

Coping with advanced cancer



About this booklet

This booklet is for people who have cancer that has come back or spread. This is sometimes called advanced cancer.

There is information about some of the concerns you may have and advice about ways of coping. It talks about treatments and your feelings. It also has practical information about getting help and support.

We hope it helps you deal with some of the questions or feelings you may have.

We cannot give advice about the best treatment for you. You should talk to your doctor, who knows your medical history.

How to use this booklet

This booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the contents list on page 3 to help you.

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

On pages 86 to 95, there are details of other organisations that can help.

There is also space to write down questions and notes for your doctor or nurse (page 96).

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

For more information

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

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

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

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

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What does advanced cancer mean?

Advanced cancer is cancer that has spread or come back. It is usually used to describe cancer that cannot be cured.

Doctors sometimes use other words to describe advanced cancer. For example, they may use metastatic or secondary cancer to describe cancer that has spread to other parts of the body. Depending on the cancer type, it may also be called stage 4 cancer.

Some people find out they have advanced cancer when they are first diagnosed. For others, the cancer may spread or come back after treatment.

Can advanced cancer be treated?

Treatment may help to control the cancer or manage its symptoms. Your cancer doctor or specialist nurse will explain what treatments may be helpful. This can depend on:

- the type of cancer
- the areas of the body affected
- any symptoms you have.

Treatment for advanced cancer may include:

- surgery
- radiotherapy
- chemotherapy
- hormonal therapies
- targeted therapies
- immunotherapies
- a combination of treatments.

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You may have treatment to control the cancer. Sometimes, treatment can control advanced cancer for a long time. This can sometimes be years. During this time, you may be able to continue with your life and do the things that are important to you.

Sometimes it is not possible to stop the spread of the cancer. You will still have treatment to manage symptoms and help you feel as well as possible. This is called supportive or palliative care. This may include:

- medicines to help manage symptoms such as pain or sickness (nausea)
- radiotherapy to help reduce pain or bleeding caused by cancer
- emotional support to help you cope with any difficult feelings you have.

How you may feel

It is common to have many different reactions and feelings when you find out that cancer has come back or spread. You may feel shocked and find it hard to understand. You may feel angry or frightened about the future.

These feelings can be difficult. They usually become easier to manage over time and as you start making decisions and plans. We have information about coping with difficult feelings on pages 30 to 39. You might also find our booklet **How are you feeling? The emotional effects of cancer** helpful (page 80).

Knowing that your illness may not be curable might help you think about:

- what is important to you
- how you want to live your life.

You may want to focus on things you enjoy or want to achieve.

It might also make you think about planning ahead. If you feel ready to do this, you may want to write down your wishes.

This might include:

- what is important to you
- how and where you would prefer to be cared for.

This is called advance care planning (pages 67 to 71).

Making decisions about treatment

You may want to find out about all your options before making treatment decisions. Your doctor can usually give you information on how well a treatment may work. They will consider what is important to you and how treatment may affect you. This will help you both decide the best treatment for you.

You may choose to have one treatment instead of another because:

- the side effects are different
- it means you will spend less time at the hospital.

You will usually have some time to think about your treatment options. It can help to discuss these with family or friends, as well as the doctors and nurses looking after you. Your cancer doctor will have the most up-to-date information about treatments. If you have a specialist nurse, they can also explain the possible benefits and side effects of treatment. It is important to make the treatment decision that feels right for you.

You may have questions you want to ask your cancer doctor or specialist nurse. Before your next appointment, it can help to make a list of any questions. You may also want to write down your thoughts about the benefits and disadvantages of a certain treatment.

You may find it useful to record the discussion with your cancer doctor, so you can remember what you both said. If you want to do this, make sure you ask them first. Recordings can also be helpful for family or friends to listen to. This means you do not have to keep repeating information. You may find it helpful to take a family member or friend with you to your appointment. They can write down notes for you, or remind you of any questions you want to ask.

Questions you could ask

- What are my treatment options?
- Does this treatment aim to help me live longer or control my symptoms?
- If I have treatment, how much longer am I likely to live for?
- What will happen if the treatment does not work or stops working?
- What will happen if I do not have treatment?
- How long will it be before I feel the benefit of any treatment?
- What are the side effects?
- Can I keep working?
- Will I need to stay in hospital and, if so, for how long?
- Could I get any financial benefits?

If a treatment is not working

You may need to have treatment for a while to see if it is helping you. Sometimes, the treatment only causes side effects and has no benefits. In this case, you may want to think about whether you want to continue with treatment. Making treatment decisions like this is always difficult. Before you decide what to do, it may help to talk to your cancer doctor, specialist nurse and family or friends.

If you decide not to have further treatment, your cancer doctor and specialist nurse will support you and make sure your symptoms are managed.

Getting a second opinion

A second opinion is an opinion from a different doctor about your treatment. If you think you want a second opinion, talk to your cancer doctor or GP first. Tell them your concerns or ask them to explain anything you do not understand. This might help reassure you.

If you still want a second opinion, you can ask your cancer doctor or GP to arrange it. They are usually happy to do this. You may have to travel to another hospital to get a second opinion. Getting a second opinion could delay your treatment. Check with your doctor whether this delay could be harmful to you.

If the doctor you see for the second opinion gives you the same advice, this may reassure you. Sometimes they give you other treatment options to think about.

We have more information about getting a second opinion on our website. Visit [macmillan.org.uk/second-opinion](https://www.macmillan.org.uk/second-opinion)





Clinical trials

Current treatments can be helpful for many people with advanced cancer. But cancer doctors are always looking for better ways to treat cancer and manage its symptoms. One way to do this is through cancer research trials (clinical trials). Trials help to improve knowledge about cancer and develop new treatments. Any new drug that is developed will go through trials to make sure it works and is safe.

Taking part in a trial

Your cancer doctor or specialist nurse may talk to you about taking part in a clinical trial. Or you could ask them if there are any trials suitable for you.

Usually, cancer clinical trials happen in several hospitals around the country. You may have to travel to take part in a trial.

A research nurse or doctor will give you information about the trial. It is important to understand what is involved before you agree (consent) to take part. You can ask the research nurse or doctor any questions you have.

They will also explain the possible benefits and any possible risks of the trial. Clinical trials are designed to be as safe as possible. The researchers will monitor you closely during and after the trial.

If you decide not to take part in a trial, your cancer doctor and specialist nurse will respect your decision. You do not have to give a reason for not taking part. Your decision will not change your care. Your cancer doctor will give you the standard treatment for the type and stage of cancer you have.

We have more information on our website. Visit [macmillan.org.uk/clinical-trials](https://www.macmillan.org.uk/clinical-trials)

Complementary and alternative therapies

It is important to tell your specialist doctor or nurse if you are using any complementary or alternative therapies. This is because some therapies may make conventional cancer treatments less effective, or increase their side effects.

Complementary therapies

Complementary therapies are often used alongside conventional cancer treatments such as chemotherapy and radiotherapy. They are not used to treat cancer. But they may help to reduce anxiety, improve sleep, and help you to cope with other symptoms. Complementary therapies include relaxation techniques (such as mindfulness) and breathing exercises.

We have more information in our booklet **Cancer and complementary therapies**.

You can order our booklets and leaflets for free.

Visit be.macmillan.org.uk or call us on **0808 808 00 00**.



Alternative therapies

Alternative therapies are treatments that are used instead of conventional medical treatments. Some alternative therapists claim their therapies can treat or cure cancer, even if conventional treatments have not been able to. There is currently no evidence to show that alternative therapies are effective in curing cancer or slowing its growth.

Unfortunately, there have been cases where people have refused conventional treatments and chosen alternative treatments instead. Some alternative therapies, although natural, can have serious side effects and can make people unwell. Many alternative therapies can also be expensive. If you decide to use an alternative therapy, it is important to check it is safe. It is also important to check the credentials of the therapist offering the treatment.

Asking about how long you might live

You may want to have an idea of how long you might live. This is called a prognosis or life expectancy. Or you may not want or need to know. You may never ask this question.

Your doctors cannot be certain what will happen or how long you might live. Cancer affects people differently and it can be hard to say how it might progress. Different things will affect how long you might live. For example, it may depend on how the cancer responds to treatment and how quickly it grows. This means your doctors may not be able to answer your questions fully. But they can usually give you an idea based on the type of cancer and your situation.

Your healthcare team and your family or friends may wait for you to ask or talk about how long you might live. Or they may talk about it straight away. If you are not comfortable discussing it, it is okay to say so. It is important to do what feels best for you.

Your family or friends may want more information than you do. If you are happy for them to find out about your situation in more detail, tell your cancer doctor or specialist nurse. Your doctor or nurse needs to know:

- who you are happy for them to talk to about your situation
- that you agree to them talking to your family or friends without you being there.

Who you can talk to

It may be difficult to think of everything you would like to say or ask during your hospital appointments. There may be times you just need to talk about what is happening and how you are feeling.

You may have a key worker or specialist nurse who you can contact for advice and support. Or you may have people close to you who will listen and help.

Sometimes it is also useful to talk to someone you do not know. Your family or friends may find this helpful too. Our cancer support specialists can give you information and support with feelings. You can call them on **0808 808 00 00** or chat to them online. Or visit our Online Community to talk with other people in a similar situation, share your experience, and ask an expert your questions (page 85).





Coping with advanced cancer

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Coping with day-to-day life

There are a lot of unknowns when you are living with advanced cancer. You may worry about:

- your treatment
- how symptoms may affect you
- losing your independence or mobility
- the effect of the cancer on your family and friends
- work or money
- how you will cope as the cancer develops.

Uncertainty can be one of the hardest things to deal with. It is understandable and natural to worry about these things.

These feelings can make it difficult to live life the way you would like to. And it is difficult to make plans when you do not know what is going to happen. There may be times when the cancer is all you can think about. It may feel as if many things are happening that are out of your control.

Dealing with your worries

Sometimes it can help to work out what things worry you most. Take time to think about or write these down. For each worry, ask yourself if it is something you can change, or something that might happen or is out of your control.

Things you can change

Focus on making decisions about things you can do something about. Can you do anything to deal with the worry straight away? If not, think about what you want to do and make a plan. When will you do this and how? What do you need to get the plan done? Do you need to ask anyone for help?

Things that are out of your control

Often we worry most about things we cannot change, or things that might happen in the future. There are still ways to change how you react to these worries. It can be helpful to realise you are worrying about something you cannot control. This can make it easier to let go of the worry, or change your focus to something else. Exercises such as mindfulness techniques can also be helpful for coping with difficult thoughts and worries.

Ask for information and support

You do not have to cope with worries and fears on your own. If you need more information or support to understand what is happening, there are people and places who can help with this. You might want:

- medical information
- emotional and psychological support
- spiritual comfort
- practical advice.

Talk to your GP, or your specialist doctor or nurse at the hospital, for information about what is available in your area. You can also talk to one of our cancer support specialists on the Macmillan Support Line. Call **0808 808 00 00** or chat to them online.

Try to get the most out of appointments with your healthcare team. Think about and write down any questions you want to ask before you see them. Your team will do their best to answer your questions. You can take notes during your appointment, so you do not forget what was discussed.

Looking after yourself

Medication

Remember to take any medications exactly as your doctor, nurse or pharmacist has explained. These might be:

- treatments for the cancer
- medicines to help prevent or reduce symptoms or side effects.

Keep an up-to-date list of your medicines at home. Take it with you to appointments and if you go to stay somewhere. Tell any family, friends, or carers where the list is. If you become unwell, they can tell health professionals what medications you are taking.

Healthy lifestyle

Eating well and keeping active are positive choices that can help you feel better and more in control.

A healthy, balanced diet may help you maintain or regain strength. If your appetite is poor, ask your GP, cancer doctor or nurse if they can refer you to a dietitian. They can suggest what might help to build up your diet. We also have more information that may help if you have symptoms or side effects that are making eating difficult. We have more information in our booklet

Eating problems and cancer.

Keeping active can improve symptoms such as tiredness (fatigue), poor appetite, constipation and weak muscles. It can also help reduce stress and help you sleep better.

Physical activity is safe if you have advanced cancer. You should start slowly and gradually build up the amount that you do. Ask your GP, cancer doctor or nurse for advice before you start any type of exercise. You may need to avoid some types of physical activity. For example, if the cancer is in the bones or you have bone thinning, you should usually avoid high-impact activities. These include running, football or tennis.

We have more information in our booklet **Physical activity and cancer**.

You can order our booklets and leaflets for free.

Visit be.macmillan.org.uk or call us on **0808 808 00 00**.



Help from family and friends

You may want to talk about your situation with someone close to you such as family, friends, a partner, neighbours or colleagues. Try to choose people you trust and can talk openly with.

Make a list of things you need or would like people to help with. These might include housework, gardening, looking after a pet or going to appointments with you. It can be hard to ask for help. But the people close to you may be happy to have specific things they can do. Accepting any offers of help can reduce stress and may make you feel more in control.

Complementary therapies

Some people find that complementary therapies help them cope with the stress of cancer and its treatments. Many therapies are relaxing and may improve your mood. Some may help you cope with cancer symptoms or treatment side effects. Some types, such as relaxation and visualisation, can be done at home using CDs or podcasts. Getting this type of support can help you feel more in control. It can be a positive way of looking after yourself.

We have more information in our booklet **Cancer and complementary therapies** (page 80).

Mindfulness

Mindfulness is about learning to notice what is happening within and around you. It helps you learn to focus on the present. It encourages you to become aware of your thoughts and feelings, without making judgements about them. This can mean you spend less time worrying about the future.

Mindfulness-based cognitive therapy (MBCT) is a specific technique that may be helpful. It uses meditation, yoga and the breathing techniques of mindfulness. It also uses some cognitive behavioural therapy (CBT) techniques to help you change unhelpful thought patterns. CBT is a talking therapy that can help you manage your problems by changing the way you think and behave.

Be Mindful is an online MBCT course which is approved by the NHS. Visit **bemindfulonline.com** to find out more.



Help with pets

Looking after a pet can sometimes become a worry because of cancer and its treatment. You may be worried if you:

- are struggling to look after your pet or are no longer able to look after them
- have to go into hospital for a time.

You may want to plan to make sure your pet is looked after.

Friends, family or neighbours may be able to help. There are also some organisations that offer services such as dog-walking or pet-sitting. If you need to be away from home for a while, some organisations may be able to foster your pet.

We have more information on our website. Visit [macmillan.org.uk/pet-care](https://www.macmillan.org.uk/pet-care)

Things I need help with

You can use our table on the next page to write down anything you need help with and who can help.

Coping with your feelings

It is common to have many different emotions when coping with advanced cancer. You may feel uncertain and frightened about the future. Or angry and sad about your situation and the effect the cancer is having on you and those close to you.

There is no right or wrong way to feel. Difficult feelings usually become easier to manage with time and support from family, friends and healthcare professionals.

Uncertainty

Feeling that you have some control in your life may make you feel secure. But being told your cancer is advanced can take away that feeling. You may worry about how you will cope as the cancer develops. Or you may be concerned about practical issues, such as your work or finances. Uncertainty can be hard to deal with as it is difficult to make plans when you do not know what is going to happen.

You may find the following booklets helpful (page 80):

- **Work and cancer**
- **Managing your energy costs**
- **Housing costs**
- **Planning and managing your finances.**

Thinking about what you can control right now can help. For example, you can still make choices about treatment, or how you use your time.

Fear

Many people with advanced cancer feel frightened. You may feel afraid of:

- the illness itself
- its symptoms
- the treatment and possible side effects.

You may be worried about the future, or about dying. Often, talking through what may or may not happen can make it less frightening. You may find your fears are worse than the reality. Talking to a professional, such as a nurse or counsellor, can help you plan for what might happen. This can help reduce your fears.

Anger

It is common to feel angry if you have advanced cancer. You may feel angry about being unwell and having to cope with treatment and side effects. You might also be angry about the impact the cancer has had on your life and your future. For example, it may have affected your ability to work or your relationships.

You may get angry with your family, friends or partner. Tell them you are angry at your illness and not at them. Finding ways to relax can help with anger.

You may feel angry about some aspects of your healthcare. For example, you may be frustrated if there are problems with getting test results or having certain treatments. Talk to your doctors if this is the case.

Talking about your feelings

Everyone expresses and manages their feelings differently. Sometimes it may be clear that you are angry or upset. But sometimes, one emotion can hide another. For example, you might feel scared but show this by being angry or irritable. People close to you may not realise how you are feeling and how much you might be struggling. It may even be hard for you to understand why you are behaving in a certain way.

Talking about your feelings can help. But it is not always easy to do. It is important to talk to someone you trust. This might be a close friend, partner or family member. They may be able to give you the support you need.

Your loved ones may tell you to be positive. No one feels positive all the time, and it can be very difficult when the future is uncertain. Try telling them that you know they are trying to help, but it is hard to feel positive sometimes.

You may find it easier to talk to a healthcare professional. Your GP, specialist nurse or healthcare team at the hospital can support you. They will usually ask how you are feeling at appointments, and this can give you a chance to talk. Or you could tell them you are struggling with your feelings and would like to talk to someone. This is the time to be kind to yourself and ask for any help and support you need.

If you are finding it very difficult to cope with your feelings about cancer, you may need more specialised emotional support. This could be from a counsellor or psychologist (page 34). If you think you may need this, ask your GP or cancer doctor to refer you.

Other things you can do

There are other things you can do to help you cope with your feelings. You could keep a diary or journal so you can write down your thoughts and feelings. This can include good feelings as well as harder ones. If other people are finding it hard to understand how you are feeling, you could show them part of your journal.

Thinking about what you can control may help (pages 22 and 23). It can help to stop worrying about what may happen in the future and focus on what you can do now. You might want to become more involved in your care. Or you may want to think about what you can do to look after yourself.

Many people use complementary therapies to help them cope with symptoms, stress or anxiety. These therapies include:

- meditation
- visualisation
- relaxation
- aromatherapy
- mindfulness.

You can learn about many of these methods on YouTube, or through podcasts and downloads. You can listen to them whenever you want. But make sure they are from a reliable source. It should be clear who has produced them and that they are regularly updated.

We have more information about complementary therapies (page 26).

Support with your feelings

Counsellor

Counsellors are trained to listen and help people talk through their situation and the difficulties they face. They will not give advice or answers. But they can help you find your own ways to solve problems. Talking with a trained counsellor can help you express and understand your feelings. It can also help you find ways to deal with these feelings or the problems they relate to.

GP practices, hospitals and hospices often have their own counsellors. Or they should be able to refer you to one. You can talk to one of our cancer support specialists to find out about counselling in your area (page 80). The British Association for Counselling and Psychotherapy can also give you details of counsellors in your area (page 88).

Your family might also find counselling helpful if they are finding it difficult to cope with their emotions.

Psychologist

Some people may find their emotions are too difficult to cope with. Anxiety and depression can cause problems sleeping and make other symptoms such as pain and breathlessness worse. If this happens to you, you may find it helpful to see a clinical psychologist.

Clinical psychologists are experts in understanding how people feel, think and behave. They may be part of the hospital cancer team or the palliative care team. They specialise in providing psychological and emotional support to people. Some psychological services also offer support to carers and family members.

Support and self-help groups

Your family, friends or partner may be able to give you all the support you need. But you may find it helpful to talk to people who are in a similar situation to you.

There are support groups for people with cancer and their families and friends. These groups mean you can talk to people who may be in a similar situation or facing the same challenges. Some groups meet in person while others may meet using a video conferencing service. Not everyone finds talking in a group easy. You can usually try a group to see what it is like before deciding whether to go regularly.

You can search for groups in your area. Visit [macmillan.org.uk/in-your-area](https://www.macmillan.org.uk/in-your-area) Or our cancer support specialists can help you find local groups (page 80).

As well as support groups, there are other types of online support. These include social networking sites, forums, chat rooms and blogs for people affected by cancer. You can use these to share your experiences, ask questions, and get and give advice. You might find it useful to visit our Online Community (page 85).



Talking about death

Some people feel calm about the fact they are going to die. But others are frightened by the thought.

Dying is something that will happen to all of us. But it is not something that is easy to talk about. Most people do not talk about it very much. Your doctor or specialist nurse can talk to you about death and dying. They will do their best to answer your questions. They can also help you have difficult conversations with people close to you.

There are also events called 'death cafés' which are safe places to meet with other people to talk about death. There are no agendas or objectives at a death café meeting. They are led by someone who helps guide and support the conversation.

Being with others who are having similar feelings and emotions can make it easier to talk about your own feelings. Death cafes are held in different places, such as a library or community hall. Some hospices help with these and have dates of when and where they are being held locally. Visit **deathcafe.com** to find out more about where and when death café meetings are happening.

Spiritual and religious support

Spirituality can mean different things to different people. It may be religious, or it may be expressed in other ways. This can be through music, arts, nature, or how you relate to your family or community.

Many people find their faith offers them emotional support and strength during their illness. Some people may find they become more aware of religious or spiritual feelings. Others may find themselves questioning their faith.

Most people need to have a sense of meaning in their lives and to feel they are loved and valued. If you are seriously ill, having some hope and being at peace with your situation can also be important.

You may find it helpful to talk through your thoughts and feelings with someone you trust. This may be a close friend, partner or family member, a health and social care professional or a chaplain or religious leader. You can speak to a chaplain or religious leader even if you are not religious. They are usually good listeners and may be able to help you work out your thoughts and feelings. They are used to dealing with uncertainty and being with people who are distressed.

You may prefer to talk to someone who is not religious. Humanists UK has volunteers who can offer non-religious pastoral support (page 89). Your GP, specialist nurse or cancer doctor may also be able to help you find a non-religious counsellor or pastoral carer to talk to. You can search for counsellors on the British Association for Counselling and Psychotherapy website (page 88).

You can find information about spiritual issues on the Marie Curie website (page 86). This is a charity that provides care and support at the end of life.

Medicines that can help

You may be finding it very hard to cope. Your GP, cancer doctor or palliative care doctor may be able to give you medicines to help. These may be anti-depressants, anxiety-reducing drugs or sleeping pills. Anti-depressants can take a few weeks to start working properly. Medicines are not likely to change how you think about things, but they can help you feel better.

We have more information in our booklet **How are you feeling? The emotional effects of cancer** (page 80).

If you live on your own

Living on your own can add extra stress. You may value your independence, but being ill may make you feel lonely and frightened.

People who care about you will want to help in any way they can. It is ok to ask for and accept their help.

Some people may be happy to help in practical ways, such as shopping or helping with your garden. You could make a list of practical things that would make your life easier. If people offer to help but are not sure what to do, they can choose to do something from your list.

Other people may be able to talk with and listen to you. This could help you to share your worries and fears.

Marie Curie (page 86) and Age UK (page 92) have free helper services in parts of the UK. Some hospices may also offer this. Someone can visit you to have a chat over a cup of tea, help you get to an appointment or run an errand. There may be help and support available from health, social care and voluntary organisations. Your GP, social worker, local cancer information centre or district or community nurse can help you with this.

Coping with relationships

Your partner, family or friends can all offer support when you are coping with advanced cancer. But it can be very upsetting or painful to talk about your illness with people you are close to.

Family and friends

Your family or friends may be unsure if you want to talk about your illness and treatment. They may wait for you to talk about it. Some people may avoid talking about your illness, or try to avoid you because they are worried they may say the wrong thing.

Talking about a difficult situation is not easy. But talking can help you and your family or friends cope with your situation. And you may find that talking brings you closer together. We have information about talking about cancer in our booklets **Talking about cancer** and **Talking to children and teenagers when an adult has cancer** which you may find helpful.

We also have information to help your family or friends talk about your illness and support you in our booklet **Talking to someone who has cancer**.

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



Your partner

If you have a partner, you may find that the uncertainty of the future, or side effects of treatment, can affect your relationship. Sometimes partners try to protect each other. They avoid talking about the illness as they do not want to upset the other person. But talking about what is happening and how you both feel can help you both feel less alone. You might also find that being open about the situation and your feelings strengthens your relationship.

It may help you and your partner to keep to a normal routine as much as possible. Having a routine can help when you are dealing with a difficult situation.

There may be times when you do not get on well. Some couples find that problems are harder to deal with because they feel they have less time.

For some couples, having a short break from each other can help relieve stress. Or you may find other ways to manage stress that work better for you. For example, doing some physical activity or listening to some relaxing music may help. Talking to someone outside of your situation may also help. This may be a family member, friend, health professional or counsellor (page 34).

Sexual wellbeing

Having advanced cancer can affect how you feel about sex and intimacy. This may depend on the type of cancer you have, or any treatment and side effects.

Sex can still be part of your life if you have advanced cancer. You may find that you need to make some changes. Getting used to this can take some time. You may not feel like having sex, or you may be unable to. But there are still ways of showing how much you care about your partner.

You may feel less attractive, or worry that a partner finds you less attractive. A partner may worry that having sex could harm you or make the cancer worse. This is not the case. Talking openly about your concerns can help sort out any confusion. This can also give you the chance to talk about what you can each do to enjoy sex.

It can be embarrassing to talk about. But many people find it helpful to get some support. Your GP, specialist nurse or hospital doctors may be able to help you have these types of conversations with your partner.

There are also organisations that can help people who are having problems with sex and relationships. These include:

- Relate (page 89)
- the College of Sexual and Relationship Therapists (page 89)
- the LGBT Foundation (page 93).

Your GP, practice nurse, community nurse, or palliative care nurse may also be able to help you find support locally.

It is important that you do not get pregnant, or make someone pregnant, during and for a time after some treatments. This is because some treatments and tests can be harmful to a baby in the womb. Your cancer doctor or specialist nurse can give you advice if you need more information about this.

We have more information in our booklet **Cancer and your sex life** (page 80).

Talking to children and teenagers

You may not know what to say to children about the cancer. Many hospices have family or carer support services that offer support to families of people with advanced cancer. Your community nurse, palliative care nurse or GP may be able to refer your family, including children, to this service.

Children

It is never easy to tell children you have advanced cancer. But it is best to be as honest as you can. Try to give them information they can understand.

Children are often aware of what is happening around them. Even if you do not say anything, they may sense that something is wrong and become frightened. If they are told everything is fine, they may imagine explanations that are not true. They may also find it hard to talk about how they are feeling.

Children sometimes think they are somehow to blame for your illness. It is important to help them understand it is not their fault.

It may help to talk to them when other adults are there, such as your partner, a family member or a close friend. This helps children know who they can talk to and who can support them. It is usually a good idea to tell the nursery or school what is happening, as they can offer support too.

Children of any age may worry that you are going to die. If your cancer is likely to be controlled for a long time, tell them this. But if the cancer is more advanced, it is helpful to prepare them for your death. This can be difficult and you may need help and support. We have more information in our booklet **Preparing a child for loss**, which you may find helpful (page 80).

Teenagers

Teenagers may find the situation especially hard. Some may want to help. But they may find they have more responsibilities at home, at a time when they want to be more independent.

Teenagers may find it hard to talk to you or show how they feel. It is important to encourage them to ask any questions they have and make sure they feel involved. They may find it easier to talk to someone else, such as a close family member, friend, teacher or counsellor. It can often help to tell teachers about your situation so they know what is going on and can offer support. If the teenager is working, you could encourage them to tell their employer.

They may also find support online. If you are a parent, your children may find Riprap helpful (page 87). It is a website that offers information and support for teenagers who have a parent with cancer.

We have more information in our booklet **Talking to children and teenagers when an adult has cancer** (page 80).

Other people

Some people may feel unsure about how to talk to you. They may wait for you to talk about your situation before they say anything.

You can tell people as much or as little as you want to about your health. You can also tell them how you would like them to treat you and whether you want to talk about your situation or not. You might find it helpful to plan answers to any questions. This can help guide the conversation in the way you would like.

Other people may find it helpful if you can tell them how they can help you. For example, you could suggest helping you with housework, or driving you to hospital appointments. Or you could ask them to organise something for you to do together, to help take your mind off your situation.

Having time to yourself

There may be times when you want to be on your own. This is natural.

If you want to have some time alone, you could ask other people to answer the door or phone for you. Tell others you may not be able to respond to texts or emails straight away. And explain gently if you would rather people did not get in touch for a while.

If you are in hospital, there may be limits on the number of visitors you can have because of hospital rules. But if you only want certain people to visit, talk to the staff on the hospital ward.



What care and support is available?

There may be times when you need a lot of help and support from doctors, nurses and other carers. For example, this could be if you are having treatments like chemotherapy or immunotherapy, or if you need help managing symptoms. But at other times, you may need very little help from your healthcare team.

Hospital care

If you are having treatments such as chemotherapy, targeted therapy, hormonal therapy or radiotherapy, a cancer doctor will look after you. You will usually have regular check-ups with the hospital team. These might be face to face or by a phone or video call.

You might be referred to a palliative care team. This is a team of specialists who can help you manage symptoms such as pain or feeling sick (nausea). They can also offer psychological support. They are usually based in hospitals and hospices.

Care at home

You may want to be at home as much as possible. But you may need some nursing care or support from other professionals to help you manage. Having support can help both you and your carers.

The support and services available are different across the UK. Your GP or social worker can talk to you about what is available in your area.

We have listed some of the people who are most likely to be involved in your care.

GP

Your GP has overall responsibility for your care when you are at home. They can prescribe any drugs you need and arrange help from other professionals. They will also arrange for you to go into hospital or a hospice if needed (pages 53 to 54).

Nurses

There are different nurses who might visit you at home.

Community or district nurses

Community or district nurses can make regular home visits. They provide nursing care such as changing dressings, giving medicines and supporting your carers. They can also arrange practical aids, such as pressure-relieving mattresses or commodes.

Palliative care nurses

Palliative care nurses may be called different things, including palliative care clinical nurse specialists or hospice specialist nurses. Palliative care nurses are sometimes called Macmillan nurses. But not all Macmillan nurses specialise in palliative care.

Palliative care nurses are experts in managing pain and other symptoms. For example, they can advise you about pain medicines if your pain is not well managed. They also give emotional support to you and your family, partner or friends.

A palliative care nurse may speak to you on the phone or visit you at home to see how you are and make sure any symptoms are being managed. They can also refer you to any other services provided at your local hospice. Palliative care nursing services are free. Your GP or your doctor or nurse at the hospital can refer you.

Marie Curie nurse or healthcare assistant

In some parts of the UK, you can get support from a Marie Curie nurse or healthcare assistant (page 86). A nurse can advise you about medication. A healthcare assistant can help with practical tasks such as washing and dressing. Marie Curie can sometimes provide nursing overnight from a registered nurse or healthcare assistant. Your GP or district nurse can tell you if Marie Curie nurses are in your area.

Other professionals

You may also get support from other professionals at home.

Occupational therapists

Occupational therapists working in the community can help you keep your independence. They can assess your situation and arrange for any aids or changes you need. Aids might include toilet frames, handrails or a wheelchair. A change might be something like fixing safety rails in your bathroom or making doors wider.

An occupational therapist may be able to help you change your daily routines and activities to help you manage low moods. Some can also help you manage anxiety, fatigue and breathlessness.

Physiotherapists

Physiotherapists can help keep you moving. They can advise you and your carers on the best and safest way for you to move around your home. They can also offer treatment and exercise programmes to help you manage symptoms such as pain, breathlessness and fatigue.

Social services

Social services can help if you find some everyday activities difficult. Social care can include getting help with:

- personal care, such as washing and dressing
- tasks like cleaning and cooking.

There are different ways to access social care. Your hospital team, GP or district nurse can refer you to social services. Or you can refer yourself.

You will have a needs assessment before any care is arranged. A social worker will ask you about your daily routine and what you find difficult. Sometimes an occupational therapist or nurse may do this instead.

Each local authority has its own assessment procedure. Local authorities will have information on their website. They can also provide an up-to-date list of local providers and can signpost you to services. You can find your local authority by visiting [gov.uk/find-local-council](https://www.gov.uk/find-local-council)

You usually have to pay towards the cost of services. This depends on your financial situation. If you have a lot of care needs, you may be eligible for funding for your care. Your GP or a social worker can tell you more about this.

If you prefer, you can arrange care privately. There are a lot of private organisations providing care, including overnight care. Any care provider must be registered with the Care Quality Commission (page 94). Your local adult social services department should be able to give you details of approved private agencies. You can also ask friends or family members for recommendations. The Homecare Association can also give you details of homecare providers that follow its code of practice (page 94).

Charities and volunteers

Age UK has more information about accessing care (page 92). Local branches may be able to help if you just need a bit of help with shopping, gardening or housework.

British Red Cross has volunteers that can help with shopping and tasks like posting letters and picking up prescriptions (page 92). It can also lend equipment, such as wheelchairs and commodes. Services vary in different parts of the country.

The Royal Voluntary Service has a range of services working throughout the UK (page 92). Its volunteers support people in need. It also assists the NHS if needed.

There are local volunteer schemes in some parts of the country that can arrange for someone to visit you at home. They can provide company for you and give your carers a break. Check notice boards at your GP surgery, local library, community centre or church. Your local hospice may also know about volunteer schemes.

Hospices

If you have symptoms that are difficult to manage, you may need extra support. Your doctor or nurse may refer you to a hospice or palliative care (symptom control) team in a hospital.

Hospices specialise in caring for people who have an illness that cannot be cured. They have doctors and specialist palliative care nurses who are experts in controlling symptoms such as pain and nausea (feeling sick). They also provide emotional support.

You can go into a hospice for different reasons. For example, you may stay there for a short time to get your symptoms under control. Some hospices offer respite care. This means you can go in for a short time to give your carers a break. Your palliative care team can tell you what is available at your local hospice.

You may decide that you would prefer to die in a hospice. You will need to discuss your wishes with your GP and the hospice team involved with your care. You may also want to talk about your wishes with close family members, friends or a partner.

Hospices are very different to hospitals. They are smaller and quieter, and aim to provide care to suit each person's situation. Visiting is usually less restricted than in a hospital. As well as practical nursing care, they may offer other services for patients and their families. These may include counselling (page 34), complementary therapies (page 26), spiritual care and psychological support.

Accommodation and care in a hospice are free of charge. There is a limited number of beds in each hospice, so there may be a waiting list.

You can find out more about your local hospice from your GP, district nurse or palliative care nurse. Hospice UK also has useful information about hospices and where they are across the UK (page 86). If you are not sure about the idea of hospice care, you can ask to visit a hospice. The staff can show you around and talk through any questions or concerns you have.

Residential homes or care homes with nursing

If you might need care for some time, you may prefer to be looked after in a residential care home, or care home with nursing (nursing home). A nursing home has qualified nurses on their staff to provide nursing care. They usually offer short-stay or long-stay care.

When you have advanced cancer, it is important to think about the care you might need in the future. Even if you do not have any nursing needs now, you may need nursing care as your illness progresses. Planning ahead can help you avoid having to move from a residential home into somewhere that offers nursing care if you need this.

Your GP, district nurse or social worker can arrange for you to stay in a care home, either with or without nursing care. They can explain the different types of care homes.

Many care homes are privately owned. However, some are run by a charity or the local council. You usually need to contribute towards the costs of staying in a care home. This depends on your financial situation.

NHS UK has information about care homes and funding for care (page 88). You may be able to get a list of local care homes from your local county council. **carehome.co.uk** also has information about care homes and funding (page 94).



Managing symptoms and side effects

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Symptoms and side effects of advanced cancer

You may have symptoms caused by the cancer, or have side effects from treatments. Your doctors and nurses will ask you if you have any symptoms and side effects. It is important to tell your healthcare team about them so they can help.

You may continue to have treatment to slow down the growth of the cancer. But for some people, treatment may aim to help manage symptoms rather than shrink the cancer. In this case, treatments will help you feel better and have the best possible quality of life. This is called supportive or palliative care.

There are palliative and supportive care teams based in hospitals, hospices or in the community (pages 48 to 55). They are experts in helping manage symptoms, such as pain or nausea. Your GP or cancer doctor can refer you to a palliative care team.

Managing pain

Not everyone with advanced cancer has pain. If you do have pain, it is important to tell your healthcare team so they can treat it. They can usually control the pain well with painkillers. You may need a mild painkiller such as paracetamol. But if you have a lot of pain, you may need a stronger painkiller. There are lots of pain relief medicines. Your healthcare team will help you decide the best way to manage your pain. They may refer you to a palliative care team or pain clinic.

Painkillers can be given in different ways including tablets, injections under the skin and patches. As well as painkillers, other medicines and treatments can also be used to relieve pain. These include:

- radiotherapy
- steroids
- bone-strengthening drugs called bisphosphonates.

Some people find complementary therapies, such as acupuncture, hypnotherapy and relaxation techniques can help relieve pain (page 26). Specialist pain clinics may offer these. Tell your nurse or doctor if you would like to consider complementary therapies to help manage your pain.

We have more information in our **Managing cancer pain** booklet (page 80).

Changes in appetite or eating habits

You may find your eating habits change. This may be because you do not have much of an appetite, or you no longer like the taste or smell of some foods. Some cancers or treatments can affect eating. For example, some may cause difficulty swallowing or make you feel sick (nausea).

Even if you are eating well, you may lose weight. This is because the cancer can change the way your body uses food and energy.

Talk to your nurse or doctor if you are concerned about:

- losing weight
- changes in eating habits
- your ability to swallow.

You can also ask to see a dietitian, who can help you find ways to eat well.

People close to you may be concerned if you are eating less, and they may not understand the reasons why. They may feel upset if you are unable to eat food they have prepared for you. It can help to explain why you find it hard to eat and how they could help you.

We have more information in our **Eating problems and cancer** booklet (page 80).

Things that can help

- Have frequent snacks or small meals, rather than 3 meals a day. Only eat what you can manage and do not force yourself to eat.
- Do not worry if the food you want to eat is not always healthy. Sometimes it is more important to eat foods you enjoy. You can try healthier foods again if your appetite improves or your sense of taste comes back.
- If you can only eat or drink small amounts, choose foods or drinks that will give you energy and protein. This will help you get the most out of what you eat.
- Try keeping a flask or cool bag with drinks and snacks nearby. You can then eat or drink something whenever you feel hungry, including during the night.
- If you do not feel able to eat solid food, try a nourishing drink or soup. You can make a smoothie by blending or liquidising soft fruits (fresh or frozen) with fortified milk, fruit juice, and ice cream or yoghurt. Your doctor, nurse or dietitian may also recommend or give you supplements.
- If you want to eat but do not like the smell of cooking, ask someone else to cook your food.
- If you need help with cooking or eating, talk to your GP or contact your healthcare team at the hospital. They may be able to arrange meals on wheels or home help for you.

Tiredness (fatigue)

You may find you get tired easily and that your body no longer feels as strong. You may still feel tired after rest and sleep. And you may feel exhausted, even after doing small tasks. This is called fatigue. It may be because of the cancer or the side effects of treatment.

Things that can help

- Try to pace yourself. Save your energy for the things that matter to you and that you enjoy.
- If you have important things that you need or want to do, do them when you have more energy.
- Organise your day so you have some time to rest every day.
- Try not to overdo things when you have lots of energy, as you may feel tired for several days afterwards.
- If you are too tired to cook, there are organisations and shops that can deliver ready-made meals. You can store these in a freezer until you want to use them.
- Physical activity can help give you more energy and reduce tiredness. It is safe to do some gentle physical activity, such as going for a walk, when you have advanced cancer.
- Use equipment that helps you with daily tasks, such as a raised toilet seat, bath board or walking frame. Sit down to do tasks if you can.
- Practical aids, such as walking sticks, walking frames or wheelchairs, can help you move around so you can be more independent. Many shopping centres and supermarkets offer electric wheelchairs. If they do not, you can check what is available in your local area on the ShopMobility UK website (page 92).

We have more information in our booklets **Coping with fatigue (tiredness)** and **Physical activity and cancer** (page 80).

Difficulty sleeping

There are many reasons why you may find it difficult to sleep. These include:

- having symptoms that are not well controlled, such as pain or breathlessness
- feeling anxious, depressed or stressed
- taking medicines which can keep you awake, such as steroids
- other factors, such as light or noise, or sleeping too much during the day.

Tell your doctor or nurse if you are not sleeping well. Also tell them about any specific worries or symptoms that might be affecting your sleep. They may be able to suggest things to help. For example, they may suggest taking some medications at a different time of the day. Sleeping tablets can help some people. Your doctor can prescribe these if they think they will help.

We have more information at [macmillan.org.uk/trouble-sleeping](https://www.macmillan.org.uk/trouble-sleeping)

Things that can help

- Try to go to bed and get up at about the same time every day.
- Doing gentle exercise and keeping your mind busy can help you feel naturally tired and ready for sleep. Walking, reading, playing games or doing puzzles may help.
- Try to have a relaxing routine before bed. Have a warm bath or shower, with relaxing oils. Listen to an audiobook, a sleep podcast, a relaxation exercise or music.
- Avoid using a screen, such as a TV, computer, tablet or smartphone, for at least 1 hour before going to bed.
- Simple breathing and relaxation exercises may help to reduce anxiety and stress. You can learn them at home using a CD, DVD or podcast.
- Try having a warm drink before going to bed. Avoid stimulants like caffeine and alcohol, as they will keep you awake.
- Keep a notebook by your bed. If you wake up during the night, you can write down anything you are worried about or need to do. You can work through your list during the day and get support and advice from your loved ones, carers or healthcare team.
- Keep your bedroom for sleeping. If you wake up during the night, try not to toss and turn. Go into another room if you can. When you feel sleepy, go back to bed again. If you need to sleep during the day, go to your bed and sleep there.
- Try to reduce light and noise – wearing an eye mask might help if your room is too light.

Other symptoms

You may have other symptoms, depending on the type of cancer you have and the treatment you are having or have had. These can include:

- bowel or bladder problems
- breathlessness
- a swollen tummy, caused by a build-up of fluid (ascites)
- feeling sick
- low mood or anxiety.

Talk to your GP, cancer doctor or specialist nurse about any symptoms you have, especially if they are not being well controlled. They will look at the best ways to treat and manage them.

We have more information in our booklet **Managing the symptoms of cancer** booklet that you may find helpful.

You can order our booklets and leaflets for free.

Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.





Planning ahead

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Ways to plan ahead

Many people choose to plan for a time when they are less well. Doing this while you are well can help your family, partner, friends and health and social care professionals know what you would like. It can also help you feel more in control.

It is best to write down your wishes and preferences. There are different documents you can use. Your healthcare team can tell you more. There is no guarantee your wishes can be carried out. But the people looking after you will follow your wishes as much as possible.

Planning ahead is sometimes called advance care planning. There are different ways to plan ahead. You might want to think about:

- how you would like to be cared for when you become less well
- where you want to be cared for when you are approaching the end of your life
- who will look after your affairs (for example, your money or property) if you are no longer able to do so
- anything else that might be important to you as you approach the end of your life.

You may also want to consider the following:

- **Advance decision to refuse treatment** – this is a decision about any treatments you do not want to have. It is also called an advance directive, advance decision, or a living will.
- **Power of attorney** – this is a legal document that lets you choose (appoint) someone to make decisions for you if you are unable to make them yourself. These can be legal or financial decisions. In England, Wales and Scotland, you can also appoint an attorney to make decisions about your healthcare.

Advance care planning is different across the nations of the UK. Your GP, cancer doctor, specialist nurse, or palliative care team can tell you more. It can be helpful to speak with your family, partner or friends about any plans you want to make.

Organising your affairs

Organising your affairs is part of advance care planning. It can be difficult going through your finances. It can also be upsetting thinking about who will get your belongings. However, it may mean your family or friends do not have to make difficult decisions after you die. It can also prevent financial difficulties that may happen if you do not make your wishes clear. When you have sorted out your affairs, you may feel relieved and more able to concentrate on the present.

We have more information in our booklet **Sorting out your affairs** that you may find helpful (page 80).



Things you can do to put your affairs in order

- Make a will, or make sure your will is up to date. A will gives instructions about who you want to give your money and belongings to when you die. Writing a will makes sure everything you leave goes to the people you want it to. It is a legal document and must be prepared properly. It is best to use a solicitor. They will make sure your wishes are clear and are carried out exactly as you want.
- If you have children aged under 18, it is important to discuss arrangements for their future. You can talk about this with their other parent, your partner, a family member or a friend. Choose guardians who would look after them if needed.
- Write a list of the people who should be told when you die. This might include your employer, your solicitor and anyone who you have named to carry out the wishes in your will. They are called the executor.
- You might want to make plans for the type of funeral you would like. For example, you may want to think about music you would like, or whether you would prefer a cremation or a burial. Tell your family and friends about any plans.
- You could write down details of any practical tasks, for example, where you get the car serviced or how to use the boiler.
- You might want to think about any social media and online accounts you have and how you would like these to be managed.
- Write a list of important documents and where you keep them. This might include the title deeds of your house, bank and building society details and any insurance policies. It can also include things like your will or your funeral plan. Make sure someone close to you knows where the list is.



Financial support

Help with money and benefits

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Help with money and benefits

When you are affected by cancer, you may need help with extra costs. Or you may need support with money if you have to stop working. We have more information online about Statutory Sick Pay and benefits you may be entitled to. We also have information for carers (page 80).

Benefits are payments from the government to people who need help with money. You can find out more about benefits and apply for them online. Go to:

- **gov.uk** if you live in England or Wales
- **socialsecurity.gov.scot** if you live in Scotland
- **nidirect.gov.uk** if you live in Northern Ireland.

The benefits system and other types of financial support can be hard to understand. Macmillan has experienced welfare rights advisers and financial guides. You can speak to them by calling the Macmillan Support Line on **0808 808 00 00**.

You can also get information about benefits and other types of financial help from Citizens Advice if you live in England, Scotland or Wales (page 91), or Advice NI if you live in Northern Ireland (page 90).

Our booklet **Help with the cost of cancer** has lots more information (page 80).

Terminal illness (special rules)

If you are terminally ill, you can apply for some benefits using a fast-track process called special rules. The rules are different depending on where you live in the UK and which benefit you are applying for. You can apply for special rules if your doctor or cancer nurse complete a form saying you have a terminal illness. If you apply for benefits under special rules, you can avoid extra assessments. You are automatically paid the higher rate for most benefits.

You must claim the benefit and explain that you are claiming under special rules. Your doctor or nurse must also fill out:

- an SR1 form – if you are claiming Universal Credit or Employment and Support Allowance
- a DS1500 form – if you are claiming Personal Independence Payment, Disability Living Allowance or Attendance Allowance
- a BASRiS form – if you live in Scotland and are claiming Adult Disability Payment or Child Disability Payment.

If you get benefits under special rules, you usually have them for a period of 3 years.

Macmillan Grants

Macmillan Grants are small, mostly one-off payments to help people with the extra costs that cancer can cause. They are for people who have a low level of income and savings.

If you need things like extra clothing or help paying heating bills, you may be able to get a Macmillan Grant. A grant from Macmillan does not usually affect the benefits you are entitled to. It is an extra bit of help, not a replacement for other support.

To find out more, or to apply, call on **0808 808 00 00** or visit **[macmillan.org.uk/grants](https://www.macmillan.org.uk/grants)**

Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance.

If you are thinking about buying insurance or making a claim, one of our financial guides can help. You can call them on **0808 808 00 00**.

We have more information in our booklet **Travel and cancer**. Our Online Community forum on Travel insurance may also be helpful, visit **[macmillan.org.uk/community](https://www.macmillan.org.uk/community)**

More information

The benefits system and other types of financial support can be hard to understand. Macmillan has experienced welfare rights advisers and financial guides. You can speak to one by calling the Macmillan Support Line on **0808 808 00 00**.

You can also get information about benefits and other types of financial help from Citizens Advice if you live in England, Scotland or Wales (page 91), or Advice NI if you live in Northern Ireland (page 90).

Our booklet **Help with the cost of cancer** has lots more information (page 80).



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About our information

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

Order what you need

You may want to order more booklets or leaflets like this one.

Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

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

Online information

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

Other formats

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

- audiobooks
- eBooks
- Braille
- large print
- British Sign Language
- translations.
- 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 **0808 808 00 00**.

The language we use

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

We try to make sure our information is as clear as possible. We use plain English, avoid jargon, explain any medical words, use illustrations to explain text, and make sure important points are highlighted clearly.

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. Our aims are for our information to be as clear and relevant as possible for everyone.

You can read more about how we produce our information at **[macmillan.org.uk/ourinfo](https://www.macmillan.org.uk/ourinfo)**

Other ways we can help you

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

Talk to us

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

Macmillan Support Line

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

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

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

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

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

Information 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 [macmillan.org.uk/informationcentres](https://www.macmillan.org.uk/informationcentres) or call us on **0808 808 00 00**.

Help with money worries

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

Financial guidance

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

Help accessing benefits

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

Help with 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 a much-needed break.

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

Help with work and cancer

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

Work support

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

Talk to others

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

Support groups

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

Online Community

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

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

Advanced cancer and end of life care

Hospice UK

Tel **020 7520 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.

General cancer support organisations

Cancer Black Care

Tel **020 8961 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 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.

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.

Riprap

www.riprap.org.uk

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

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 Inform

Helpline **0800 22 44 88**

www.nhsinform.scot

NHS health information site for Scotland.

NHS 111 Wales

111.wales.nhs.uk

NHS health information site for Wales.

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- 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.

College of Sexual and Relationship Therapists (COSRT)

Tel **020 8106 9635**

www.cosrt.org.uk

Provides information and support on sexual problems.

Humanists UK

Tel **020 7324 3060**

www.humanists.uk

Provides information about humanism, humanist ceremonies and pastoral support.

Relate

www.relate.org.uk

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

Emotional and mental health support

Be Mindful

www.bemindfulonline.com

A digital course recommended by the NHS to improve mental wellbeing.

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**

www.samaritans.org

Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

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**

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

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

Carer's Allowance Unit

Tel **0800 731 0297**

Textphone **0800 731 0317**

www.gov.uk/carers-allowance

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

Citizens Advice

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

England

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

Scotland

Helpline **0800 028 1456**
www.cas.org.uk

Wales

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

GOV.UK

www.gov.uk

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

NiDirect

www.nidirect.gov.uk

Has information about benefits and public services in Northern Ireland.

Equipment and advice on living with a disability

British Red Cross

Tel **0344 871 11 11**

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.

ShopMobility UK

www.shopmobilityuk.org

A network of centres which hire out mobility equipment to the public. This equipment is mainly manual wheelchairs, powerchairs and mobility scooters so people with restricted mobility can enjoy independence outdoors.

Support for older people

Age UK

Helpline **0800 055 6112**

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.

Royal Voluntary Service

www.royalvoluntaryservice.org.uk

Volunteers providing practical, social and emotional support. Use its website to find services offered in your area.

LGBT-specific support

LGBT Foundation

Tel **0345 330 3030**

www.lgbt.foundation

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

Live Through This

www.livethroughthis.co.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. Live Through This 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 (England, Scotland, Wales) **0808 808 7777**

Helpline (Northern Ireland) **028 9043 9843**

www.carersuk.org

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

Care homes

carehome.co.uk

Helpline **0800 808 5852**

www.carehome.co.uk

Provides advice about looking for and finding funding for a care home. Has reviews of over 100,000 care homes across the UK.

Care Quality Commission

www.cqc.org.uk

Independent regulator of health and adult social care in England. It makes sure health and social care services provide people with safe, effective, compassionate, high-quality care.

Homecare Association

Tel **020 8661 8188**

www.homecareassociation.org.uk

Provides information about homecare services available in different parts of the country.

Bereavement support

Cruse Bereavement Care

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 Care. It supports young people across the UK after the death of someone close. Offers a private message service from the website.

Winston's Wish

Helpline **0808 802 0021**

www.winstonswish.org

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

Complementary therapies

Complementary and Natural Healthcare Council

Tel **020 3327 2720**

www.cnhc.org.uk

Holds a register of therapists in 16 therapies. You can search for an accredited practitioner in your area.

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 our Senior Medical Editor Dr Viv Lucas, Consultant in Palliative Care.

With thanks to: Karen Bird, Director of Clinical Services; Michelle Buono, Macmillan End of Life Education Nurse/Palliative Care Clinical Nurse Specialist; Lisa Dennis, Consultant Nurse for End of Life Care; Professor Faye Gishen, Honorary Consultant in Palliative Medicine; and Matt Loveridge, Clinical Nurse Specialist.

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 advanced cancer information. If you would like more information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

Health Improvement Scotland/NHS Scotland. Scottish Palliative Care Guidelines. Available from **www.palliativecareguidelines.scot.nhs.uk/** [accessed Nov 2021].

NICE. End of life care for adults: service delivery. NICE guideline NG142. 2019. Available from **www.nice.org.uk/guidance/ng142** [accessed Nov 2021].

NICE. Improving supportive and palliative care for adults with cancer. Cancer service guideline CSG4. 2004. Available from **www.nice.org.uk/guidance/csg4** [accessed Nov 2021].

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

Valid from

Expiry date

Issue no

Security number

Signature

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 cancer that has come back or spread. This is sometimes called advanced cancer.

The booklet talks about some of the concerns you may have and advice about ways of coping. It also tells you about treatments, and has practical information about getting help and support.

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, eBooks, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call our support line.



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