leader. You can talk to them even if you are not sure about what you believe, or do not worship regularly. Spiritual and religious leaders are used to dealing with uncertainty. They are usually happy to listen, talk and give support and comfort.

We also have an online forum where you can share your thoughts and feelings. Visit <u>macmillan.org.uk/prayer-support-forum</u>



### Talking with the person who has cancer

It is natural for someone with cancer to have many feelings, such as fear, anger or frustration. Talking to other people can help them cope with their emotions. You can support the person with cancer by listening and talking with them. This is sometimes difficult, but the following things can make it easier.

#### **Tips for talking**

- Do not try to talk when one of you is busy or tired.
- Choose a time and place when you will be able to talk without being interrupted. But remember that sometimes, one of you may want to talk without planning it.
- Talking about feelings can be tiring. Set a limit on how long you will talk for. You could plan to do something nice together afterwards.
- When the person with cancer is talking, pay attention to what they are saying. Try to listen instead of thinking about what you are going to say next.
- Do not feel you have to talk about the cancer. Let your partner, family member or friend talk when they are ready.
- Respect the other person's feelings. They might want to talk about things you find hard to hear.
- It may not be helpful to tell the person about other people's stories. Cancer is different for everyone.

- Showing empathy is helpful. If they start to cry as they talk, you could say something like, 'I can see how upsetting this is for you'. Or you could simply sit with them and hold their hand.
- Try not to say that everything will be fine or encourage them to be positive. It is better to let people speak honestly about their feelings.
- Try to repeat back what you have heard. This helps you check you have understood things correctly and shows you are listening. You might say things like, 'So you mean that...?'.

#### Listening to someone

Listening is just as important as talking. We all like to feel we have been heard, especially when talking about something serious.

You may feel unsure about how to comfort the person you care for. But just listening to them when they want to talk can make a real difference. Silences do not need to be awkward. They give you a chance to focus your thoughts and reflect on what has been said. You do not need to have all the answers. Listening can be enough.

Listening and talking can help you both understand what the other person is feeling.

#### **Dealing with difficulties**

When you are supporting someone with cancer, you may both feel stressed. You may be angry or upset about the cancer, but this can be hard to express. People might express how they feel by getting angry or upset with the people they care about the most. You may argue or find it difficult to talk to each other.

There are things you can do to help manage this:

- Try to understand each other's feelings.
- Ask the other person what they think or how they feel. It might be different to what you thought.
- Allow each other to talk, even if you disagree with what the other person is saying.
- Avoid words like 'never' and 'always'. For example, do not say 'You never listen to me,' or 'I always call you'. These words can make the other person defensive.
- Talk to the other person about how what they do makes you feel. Instead of saying, 'You are thoughtless – I have to remember everything', try saying, 'I feel stressed when I have a lot to remember'.
- <u>Write down your feelings</u>. This can help you think about what is important to you and help you deal with some of your worries.

#### Not talking

It is also important to have conversations about things other than cancer. There will be times when you prefer to talk about everyday subjects such as friends, sport, hobbies or TV. Or sometimes you may just want to sit quietly together. It is okay not to talk all the time. "The best thing was when my friend surprised me by coming back from university for a visit. He didn't have to say much. It was just him talking about normal stuff and telling me funny stories. For a minute, it felt like everything was normal again. "

Amrik, diagnosed with Hodgkin lymphoma



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## **Telling other people**

When you first find out that someone you care about has cancer, you may both need time to adjust before telling anyone else. This is normal.

Telling other people about the diagnosis can be hard to begin with. But it means that you can all get the support you need.

The person with cancer may find it hard to tell others. It is their decision when to share their diagnosis. But if you are supporting them, you may also need support. Try talking to them about why it would help you to have support from other people. They might agree to you telling a trusted friend or family member. Or they might set a date for telling other people. For example, this may be after their test results come back.

Contacting family members or friends after test results or doctor's appointments can be tiring. If you do not feel you can do this yourself, you could ask someone that you both know and trust to do it. Ask the person with cancer what they want other people to know.

You can also contact us for support. We are available to talk over the phone or online when you need us. Call us on <u>0808 808 00 00</u> or join our Online Community at <u>macmillan.org.uk/community</u>

# Talking to children about cancer

Deciding what to tell children about cancer is difficult. It can be hard to know what to tell them, and you may be worried about upsetting them. Children do not always show their feelings, but their behaviour may change at home or at school.

Talking to children about the cancer can:

- help them understand what is going on
- help them feel supported
- prepare them for any changes.

It may also help with some of your own anxiety. For example, not telling them about hospital appointments may cause extra stress.

How much you tell children will depend on their age and how mature they are. It may be best to start by giving them small amounts of information, and then tell them more when they are ready. Teenagers usually understand what cancer is. Some will want to know more.

Whether they are teenagers or young children, talking about the cancer helps them cope.

#### **Teenagers**

It can help to encourage teenagers to ask questions, ask them their opinion and try to give them time to think about what is happening. They may have to, or want to, take on more responsibilities to help. This could be cooking meals or looking after younger children. This can be hard at a time when they may want more freedom and independence.

Sometimes teenagers may find it hard to talk about a cancer diagnosis. You can encourage them to talk to someone they trust, who can support and listen to them. This might be a grandparent, family friend, teacher or counsellor. They may also find support online. The website <u>riprap.org.uk</u> offers information and support for teenagers who have a parent with cancer.

We have more information in our booklet <u>Talking to children</u> and teenagers when an adult has cancer.

## **Getting support**

When someone you care about has cancer, it is important to remember that you do not have to cope on your own. Think about the kind of help you might need from a partner, other family members, friends and neighbours.

Try making a list of things that you need help with. For example, you might need help with:

- shopping
- taking the children to and from school
- collecting prescriptions.

People often want to do something, but are not sure how to offer their help. They may be waiting for you to ask. If you seem to be coping, your family and friends may not realise how much you need their help.

Some people may be able to help regularly for a few hours a week. Others may prefer to help every now and again. If someone offers something that is not the support you need, it is okay to say no.

Some people may want to help with practical things. Others may be good listeners and let you talk about your worries. It is important to remember that you may need emotional support. Having other people you can talk to can be really helpful.

You may find it helpful to use the <u>communication plan</u> to think about people who can offer you emotional and practical support. "Looking after somebody with cancer is difficult. I don't think anyone can manage without support. The more support you have, the better. And the same goes for the more informed you are. II

Tarsim, Amrik's mother

#### Who could help?

Think about the people in your life who can give you emotional and practical support. These are people you can depend on and who you trust. They might include a partner, friends, neighbours, family members, someone you work with or a health professional.

#### Making a communication plan

If there are lots of people involved in looking after the person with cancer, it may help to use a communication plan. Clear communication helps prevent confusion.

The plan could include:

- information that everyone needs to know
- who is doing each task
- who will speak to healthcare professionals, when they will do this, and what they will ask.

Sometimes, different people may speak to healthcare professionals. The person with cancer needs to tell their cancer team who they can share their information with.

You could use <u>this communication plan</u> to help you. We have an example that you can photocopy and use for different weeks. Or you may wish to make your own.

Carers UK also has an online and mobile app called Jointly, which you could use to co-ordinate things. Visit jointlyapp.com

#### 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			

Thursday	Friday	Saturday	Sunday
7pm: Stu taking Tamal to Scouts	9am: Stu calling physio to ask about exercises (tel 01)	10am: Pat doing the ironing	4pm: Liz visiting

# Making treatment decisions

When someone you care about has cancer, they may want to talk to you about their treatment options. Their doctor may have spoken to them about different options. Talking to them about these choices can help you understand their thoughts and feelings. But any decisions about treatment will be theirs. Visit <u>macmillan.org.uk/</u> <u>making-treatment-decisions</u>

I want to be informed and know why he's having a treatment and what's going to happen. It makes me feel more in control. It helps if you know what's happening.

Tarsim, Amrik's mother

### Finding out about cancer and treatments

Having information may make you or the person with cancer feel more in control. But remember, each of you might need a different amount of information. It can be useful to talk about what you are expecting, and what you need.

Some people want to know as much as possible about the cancer and treatment. Others only want to know enough to make decisions about treatment and how to cope with it. Some people choose not to know very much at all.

It is best to let your family member, friend or partner find out information when they are ready.

You and the person with cancer can get information from the following sources:

- We produce cancer information and have a list of <u>other reliable</u> <u>cancer information websites</u>.
- The best source of information about cancer treatment for the person with cancer is their healthcare team.
- Many hospitals have information centres, including <u>Macmillan</u> <u>Information and Support Centres</u>. You can often talk to someone face to face or pick up free booklets and leaflets.

Going to appointments is a good way for you to know what is happening. Before you go, ask the person with cancer how much they want you to be involved. They may be happy for you to ask questions, but it is best to check in advance.

Doctors and nurses cannot give you any information without permission from the person with cancer. The person with cancer can tell their doctor if they are happy for treatment information to be shared with named people. The doctor can then record this in their case notes. If the person with cancer is your partner, you do not have to be married or in a civil partnership to do this.

Having information about treatments may help you cope and support them better. If you think it would help, talk to the person with cancer. It may also be helpful for them, because:

- you could help them remember what the doctor said
- they could talk to you when making decisions
- you would know about possible treatment side effects
- with their permission, you could share information with family and friends.

#### Getting the right information

There is a lot of information available online and in print. Some of this information can be wrong or misleading. There are a lot of incorrect beliefs about cancer and cancer treatment. It is important to get information that comes from a source that you can trust, and that is up to date.

When you are reading information, it can help to look for the Patient Information Forum (PIF) Tick:



The PIF Tick means that the information is based on up-to-date evidence and follows strict guidelines. For example, this logo is on the back page of all our booklets, and on our website.

Some health information videos on YouTube also have a blue panel beneath the video. These panels are applied to videos that have been identified as reliable sources of information.

For example, videos from the NHS have the following blue panel beneath them:



We have information in a range of formats about cancer, cancer treatments and living with cancer. You can order our information by visiting <u>be.macmillan.org.uk</u> or by calling our cancer support specialists on <u>0808 808 00 00</u>.

You can also go to a local Macmillan Information and Support Centre to talk to experts and trained volunteers. They can give you support and answer your questions. You can search for groups or Information and Support Centres near you by visiting <u>macmillan.org.uk/in-your-area</u> or calling <u>0808 808 00 00</u>.

### If you disagree with a treatment decision

Sometimes you may not agree with your family member, friend or partner about treatment decisions. This can be hard for both of you. If this happens, you may find it useful to talk to the cancer doctor or specialist nurse together. This may help both of you to understand all the options.

The person with cancer has the right to make their own choices. Try to accept this and support their decision. Sometimes this can be difficult. It may help to <u>talk about your feelings</u> with someone else. Your GP or the person with cancer's specialist nurse may be able to arrange for you to see a counsellor.

## Work and money

If your close friend, family member or partner has cancer, you may want or need to give up work to look after them.

We have more information about your rights at work in our booklet Working while caring for someone with cancer that you may find helpful.

If you or the person with cancer needs to work fewer hours, this can affect your household income. You may be able to get benefits and financial support. We have more information in our booklet <u>Help with the cost of cancer</u>.

Macmillan's welfare rights advisers can offer advice to people with cancer, their family, and carers. They can help with accessing benefits and other types of financial support. They can look at your individual situation and find the best solutions for you.

You can also speak to one of our financial guides. They can advise you on your financial situation and give information about insurance and pensions. Getting advice early may save you a lot of time and worry.

Call the Macmillan Support Line on <u>0808 808 00 00</u>. You could also speak to your local <u>Citizens Advice</u> or <u>Advice NI</u>.

You can call our welfare rights advisers on <u>0808 808 00 00</u>, Monday to Friday, 8am to 8pm, and Saturday to Sunday, 9am to 5pm.





## After treatment

It might take time for the person you care about to recover from the effects of treatment. They may feel tired for several months. This is normal. They may also have permanent changes to get used to.

It may take a while for both of you to deal with your feelings about everything you have been through.

They may not need any more treatment because the cancer has been cured. Or they may be living with cancer and the possibility that they will need more treatment in the future.

If your roles changed during cancer treatment, they may slowly return to how they were before. Or you may want to do things differently.

We have more information in our booklet <u>Life after cancer treatment</u> that you might find helpful.

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

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## When treatment is no longer working

If the cancer comes back or has spread, there may come a time when treatment cannot control it. The person with cancer may be told that they only have a while to live.

They may become ill over many months. Or they may become ill more quickly. It is not possible to know when someone may die.

#### Your feelings

Finding out that someone's cancer cannot be cured can be very difficult to cope with. It can be very hard for family members and friends, as well as the person with cancer. You will have lots of different emotions and may need support to deal with them. These feelings and emotions will also change over time.

You might find it hard to believe that the cancer cannot be cured. After a few days, the shock and disbelief may be replaced by other feelings. These may make it difficult for you to think clearly. You might need some time with a partner, family member or close friend to cope with the news yourself. It may also help to talk to a counsellor. Macmillan's cancer support specialists can also provide advice and support. You can call them on <u>0808 808 00 00</u>. Or visit our Online Community at any time of the day or night at <u>macmillan.org.uk/</u> <u>community</u>

Try to stay connected with the person with cancer and keep communicating. You can provide support and reassurance now more than ever.

If the person with cancer is not going to get better, you might have strong feelings about your relationship with them. It is important to try and keep your relationship as normal as possible. When you do not know what to say, a hug or holding hands can be very comforting. Visit macmillan.org.uk/advanced-cancer





### **Partners**

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## If your partner has cancer

When your partner has cancer, it can feel like everything has changed. You may have many different feelings, including shock, grief, anger and anxiety.

You and your partner will probably find your own ways of coping with your feelings. Even if you have different ways of dealing with the illness, try to understand and support each other.

You might try to protect them by not being honest about your fears and concerns. But talking about your feelings can make it easier for your partner to be honest about theirs. It may help you understand each other and feel closer.

Here are some tips on how you can support your partner:

- Talk to each other about how you feel and what is important to you. Some people find this easier to do while doing another activity, such as going for a walk.
- Be aware that you may both have many difficult feelings and that these are normal.
- Make time for each other. Do things you enjoy and talk about things other than cancer.
- Work out how you cope as a couple. For example, you might laugh or cry together to help release tension.
- Ask for support and accept help from friends and family members.
- Try to keep to routines. This can help life feel more normal.

"Normally, Kate and I talk about everything going on in our lives. But with the cancer, she wouldn't talk. She'd talk about some things and about her days at work, but she wouldn't talk about how she was really feeling. ...

Mark, whose fiancée was diagnosed with Hodgkin lymphoma

#### **Relationship changes**

You may find your relationship changes because of the cancer. This may not happen straight away, but it can happen over time. Illness can add a lot of pressure to a relationship. It changes your lives and your plans.

Lots of couples feel more stressed than usual when one person has cancer. You may be coping with:

- difficult feelings
- changes in your roles (opposite)
- making decisions
- deciding what to tell other people, including any children
- changes with intimacy or in your sex life
- worries about <u>money or work</u>.

Your partner might seem different. This could be because they are very stressed, in pain, or tired. You might find you argue more because of the emotions you are both feeling.

Sometimes you may feel closer and that you love each other more. But not all relationships become stronger. Cancer sometimes causes relationship problems or makes existing problems worse. Organisations such as <u>Relate</u>, <u>Relate NI</u> or <u>Relationships Scotland</u> can help you with this.

## Changes in your role

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

During and after treatment, the person with cancer may not have the energy to do the things they did before. You may have to do these tasks. For example, you may have to do more work around the house or manage the finances. If your partner was the main earner, you may need to start working or increase your hours. This can be difficult for both of you.

If you have children, you will also be thinking about how the diagnosis may affect them and <u>how to deal with this</u>.

Making changes at work or at home can be tiring. It may mean you have less time for things like:

- spending time with friends or family
- work
- hobbies.

This can lead to resentment, or you may feel you are not doing enough. This can lead to guilt.

These changes can be hard for you and your partner. It is important to talk to each other about how you feel and what matters to you.

You may feel helpless or unsure about how to comfort your partner. You may also worry about how you will cope with caring for them.

These are normal reactions. Remember, although you have not been diagnosed, you are going through your own experience of cancer. It is okay to ask for help for yourself as well as for your partner.

#### Supporting your partner

Try to be yourself and live as normally as possible. Behaving differently may make your partner feel more aware of the cancer.

It can help to ask your partner what support they would like and find useful. This makes sure you help where it is most wanted and needed. It can also help you avoid misunderstandings.

Here are some tips:

- Let your partner know that you are there to help, but they are still in control.
- Make a point of asking whether they need you to do something specific.
- Let them take as much responsibility as they can or want to for their own care, family issues, finances and other decision-making.

#### Supporting each other

You will have a lot to cope with. Many couples find it helps to work together as a team.

It may help to write down a list of priorities. Together, you can plan what things are most important and what help you might need in different areas. Try to find ways you can help each other so that you both feel cared for.

It is important to think about what support you can get from other people. Family and friends often want to help. They may be able to help you with some everyday tasks you no longer have time for. We have more information about <u>getting support</u> from your friends and family.

#### Making time for you as a couple

Doing things that you both enjoy is a way of staying close as a couple and can help you cope with changes better.

Many people prioritise the things they think they should do, such as household tasks. Because of this, they may not have the energy to do things that they want to do. It is important to make time for doing things you enjoy. It can remind you what brought you together as a couple. And it may help to balance out the impact of the cancer.

## Your sex life

Cancer and its treatment may affect intimacy and sex between you and your partner. But it does not have to mean you stop having sex or being intimate. Many people with cancer still have sexual feelings and enjoy their sex life, whether they are in a relationship or not.

If your partner is having treatment, you may both be tired or stressed. You might be focused on getting through the treatment.

If your partner has had surgery or is in pain, you may worry about hurting them during sex. Or you may feel guilty for wanting to have sex when your partner is not well.

Fears about cancer might put you off having sex. But cancer cannot be passed to another person through sex or by being intimate, such as when kissing. And having sex will not affect how well a cancer treatment works.

Changes in your partner or in your relationship can also affect your desire for sex. Some people find it difficult to be a carer for their partner and still think about them sexually. Coping with a diagnosis of cancer in your partner can lower your sex drive.

Sex and being intimate can feel less important for lots of reasons. For some people, sex becomes more important. Try to talk about it together and listen to each other.

We have more information at macmillan.org.uk/sex-and-cancer

#### Possible effects on your sex life

Your sex life can be affected by:

- your partner having physical effects of cancer or its treatment
- how your partner thinks and feels about their body this is called body image
- emotional changes in you or your partner, such as depression or anxiety
- changes in your relationship.

Some cancer treatments may directly affect the ability to have sex or orgasms. This can happen if a treatment affects the sex organs or their nerves and blood vessels. It can also happen if your partner has a treatment that affects the balance of sex hormones in their body.

Treatments that may have this effect include:

- hormonal therapy
- radiotherapy to the area between the hips (pelvis)
- surgery to the area between the hips.

We have more information on how treatments can affect sex life and what can help in our booklet <u>Cancer and your sex life</u>.

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

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## If you or your partner are LGBTQ+

If you or your partner are LGBTQ+, you may have additional worries.

You may have questions about whether this will affect their cancer treatment. Sexual orientation and gender identity should not affect access to the right healthcare. Their healthcare team should offer care, support and information that meets their needs. But we know that sometimes LGBTQ+ people may face extra challenges in getting the right help.

The cancer may make your relationship public for the first time. For example, you may tell healthcare professionals during hospital appointments, or when asking questions about impacts. You might be worried that professionals will assume things about your relationship, or not recognise you as a couple. It can be hard to know how to deal with this.

If you are a same-sex couple, it might help for your partner to tell their doctor or specialist nurse about their sexuality. This may make it easier for you to go to appointments with them. You may both feel more supported if other people know about your relationship.

If your partner is transgender (trans), the cancer might bring up issues about a gender they do not identify as. This can be very difficult for your partner, and for you, to cope with. Talking to the cancer doctor or specialist nurse about this can help. If you or your partner are not getting the support you need, it is important to remember that the law protects you. You should not be treated any differently because of how you identify.

Sometimes talking about these issues can help you cope. There are organisations that can offer support. You can also call us on <u>0808 808 00 00</u>. Our cancer support specialists are experts in supporting anyone who is affected by cancer. Or you could talk to people in the Online Community forum for lesbian, gay, bisexual and trans people. Visit <u>macmillan.org.uk/community</u> There are other <u>organisations that can help</u>.

We have more information about LGBTQ+ people and cancer treatment in our booklet LGBTQ+ people and cancer.

We have more information sspecifically about trans and non-binary people and cancer on our website. Visit <u>macmillan.org.uk/trans-and-non-binary</u>



## Families

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## If your family member has cancer

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

Although all families deal with stress or tension at times, a cancer diagnosis may test a family in new ways. You may have many <u>different</u>. <u>feelings</u>, including shock, grief, anger and anxiety. As families or couples come to terms with a diagnosis, it is common to feel upset. There may be arguments. It is important to talk about your worries and anxieties with each other. Do not be afraid to ask questions.

It is also important to be honest with each other about how you feel. Your family can provide emotional support. Talking to each other about what is happening can be an important way of helping you all cope. Not talking could cause tension. "Some days I feel down. Sometimes I'm lonely and feel it would be nice to get more help. But I feel really good when my dad feels good. Sometimes it takes its toll, and that's okay – the better days are worth it. "

Amy, whose father was diagnosed with prostate cancer

## Changes in your role

When someone in your family is diagnosed with cancer, the role you have and your relationship with the person may change.

During and after treatment, the person with cancer may not have the energy to do the things they did before. You and other family members may do these tasks. Or you may have to adjust to new roles. Making changes can be tiring. It may mean you have less time for things like:

- spending time with friends or family
- work or school
- hobbies.

If life is becoming very busy, it may help to write down a list of priorities. As a family, you can plan what things are most important. Try to split any tasks between family members so you can support each other.

It is common to feel you should reject offers of help from other friends and family. But do not be afraid to ask for help. It can lessen some of the burden on you. The person helping may also feel good knowing they have made a difference.

It is important for the person with cancer to have a role, too. They may want to support other family members, as well as getting support themselves. You might find using a communication plan helps to organise everyone and prevent confusion. We have an <u>example</u> <u>of this</u>.

### If your parent has cancer

If your parent has cancer, you may find yourself looking after them for the first time. For example, you might help them wash or get dressed.

Having to care for your parent in ways you have not done before might cause lots of different emotions. You may feel anxious, embarrassed or resentful. Your parent might feel these emotions, too. You and your parent could have a conversation about who does what and who makes decisions. This will help to support you both and reduce anxieties.

There may be practical solutions, too. For example, if you are helping your parent wash, they might want to wear a dressing gown. This can help them feel less exposed or embarrassed.

It can help to share responsibility for looking after your parent. This might be with siblings if you have them, or other family members. It can help to split the responsibilities clearly, so each person knows what to do. You could use a <u>communication plan</u>.

If you need help with caring for your parent, there are <u>organisations</u> <u>that can support you</u>. We also have more information at <u>macmillan.org</u>. <u>uk/carer-support</u>

### **Young carers**

If you are under the age of 18 and looking after someone with cancer, you are a young carer. It may be your mum or dad who has cancer, or your brother or sister. It could be a friend, grandparent, aunt or uncle. This can be very difficult and may affect your life in many ways. We have separate information for young carers at <u>macmillan.org.uk/young-carers</u>





If your friend has cancer

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# If your friend has cancer

When a friend is diagnosed with cancer, you may have many different feelings. These may continue as your friend goes through treatment. If they are a very close friend, you might find their diagnosis particularly difficult to cope with.

Your friend may have support from their family or a partner. But you can support them too. Talk to your friend and find out how you can help. Perhaps you can do practical things, such as going to appointments with them or spending time with them when family members are unable to.

Your friend might need someone to talk to. They may 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. You might worry about saying the wrong thing and avoid certain topics. We have more information in our booklet <u>Talking with someone who has cancer</u>. This may help you feel more confident talking with your friend.

Your friend may not have a family supporting them, but they may have a group of very supportive friends. This can sometimes cause issues when friends do not agree on what needs to be done and who will do it. If this happens, it might help for you all to sit down and talk with the person with cancer. You can discuss the situation and ask them what they want. You may find our <u>communication plan</u> a useful way of organising who does what. Even if you have difficulties, you might find you all appreciate each other more and become better friends. If your friend does not have anyone else to help them, you may feel responsible for their care. It is not only partners or family members who become carers. If you provide a lot of support to someone with cancer, you may be a carer. This means you could get some support to help you do your caring role.

If your friend starts to need more help, you might feel pressured to do more for them. You do not have to do anything you do not feel comfortable with. Local authorities and health and social care trusts are responsible for arranging services that people need. We have more information about the <u>help that is available</u>.

If you are a friend of someone with cancer, we are here for you. Call us for information or support.

Call the Macmillan Support Line free on 0808 808 00 00, 7 days a week, 8am to 8pm.







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"We spend time together in the garden. We buy snacks and watch films in the living room.
I love helping my dad and I love seeing how little he has to worry when we're together. II

Amy, whose father was diagnosed with prostate cancer

# **Being a carer**

You are a carer if you give any unpaid help and support to someone with cancer who could not manage without your help. Caring can mean:

- emotional support
- helping with daily tasks
- being a good listener
- helping with personal care such as bathing and dressing
- driving to appointments
- talking to healthcare professionals on the person's behalf.

Many partners, family members and friends of people with cancer become their carer. We have more information about this in our booklet <u>Looking after someone with cancer</u>.

Lots of young people are carers too. If you are aged under 18 and looking after someone with cancer, you are a young carer. Visit <u>macmillan.org.uk/young-carers</u>

Being a carer can be rewarding. But the physical and emotional demands can be difficult. You might have a lot of <u>different emotions</u>. Recognising you are a carer can be an important step in getting the extra help and support you need.

# **Getting support**

As a carer, you may feel you have to do everything yourself. But there are lots of different types of support available. Getting support and having someone you can talk to about how you feel might help you cope. Try to accept help as much as you can. This can help the person you are caring for too.

# Help from family and friends

Family and friends may be able to help you with your caring responsibilities. This means you have <u>time to take</u> <u>care of yourself</u> as well as the person you are caring for.

It is helpful to think about the kind of help you might need from others. You could start by making a list of tasks you need help with. This might be doing grocery shopping, collecting prescriptions or taking children to school. Try to talk openly about what you are doing and how they can help.

Sometimes it is helpful to have a record of who is helping, when they are coming and what they are doing. You could use a:

- communication plan
- rota for the different days of the week
- digital shared calendar so that everyone can see it and add details.

<u>Carers UK</u> also has an online and mobile app called Jointly, which you could use to coordinate who is doing what. Visit jointlyapp. <u>com</u>

### **Carer's assessment**

Any adult who cares for another adult can have a carer's assessment. This is an assessment of your needs. In Scotland, it may be called an adult carer support plan. In Wales, it is called a carer's needs assessment. We use the term 'carer's assessment'.

A carer's assessment is done by a social worker. The assessment may help you get practical support. This could mean equipment to help with caring or help from a paid carer. To arrange an assessment, contact your local adult social services, social work department or health and social care trust. You can find them in your local phone book or online.

We have more information at macmillan.org.uk/carer-support

### Needs assessment

You can also help make sure the person with cancer has a needs assessment. To ask for a needs assessment, contact the adult social care service at your local council. You can call them or do it online. Search <u>gov.uk</u> for 'needs assessment social services'. A social worker or occupational therapist (OT) usually does the assessment. They consider what support the person with cancer may need.

We have more information you may find useful in our booklet Looking after someone with cancer.

# **Breaks from caring**

When you are looking after someone with cancer, you might need to take time off. If you do not take a break, you could become very tired, stressed or unwell. These breaks are sometimes called respite care.

There are different ways to get respite care, including:

- having a <u>carer's assessment</u> this is to see if you can get services that allow you to have time away from caring
- contacting a <u>carers' organisation</u> that offers free respite care

   they may be able to give you a temporary break from caring
   or offer other support.

Sometimes the person with cancer may not understand that you need a break. But it is good for both of you to have some regular time apart. You will have more energy when you return.

Call the Macmillan Support Line free on 0808 808 00 00, 7 days a week, 8am to 8pm.



## Making time for yourself

When you are looking after someone with cancer, it is important to look after yourself too. Taking time to focus on your own health and well-being will also benefit the person you care for. We have more information in our booklet <u>Looking after someone with cancer</u>.

Try to have regular breaks to do something you enjoy. This could just be:

- going for a walk
- meeting friends
- going for a meal.

Keep doing the little things you enjoy too. This will help you through any difficult times. For example, you could buy your favourite magazine and give yourself time to read it. Or make time to practise your hobby.

Make time to look after your own physical and mental health. It is important to talk to your GP if you have any concerns about your health.



# Work and money

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

You have rights at work that may make it easier to keep working while you are caring. These include the right to:

- ask for flexible working arrangements
- take unpaid time off in an emergency.

You may also be able to get financial support from the government.

If you would like more information, you may find these booklets useful:

- Working while caring for someone with cancer
- Your rights at work when you are affected by cancer
- <u>Help with the cost of cancer</u> there is also an easy read option called <u>Claiming benefits when you have cancer</u>.

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

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# Your feelings

Looking after someone you care about can cause many <u>different feelings</u> <u>and emotions</u>. You may find that caring for your partner, family member or friend brings you closer together. But sometimes it can feel very difficult and you may feel alone.

Try to talk about your feelings with your family or friends, or with the healthcare team. If you are very tired or stressed, talk to your GP. They may be able to suggest some things that could help.

We have more information about some of the challenges carers face and how they cope in our booklet <u>Looking after someone with cancer</u>.

It may help to talk to other people in a similar situation. You could do this in the carers' group on our <u>Online Community</u>. You can also find out about support groups in your area by visiting <u>macmillan.org.uk/</u><u>inyourarea</u> or calling us on <u>0808 808 00 00</u>.

When I'm looking after Amrik, I do things for him – like making him his favourite foods. You do feel useless because there's nothing else you can say. He's an adult, not a child you can fuss over.

Tarsim, Amrik's mother



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# **About our information**

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

### Order what you need

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

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

### **Online information**

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

### Other formats

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

audiobooks

• interactive PDFs

- Braille
- British Sign Language
- large printtranslations.

• easy read booklets

Find out more at macmillan.org.uk/otherformats

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

#### The language we use

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

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

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

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

To find out more about how we produce our information, visit <u>macmillan.org.uk/ourinfo</u>



# Other ways we can help you

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

#### Talk to us

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

#### Macmillan Support Line

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

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

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

You can also email us, or use the Macmillan Chat Service via our website. You can use the chat service to ask our advisers about anything that is worrying you. Tell them what you would like to talk about so they can direct your chat to the right person. Click on the 'Chat to us' button, which appears on pages across the website. Or go to <u>macmillan.org.uk/</u> <u>talktous</u> If you would like to talk to someone in a language other than English, we also offer an interpreter service for our Macmillan Support Line. Call <u>0808 808 00 00</u> and say, in English, the language you want to use. Or send us a web chat message saying you would like an interpreter. Let us know the language you need and we'll arrange for an interpreter to contact you.

#### **Macmillan Information and Support Centres**

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

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

#### Help with money worries

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

#### **Financial guidance**

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

#### Help accessing benefits

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

#### Help with energy costs

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

#### **Macmillan Grants**

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

Call us on <u>0808 808 00 00</u> to find out more about Macmillan Grants.

#### Help with work and cancer

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

#### Work support

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

#### Talk to others

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

#### Support groups

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

#### **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 <u>macmillan.org.uk/community</u>

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

#### Macmillan healthcare professionals

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

# Other useful organisations

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

#### General cancer support organisations

#### **Black Women Rising**

#### www.blackwomenrisinguk.org

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

#### **Cancer Black Care**

#### Tel 0208 961 4151

#### www.cancerblackcare.org.uk

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

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

#### Helpline 0800 783 3339

www.cancerfocusni.org

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

#### **Cancer Research UK**

#### Helpline 0808 800 4040

www.cancerresearchuk.org

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

#### **Cancer Support Scotland**

#### Tel 0800 652 4531

#### www.cancersupportscotland.org

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

#### **Macmillan Cancer Voices**

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

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

#### Maggie's

#### Tel 0300 123 1801

#### www.maggies.org

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

#### **Penny Brohn UK**

#### Helpline 0303 300 0118

www.pennybrohn.org.uk

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

#### Riprap

#### www.riprap.org.uk

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

#### Tenovus

#### Helpline **0808 808 1010**

#### www.tenovuscancercare.org.uk

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

#### General health information

#### Health and Social Care in Northern Ireland

#### www.northerntrust.hscni.net

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

#### NHS.UK

#### www.nhs.uk

The UK's biggest health information website. Has service information for England.

#### NHS 111 Wales

<u>111.wales.nhs.uk</u> The NHS health information site for Wales.

#### **NHS Inform**

Helpline **0800 22 44 88** <u>www.nhsinform.scot</u> The NHS health information site for Scotland.

#### **Patient UK**

#### www.patient.info

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-related and illness-related websites.

#### Counselling

#### British Association for Counselling and Psychotherapy (BACP)

#### Tel 0145 588 3300

#### www.bacp.co.uk

Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on the 'How to find a therapist' page.

#### Relate

#### www.relate.org.uk

Offers a range of services to help with couple and family relationships. Available face to face, by phone and online.

#### **Relate NI**

#### www.relateni.org

Offers counselling services to support people and their relationships across Northern Ireland. Available face to face, by phone and online.

#### **Relationships Scotland**

#### Tel 0345 119 2020

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

Provides relationship counselling, family mediation, child contact centres and many other forms of family support services across all of mainland and island Scotland.

#### UK Council for Psychotherapy (UKCP)

#### Tel 0207 014 9955

#### www.psychotherapy.org.uk

Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

#### Emotional and mental health support

#### Mind

Helpline 0300 123 3393

www.mind.org.uk Provides information, advice and support to anyone with a mental health problem through its helpline and website.

#### Samaritans

Helpline **116 123** Email **jo@samaritans.org** <u>www.samaritans.org</u> Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

#### Financial support or legal advice and information

#### Advice NI

Helpline 0800 915 4604

www.adviceni.net

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

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

Helpline **0800 232 1271** Textphone **0289 031 1092** 

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

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

#### **Carer's Allowance Unit**

Tel 0800 731 0297

Textphone **0800 731 0317** 

www.gov.uk/carers-allowance

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

#### **Citizens Advice**

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

#### England

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

#### Scotland

Helpline **0800 028 1456** <u>www.cas.org.uk</u>

#### Wales

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

#### **Civil Legal Advice (CLA)**

Helpline **0345 345 4345** Textphone **0345 609 6677** 

www.gov.uk/civil-legal-advice

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

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

#### Tel 0800 587 0912

Textphone 0800 012 1574

www.nidirect.gov.uk/contacts/disability-and-carers-service Manages Disability Living Allowance, Attendance Allowance, Carer's Allowance and Carer's Credit in Northern Ireland. You can apply for these benefits and find information online or through its helplines.

#### GOV.UK

#### www.gov.uk

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

#### Jobs and Benefits Office Enquiry Line Northern Ireland

Helpline **0800 022 4250** Textphone **0800 587 1297** 

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

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

#### Law Centres Network

#### www.lawcentres.org.uk

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

#### Local councils (England, Scotland and Wales)

Your local council may have a welfare rights unit that can help you with benefits. You can also contact your local council to claim Housing Benefit and Council Tax Reduction, education benefits, and for help from social services (the Social Work department in Scotland).You should be able to find your local council's contact details online by visiting:

#### England

www.gov.uk/find-local-council

#### Scotland

www.cosla.gov.uk/councils

#### Wales

www.gov.wales/find-your-local-authority

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

Tel 0300 123 3233

#### **Money Advice Scotland**

#### www.moneyadvicescotland.org.uk

Use the website to find qualified financial advisers in Scotland.

#### **NI Direct**

#### <u>www.nidirect.gov.uk</u>

Has information about benefits and public services in Northern Ireland.

#### **Northern Ireland Housing Executive**

#### Tel 0344 892 0902

#### www.nihe.gov.uk Offers help to people living in socially rented, privately rented and owner-occupied accommodation.

#### StepChange Debt Charity

#### Tel 0800 138 1111

#### www.stepchange.org

Provides free debt advice through phone, email, the website and online through live chats with advisers.

#### Unbiased.co.uk

#### Helpline **0800 023 6868**

#### www.unbiased.co.uk

You can search the website for qualified advisers in the UK who can give expert advice about finances, mortgages, accounting or legal issues.

# Equipment and advice on living with a disability or sensory loss

#### **British Red Cross**

#### Tel 0344 871 1111

#### www.redcross.org.uk

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

#### **Disability Rights UK**

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

#### www.disabilityrightsuk.org

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

#### Living Made Easy

#### Helpline 0300 123 3084

#### www.livingmadeeasy.org.uk

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

#### **Motability Scheme**

#### Tel 0300 456 4566

#### www.motability.co.uk

The scheme enables Disabled people to exchange mobility allowances they have as part of benefits (including the enhanced rate mobility component of Personal Independence Payment) to lease a new car, scooter or powered wheelchair.

#### Royal National Institute of Blind People (RNIB)

#### Helpline **0303 123 9999**

www.rnib.org.uk

Offers support and advice to blind and partially sighted people in the UK.

#### Royal National Institute for Deaf People (RNID)

### Helpline **0808 808 0123** Textphone **0808 808 9000** SMS **0780 000 0360**

#### www.rnid.org.uk

Offers support and practical advice to people in the UK with hearing loss and tinnitus.

#### Scope

#### Helpline **0808 800 3333** Textphone **18001 0808 800 3333**

#### www.scope.org.uk

Offers advice and information on living with disability. Also supports an independent, UK-wide network of local Disability Information and Advice Line services (DIALs) run by and for Disabled people.

#### Support for young people

#### **Teenage Cancer Trust**

#### Tel 0207 612 0370

#### www.teenagecancertrust.org

A UK-wide charity devoted to improving the lives of teenagers and young adults with cancer. Runs a support network for young people with cancer, their friends and families.

#### **Young Lives vs Cancer**

#### Tel 0300 330 0803

www.younglivesvscancer.org.uk

Provides clinical, practical, financial and emotional support to children with cancer and their families in the UK.

#### **Youth Access**

#### Tel 0208 772 9900

#### www.youthaccess.org.uk

A UK-wide organisation that provides counselling and information for young people. Find your local service by visiting <u>youthaccess.org.uk/</u><u>find-your-local-service</u>

#### Support for older people

#### Age UK

#### Helpline 0800 678 1602

#### www.ageuk.org.uk

Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

#### LGBT-specific support

#### **LGBT Foundation**

#### Tel 0345 330 3030

#### <u>lgbt.foundation</u>

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

#### **OUTpatients (formerly Live Through This)**

#### www.outpatients.org.uk

A safe space for anybody who identifies as part of the queer spectrum and has had an experience with any kind of cancer at any stage. Also produces resources about LGBT cancer experiences. OUTpatients runs a peer support group with Maggie's Barts.

#### Support for carers

#### **Carers Trust**

#### Tel 0300 772 9600

#### www.carers.org

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

#### **Carers UK**

#### Helpline 0808 808 7777

#### www.carersuk.org

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

#### Advanced cancer and end of life care

#### **Hospice** UK

#### Tel 0207 520 8200

#### www.hospiceuk.org

Provides information about living with advanced illness. Also provides free booklets and a directory of hospice services in the UK.

#### **Marie Curie**

#### Helpline **0800 090 2309**

#### www.mariecurie.org.uk

Marie Curie nurses provide free end of life care across the UK. They care for people in their own homes or in Marie Curie hospices, 24 hours a day, 365 days a year.

#### **The Natural Death Centre**

#### Helpline **0196 271 2690**

#### www.naturaldeath.org.uk

Offers independent advice on aspects of dying, funeral planning and bereavement.

#### **Bereavement support**

#### **Childhood Bereavement Network**

#### Tel **0207 843 6309**

www.childhoodbereavementnetwork.org.uk

A UK-wide group of organisations and individuals working with bereaved children and young people. Has an online directory where you can find local services.

#### **Cruse Bereavement Support**

#### Helpline **0808 808 1677**

#### www.cruse.org.uk

Provides bereavement support to anyone who needs it across the UK. You can find your local branch on the website.

#### **Hope Again**

#### Helpline 0808 808 1677

#### www.hopeagain.org.uk

Designed for young people by young people, Hope Again is part of Cruse Bereavement Support. It supports young people across the UK after the death of someone close. Offers a private message service from the website.

#### Widowed and Young (WAY)

#### Tel 0300 201 0051

#### www.widowedandyoung.org.uk

A UK-wide support network to help young widows and widowers rebuild their lives after the death of a partner.

#### Winston's Wish

#### Helpline 0808 802 0021

#### www.winstonswish.org.uk

Helps bereaved children and young people throughout the UK readjust to life after the death of a parent or sibling.

# Your notes and questions


#### Disclaimer

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

#### Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by members of Macmillan's Centre of Clinical Expertise.

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

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

#### Sources

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

National Institute for Health and Care Excellence (NICE). Supporting adult carers. NICE guideline [NG150]. Published 22 January 2020. Available from www.nice.org.uk/guidance/ng150 [accessed Jan 2023].

Zeng Q , Ling D, Chen W, et al. Family Caregivers' Experiences of Caring for Patients with Head and Neck Cancer. A systematic Review and Metasynthesis of Qualitative Studies. Cancer Nursing. 2023; 46,14–28. Available from https://doi.org/10.1097/ ncc.00000000000000006 [accessed Jan 2023].

### Can you do something to help?

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

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

#### 5 ways you can help someone with cancer

1. Share your cancer experience

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

#### 2. Campaign for change

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

#### 3. Help someone in your community

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

#### 4. Raise money

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

#### 5. Give money

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

#### Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

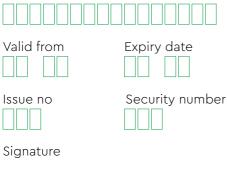
Email

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



Date /

#### Do not 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 would 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

This booklet is about coping with your feelings when someone you care about has cancer. It gives suggestions for helping yourself and getting the support you need.

This booklet is for anyone who cares about someone with cancer, including partners, family members and friends.

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

For information, support or just someone to talk to, call **0808 808 00 00** or visit **macmillan.org.uk**  Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

Need information in different languages or formats? We produce information in audio, interactive PDFs, easy read, Braille, large print and translations. To order these, visit

macmillan.org.uk/otherformats or call our support line.



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