

A practical guide to living with and after cancer

COPING WITH ADVANCED CANCER



About this booklet

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

It looks at some of the concerns you may be dealing with and has advice about ways of coping. It also talks about treatments and your feelings, and has practical information about getting help and support.

Not all of the information in this booklet will apply to you. It may cover things that don't affect you or that you don't want to read about at this time. You can use the contents on page 3 to help you decide which sections are most useful to you.

We've included quotes from people with advanced cancer in this booklet. Some of the quotes are taken from [healthtalk.org](https://www.healthtalk.org) and others are from people who have shared their stories with us. Some names have been changed.

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

We also have a video about coping with advanced cancer that you might find helpful. You can watch it at [macmillan.org.uk/copingwithadvancedcancer](https://www.macmillan.org.uk/copingwithadvancedcancer)

If you'd like to discuss this information, call the Macmillan Support Line free on **0808 808 00 00**, Monday to Friday, 9am to 8pm. If you're hard of hearing you can use textphone **0808 808 0121**, or Text Relay. For non-English speakers, interpreters are available. Alternatively, visit [macmillan.org.uk](https://www.macmillan.org.uk) At the end of this booklet are details of other useful organisations (see pages 73–79).



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FINDING OUT YOU HAVE ADVANCED CANCER

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Finding out your cancer is advanced

It's common to be overwhelmed by different feelings when you find out your cancer has come back or spread. Some people may have a cancer that is advanced when they are first diagnosed. For others, the cancer may spread or come back after treatment.

Although it is rare for advanced cancer to be cured, some people may live with it for a long time – sometimes for years. This may mean having treatments when you need them. Sometimes you may need ongoing treatment to control the cancer.

During this time, many people can carry on with their day-to-day lives and do the things that are important to them.

For some people, it may not be possible to control the cancer any longer or they may not be well enough to have treatment. In this case, their cancer doctor or specialist nurse will make sure they have treatments to manage any symptoms they may have (see pages 15–21).

When you first find out your cancer is advanced, you may feel shocked and find it hard to take in. You may feel frightened about the future, or angry with other people or yourself. These feelings usually become more manageable with time, and as you start making decisions and plans. We have information and tips to help you manage your feelings on pages 29–35.

Knowing that your illness may not be curable can give you the chance to decide what's important to you, and how you want to live your life. Concentrating on what you can enjoy and achieve can be satisfying. It may also help you cope if you find you can't meet other goals.

Some people may want to think about what they might want if they were to become less well. For example, they may want to record their wishes about how and where they would want to be cared for. This is sometimes called **advance care planning** (see pages 56–57).



Decisions about treatment

Before deciding on any course of treatment, you may want to find out as much as possible about your options. Your doctors and nurses will talk to you about what treatments may be suitable for you, taking into account your preferences and how treatment may affect you. This will help you decide on the best course of treatment together.

'I think there's probably a fear of the unknown. But once they told me, I wasn't scared any more. I said, "Okay, what are we going to do about it?"'

Claire

Treatment for advanced cancer usually aims to try to control the cancer and help you live longer. It may also help improve your symptoms and quality of life. Controlling the cancer might mean shrinking the size of the tumour or stopping it from growing for a while. As well as treatment for the cancer, your doctors will prescribe any other medicines you need to manage symptoms.

You may be offered surgery, radiotherapy, chemotherapy, hormonal therapies, targeted (biological) therapies, or a combination of treatments.

The treatment that is best for you will depend on the type of cancer and where it is in your body.

You may need to have a few treatments before you and your doctor can decide whether to continue with a full course. For example, if you are having chemotherapy to control or shrink the cancer, you may have a scan after several weeks to see what effect the treatment is having. You can carry on with the course of treatment if the scan results show it is working.

However, there may come a time when the treatment has little effect on the cancer. You may start getting the side effects of the treatment without any of the benefits. Making treatment decisions in these circumstances is always difficult. You may want to talk with your cancer doctor (oncologist), specialist nurse and family before deciding what to do.

If you decide not to have treatment, you will be given supportive (palliative) care with medicines to control any symptoms. These may include drugs to manage pain or stop you feeling sick (nausea). You might also be given cancer treatments to ease symptoms. For example, radiotherapy can help with pain as well as being a cancer treatment.

Talking about treatment options

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

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

You may find it useful to record the discussion with your doctor. If you want to do this, ask your doctor first. Recordings can also be helpful for family and friends to listen to, so you don't have to keep repeating information. You can take a family member or friend with you to your appointment. As well as giving support, they could take 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 I don't have treatment?
- How long will it be before I feel the benefit of any treatment?
- What are the side effects?
- Can I carry on working?
- Will I need to stay in hospital and, if so, for how long?

Asking about how long you might live

For some people, it is important to have an idea of how long they might live (prognosis). Others prefer to focus on their quality of life and choose to never ask the question.

Your doctors can't be certain what will happen to an individual person or when. So they may not be able to answer your questions fully. But they can usually give you some idea based on the type of cancer and your situation. Remember that cancer affects people differently and in an unpredictable way. Some people may have periods of stable disease where it is not causing too many problems. Some will live with their advanced cancer for a long time – sometimes years. But for others, the cancer develops more quickly and they will have less time.

Different things will affect how long you might live. For example, this may depend on how the cancer responds to treatment and how quickly the cancer grows. This means your doctor's view may change over time. Talking to your doctor about this may be an ongoing discussion, rather than a one-off question.

Your medical team and your family and friends may wait for you to talk about how long you might live, or they may talk about it straight away. If you are not comfortable discussing it, it's fine to say so. It is important to do whatever feels best for you.

It may be that your family and friends want more information than you do. If you are happy for them to talk about things in more detail, tell your doctor or nurse. They need 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.

It may be difficult to think of everything you would like to say or ask during your hospital appointments. You may think of lots of questions between appointments. If you do, you may have a specialist nurse who you can contact when you are not at the hospital.

Our cancer support specialists on **0808 808 00 00** can give you information and emotional support. People with cancer and their relatives sometimes find it helpful to talk to someone they don't know and who isn't emotionally involved in their situation.

Getting a second opinion

Your multidisciplinary team (MDT) uses national treatment guidelines to decide on the most suitable treatment for you. Even so, you may want another medical opinion. If you feel it will be helpful, you can ask either your specialist or your GP to refer you to another specialist for a second opinion.

Getting a second opinion may delay the start of your treatment, so you and your doctor need to be confident that it will give you useful information. If you do go for a second opinion, it may be a good idea to take a relative or friend with you and have a list of questions ready. That way you can make sure your concerns are covered during the discussion.

Clinical trials

Current standard treatments can be helpful for many people with advanced cancer. But cancer doctors are always looking for better ways of treating cancer and managing its symptoms. One of the ways to do this is through cancer research trials, often called clinical trials. Trials help to improve knowledge about cancer and develop new treatments. Any new drug that is developed will go through trials to check it is safe and effective.

Taking part in a trial

You may be invited to take part in a clinical trial, and there can be many benefits to doing this. If you decide to take part, you will be carefully monitored during and after the study. It's important to bear in mind that some treatments that look promising at first are often later found to be less effective than existing treatments. They may also have side effects that outweigh the benefits.

If you start taking part in a trial and then change your mind, you can leave the trial at any time. You will then be offered the current standard treatment for your situation.

If you decide not to take part in a trial, your decision will be respected and you won't have to give a reason. There will be no change in the way you're treated by the hospital staff, and you'll be offered the current standard treatment for your situation.

Our booklet **Understanding cancer research trials (clinical trials)** describes clinical trials in more detail. You can order a free copy by visiting be.macmillan.org.uk or calling **0808 808 00 00**.

Complementary and alternative therapies

Complementary therapies are most often used alongside or in addition to conventional medical treatment such as chemotherapy and radiotherapy. They aren't used to treat cancer, but they can play an important part in reducing anxiety. They often include relaxation techniques, for example mindfulness (see pages 34–35).

The term **alternative therapy** is often used to refer to treatments that are used instead of conventional medical treatments. Some alternative therapists claim that their therapies can treat or cure cancer even if conventional medicines haven't been able to. But no alternative therapies have been proven to cure cancer or slow its growth. Unfortunately there have been cases where false claims made about alternative therapies have led people to refuse conventional treatments that could have helped them.

Some alternative therapies although natural, can have serious side effects and could make people feel unwell. Many alternative therapies can also be expensive. If you decide to use an alternative therapy, it's important to check it's safe and to check the credentials of the therapist offering the treatment.

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

Our booklet **Cancer and complementary therapies** has more information. You can also call the Macmillan Support Line on **0808 808 00 00** if you have any questions about complementary or alternative therapies.

Managing symptoms and side effects

Whether or not you are having treatment to control the cancer, your doctors and nurses will ask you if you are having any symptoms and side effects. Symptoms can happen with some types of cancer, and side effects can be caused by cancer treatments. It is important to let your medical team know about any symptoms or side effects so they can arrange appropriate help and treatment.

For some people, treatment may no longer be able to control the cancer. In this situation, your doctor may suggest that the aim of treatment changes from trying to shrink the cancer, to managing worrying or upsetting symptoms. This is called supportive or palliative care. It will help you feel better and have the best possible quality of life.

There are palliative care teams based in hospitals and the community. They are experts in helping control symptoms such as pain. Your GP or cancer specialist can refer you to a palliative care team. See pages 50–51 for more information.

We have more information in our booklet **Controlling the symptoms of cancer**. It has a symptom diary where you can note down how you feel, any symptoms you may have and any medicines that make you feel better. You can then discuss these with your doctor. To order a copy, visit be.macmillan.org.uk or call **0808 808 00 00**.

Managing pain

Not everyone with advanced cancer has pain. But if you do, it can usually be well controlled with medicines. If you have pain, it is important to let your doctor know so it can be treated. Mild painkillers like paracetamol may work well for you, but sometimes you may need stronger drugs. Your medical team will work with you to develop the best pain control plan for your situation.

Other treatments can also be used to relieve pain. These include:

- radiotherapy
- steroids
- bone strengthening drugs, called bisphosphonates
- nerve blocks
- painkilling patches.

Some people find complementary therapies, such as acupuncture or hypnotherapy, and relaxation techniques can help relieve pain (see page 34). There are specialist pain clinics which may offer these methods of pain control.

Your GP or cancer specialist can refer you to a community palliative care team. Or they can refer you to a specialist palliative care or pain clinic.

Our booklet **Managing cancer pain** has more information. Call **0808 808 00 00** or visit **be.macmillan.org.uk** to order a free copy.

Changes in appetite or eating habits

Many people with advanced cancer notice a change in their eating habits. This may be related to a loss of appetite or to changes in the way they smell and taste food. Some cancers or treatments also cause particular problems, such as difficulty swallowing or feeling sick.

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

If you are concerned about losing weight or about changes in your eating habits, talk to your nurse or doctor. They will be able to assess the reason for the change. You can also ask to see a dietitian, who can help you find ways to eat well.

We have more information in our booklet **Eating problems and cancer**. You can order a copy by calling **0808 808 00 00** or visiting **be.macmillan.org.uk** We also have information about controlling nausea and vomiting on our website.

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. You might find it helps if you explain why you find it hard to eat and how they could help you.

Tips to help with eating problems

- Try having frequent snacks or small meals. These can be more manageable than three large meals a day.
- If you don't feel like eating some food you have been given, perhaps you could try it again in a couple of hours.
- Don't worry if the food you feel like eating is not always healthy. It is your quality of life that's important. It is more important to choose foods that you enjoy and ignore those that don't appeal to you. You can try them again if your appetite improves or your sense of taste returns.
- If you can only manage small amounts, choose foods or drinks that will give you energy and protein so you get the most out of what you eat.
- If you can't face eating, 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 can also prescribe or recommend supplement drinks and puddings for you.
- If you feel you need more help at home with cooking or eating, tell your GP or contact the dietitian at your hospital. They may be able to arrange meals on wheels or home help for you.

We have a booklet called **The building-up diet**, which has more information about eating well when your appetite is poor. You may also like our booklet **Recipes for people affected by cancer**. Call us on **0808 808 00 00** or visit **be.macmillan.org.uk** to get a free copy.

Other problems

Tiredness (fatigue)

You may find you become tired easily, and that your body no longer feels as strong. Even after resting and sleeping, you still may feel tired and find you lack energy to do things. This is called fatigue. It may be due to the cancer or the side effects of treatment. If you don't have much energy, save it for the things you really want to do. You may find it helpful to organise your daily activities so you have some time to rest every day.

Practical aids can also be useful, such as walking sticks, walking frames or wheelchairs. They may help you move around more than you could on your own so you can be more independent. Many shopping centres and supermarkets offer electric wheelchairs, but if they don't you can check what's available in your local area on the National Federation of Shopmobility's website (see page 77).

If you are too tired to cook, there are a number of organisations that deliver ready made meals that can be heated in the microwave. Visit your local council website for details of what is available in your area.

We have a booklet called **Coping with fatigue**, which includes tips on saving energy and dealing with tiredness. To order a free copy, visit **be.macmillan.org.uk** or call **0808 808 00 00**.

Difficulty sleeping

There are many reasons you may find it difficult to sleep. Sometimes the symptoms of cancer or the side effects of treatment can affect sleep patterns. For example, some medications, such as steroids, can make you feel more alert. If you think medications might be affecting your sleep, speak to your doctor about it. They may be able to suggest ways to help, like taking your medications in the morning so you don't feel wide awake at bedtime.

We have more information about difficulty sleeping and steroids on our website.

Tips for a better night's sleep

- Go to bed and get up at about the same time every day.
- Gentle exercise and keeping your mind busy with activities will help you feel naturally tired and ready for sleep. Walking, reading, playing games or doing puzzles may help.
- Get into a relaxing routine before bed. Having a warm bath or shower, reading or listening to soothing music can help.
- Make your bedroom a relaxing place to be in. Create an area that is dark, quiet and comfortable.
- Avoid large meals and stimulants like caffeine or cigarettes in the late evening. Try having a warm, milky drink before bed.

Many people find they can't sleep because of worry or anxiety. It can help to write down your concerns or talk to someone about them. You may not be able to do anything immediately, but if you note them down you can work through them the next day.

Simple breathing and relaxation exercises may help to reduce anxiety and stress. Almost anyone can learn relaxation techniques. You can learn them at home using a CD, DVD or podcasts.

Other symptoms

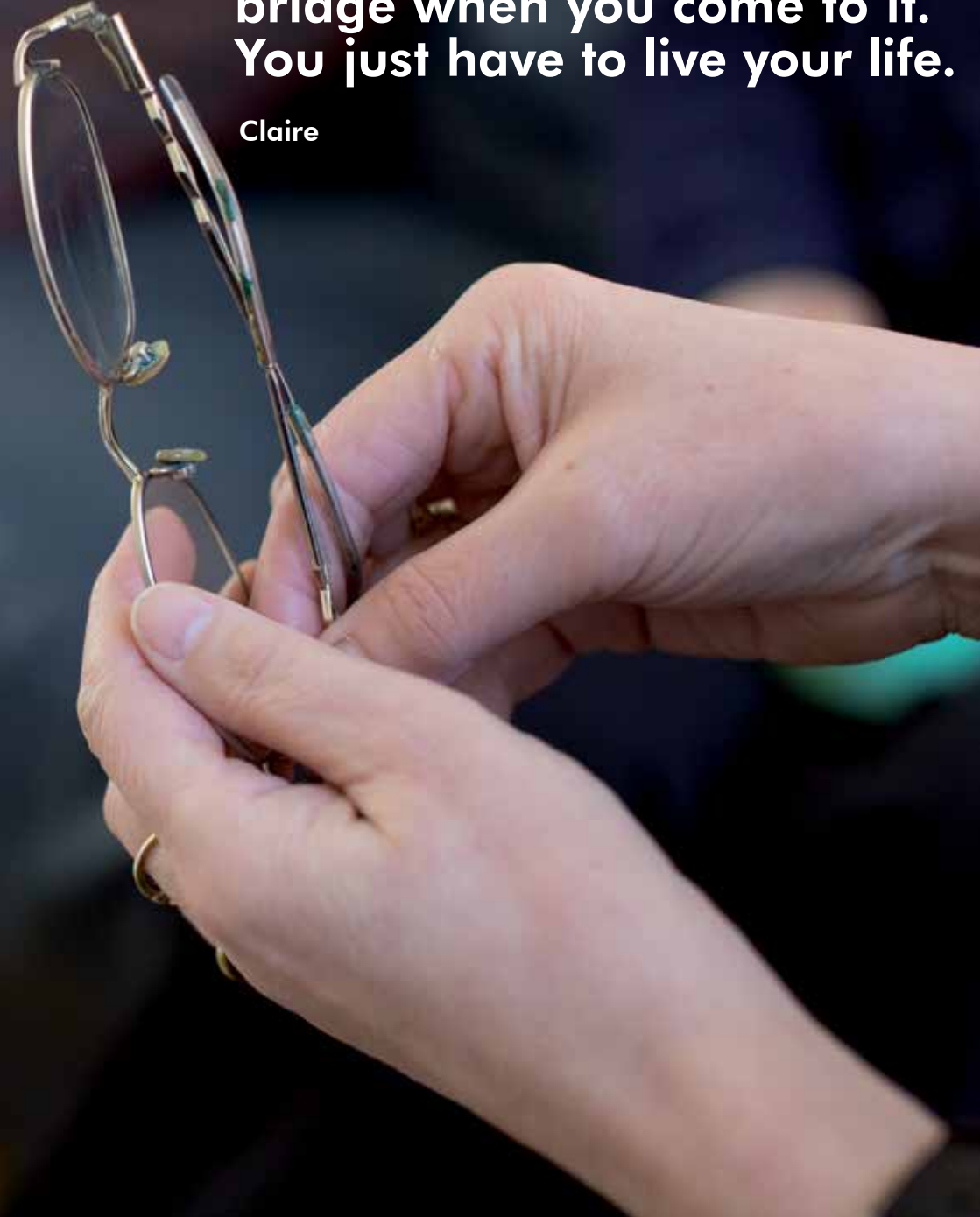
Other symptoms you may have that can be treated or relieved include:

- bowel or bladder problems
- breathlessness
- a swollen tummy caused by a build-up of fluid (ascites).

We talk about these symptoms in our booklets **Controlling the symptoms of cancer** and **Managing breathlessness**. You can order free copies from be.macmillan.org.uk or by calling **0808 808 00 00**.

**There are going to be times
that are hard, but cross that
bridge when you come to it.
You just have to live your life.**

Claire



COPING WITH THE EFFECTS OF ADVANCED CANCER

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Coping with day-to-day life

Coping with advanced cancer can mean living with doubt and uncertainty. You may be concerned about practical matters, such as your work or finances. Or you may be worried about your treatment, pain or other symptoms, or about losing your independence or mobility. You may also be anxious about the effect of the cancer on those you love and how you will all cope as it develops. These are all common thoughts people have.

Uncertainty is one of the hardest things to deal with for you and your family and friends, especially when you are trying to live life as normally as possible. It can cause a lot of tension. You may feel irritable, angry and frightened. It is difficult to make plans when you don't know what's ahead. Even if you ask your doctors what is likely to happen, they may not be able to give you a full answer because they can't say for sure.

However, many people find they can learn to live with uncertainty. One thing that can help is to take control of the things they can do something about.

What you can do

There may be times when you feel the cancer is all you think about. It can also feel like many things are happening that are out of your control. You may find that once you have dealt with some of your worries, you feel less anxious. Over the next few pages we talk about some things you can do.

Ask for information and help

You don't have to cope with your fears on your own. There are people and places you can turn to for medical information, emotional and psychological support, spiritual comfort and practical advice. Try talking to your GP, specialist doctor or nurse for information about what is available in your area. You can also contact the Macmillan Support Line on **0808 808 00 00** and talk things through with one of our cancer support specialists.

Try to get the most out of appointments with your medical team. It can help to prepare any questions you want to ask. Your doctor, palliative care nurse or a specialist nurse at the hospital will usually be able to answer most of your questions. If you are worried about things like how your cancer may affect your daily life, you may feel better by finding out more about it.

Try to think of a few key people you can talk openly with. They could be your partner, parents, grown-up children, close friends or colleagues, neighbours, or people from a local carers' or cancer support group.

If you are feeling overwhelmed, try making a list of things you need help with. You could ask your family or friends whether they could help with anything, such as housework, gardening or looking after a pet. You may find it hard to ask people for help. But you will probably find your friends and neighbours are happy to be given specific things they can do for you, such as giving you a lift to an appointment.

Look after yourself

Medication

Remember to take any medications as prescribed. This might be treatment for the cancer, or medicines to help prevent or reduce symptoms or treatment side effects. Keep an up-to-date list of your medicines at home, and take it with you if you stay somewhere else.

Healthy lifestyle

You may want to make some changes to your lifestyle. Eating a healthy, balanced diet may help some people to maintain or regain their strength. It can also improve their well-being.

If you feel well enough, try doing some physical activity. It can improve symptoms such as fatigue, pain, poor appetite, constipation and weak muscles. It also helps reduce stress and can help you sleep better. You may not have done much physical activity recently, maybe due to treatment or symptoms. If this is the case, then you should start slowly and gradually build up the amount that you do.

You may need to avoid some types of physical activity. This may be advised if, for example, the cancer is in your bones or you have bone thinning. Ask your doctor or palliative care team for advice before you start.

'I am concentrating on a healthy diet and lifestyle and I will keep being positive. I will be doing what I want to do.'

Simon

Complementary therapies

These can be a good way of helping you cope with some of the stresses caused by the cancer and its treatments. A lot of the therapies are relaxing and enjoyable, which may help to lift your spirits. Some complementary therapies can also help relieve any symptoms or side effects you may have.

Many therapies, such as relaxation and visualisation (see pages 34–35), can be done at home using CDs or podcasts.

We have more information about looking after yourself in our booklets **Healthy eating and cancer**, **Physical activity and cancer**, and **Cancer and complementary therapies**. Call us on **0808 808 00 00** or visit **be.macmillan.org.uk** to order your free copies.



If you live alone

Living alone can add extra stresses. Even though you may value your independence, being ill may make you feel very lonely and frightened.

It is all right to ask for help. People who care about you will want to help in any way they can. Some people may find it difficult to talk, but may be happy to help in more practical ways. They might be able to do things 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 then 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 (see page 73) has a free helper service available in parts of the UK. Someone can visit you to have a chat over a cup of tea, help you get to an appointment, run an errand, or just be there to listen when you need a friendly ear.

Your GP, social worker, or district or community nurse will also be able to tell you what help and support is available from health, social care and voluntary organisations (see pages 73–79).

Coping with your feelings

It is natural to have a mix of emotions when you are coping with advanced cancer. How often and how strongly you have these feelings will vary. Living with the uncertainty that comes with advanced cancer can be physically and emotionally demanding. But people often find that over time they can cope with their feelings more easily.

Fear

Many people with advanced cancer feel frightened. You may have times when you feel afraid of the illness itself, the symptoms, or the treatment and its possible side effects. You may worry about the effect it will have on your family. People often worry about the future or about dying. Sometimes it helps to talk to a professional, such as a nurse or counsellor, about your fears. Often, talking through the reality of what may or may not happen can make it less frightening. You may find your fears are worse than the reality and it may actually put your mind at rest.

Anger

It is natural to feel angry if you have advanced cancer. You may feel angry about feeling unwell, going through treatment and having to cope with the side effects. You could also be angry about the impact the cancer has had on your life. It may have affected your ability to work or your relationships. You may feel frustrated that your plans will be disrupted by tests and treatment, and that your long-term plans have suddenly become uncertain.

There may also be things about your healthcare which may cause you to feel angry. For example, delays in tests or treatments. If this is the case it is worth talking it through with your doctors.

Talking about feelings

We all express our feelings in different ways. It is often clear how someone is feeling by their behaviour, what they say and how they say it. However, sometimes one emotion can disguise another. For example, a person might be frightened but express their fear by being short-tempered, irritable, or angry with those around them. Talking about our feelings can help us understand our behaviour and what's behind it. But this isn't always easy.

If you can, find someone you can talk to about how you feel. This could be a family member or friend, but some people prefer to talk to someone outside of this circle of people. Your GP, palliative care nurse or doctors and nurses at the hospital will usually ask how you are. This will give you the chance to talk about your feelings and emotions if you want to. You might find this easy if you already know and feel comfortable with them. If you would prefer to talk to someone else, they may be able to refer you to someone who is trained to listen, such as a counsellor (see opposite page).

If managing your feelings is causing a lot of difficulties, you may be referred for psychological support (see opposite page).

Some people find that their family and friends tell them to be positive. No one feels positive all the time, and it can be especially difficult when the future is so uncertain. It's fine to tell your family and friends that you know they mean well, but that it is hard to feel positive sometimes.

Emotional support

Counselling

Counsellors are trained to listen and help people deal with difficult situations. They may be able to help you find your own solutions to the problems you are facing. Cancer can affect many aspects of your life, so this can be very helpful. Talking to someone who is supportive and not personally involved in your situation can also help those close to you.

Your GP or hospital doctor may be able to refer you to a counsellor. Or you may prefer to go to someone independent. We can give you information about how to find counselling in your area. Call us on **0808 808 00 00**.

Counselling is available for your relatives, too. They may also be struggling emotionally.

Psychological support

Sometimes emotions such as anger and fear can be symptoms of anxiety and depression. These feelings can be difficult to cope with. Some people may have physical symptoms of anxiety and depression such as pain or breathlessness. If symptoms of anxiety or depression become overwhelming, it may be possible to have psychological therapy from a clinical or counselling therapist.

Your GP or practice nurse may know more about what is available in your area. You may be able to get psychological support at the hospital. The palliative care team, your cancer doctors or your nurses will be able to make a referral.

Support and self-help groups

However supportive your family and friends are, you may find it useful to spend some time with people who are going through a similar experience to you.

There are many support groups for people with cancer and their relatives. These groups give you the chance to talk to other people who may be in a similar situation or facing the same challenges. It can also be helpful to meet people who have lived with their cancer for a long time and who enjoy life.

Not everyone finds talking in a group easy. It may help to go along to see what the group is like and then make a decision.

You can search for groups in your area online by visiting **macmillan.org.uk/in-your-area** Or you can call our cancer support specialists on **0808 808 00 00** and they can help you find local groups.

Online support

Many people now get support on the internet. There are online support groups, 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. Log on at **macmillan.org.uk/community**

Spiritual and religious support

Many people find their faith can offer them emotional support and strength during their illness. Some people may find they become more aware of religious or spiritual feelings. Other people may find themselves questioning their faith when they are told their cancer has come back or spread.

In either situation, talking to a religious or spiritual leader may help. Their role is to offer emotional and spiritual comfort, and to help you feel more at peace with your situation.

Even if you haven't attended religious services regularly in the past or aren't sure what you believe, you can still talk to a religious leader. This may be a priest, rabbi, imam or other religious leader, depending on your faith or preference. They are used to dealing with uncertainty and won't be shocked.

'Talking to somebody, whether it's one or two friends or a group of friends – you really need that support. I don't think you should try to cope with it on your own.'

Divya

Medicines that can help

Sometimes feelings of anxiety and depression start to affect your ability to deal with everything that is happening to you. In this case, your GP, hospital specialist or palliative care doctor may be able to prescribe medicines to help you cope. These may be anti-depressants, anxiety-reducing drugs or sleeping pills. Remember, anti-depressants can take a few weeks to start working.

Our booklet **How are you feeling? The emotional effects of cancer** talks about the feelings and emotions you may have and suggests ways of dealing with them. Order a free copy by visiting be.macmillan.org.uk or calling **0808 808 00 00**.

Things you can do for yourself

There are a number of things you can do yourself that can help you cope with your feelings. Some people find that keeping a **diary or journal** helps them express their thoughts and feelings.

Many people use **complementary therapies** to help them cope with symptoms, stress or anxiety. These therapies include meditation, visualisation, relaxation, aromatherapy or a combination of these techniques. You can learn complementary therapies from CDs or podcasts, or there may be local classes you can go to. Your GP or practice nurse may know more about what's available in your area.

Mindfulness is an approach that can help you change the way you think about different experiences. It aims to reduce stress and anxiety. It helps you focus on the present moment using techniques like meditation, breathing and yoga. You are encouraged to become aware of your thoughts and feelings, without making judgements about them.

A specific technique, called mindfulness-based cognitive therapy (MBCT), may be helpful. It uses the meditation, yoga and breathing techniques of mindfulness, along with some cognitive behavioural therapy (CBT) techniques to help you change your thought patterns. Cognitive (thinking) therapy focuses on any difficulties you are facing at the moment and looks for ways to change your current state of mind. This helps your thoughts become more positive. There are a few centres in the UK that offer MBCT classes on the NHS.

Our booklet **Cancer and complementary therapies** has more information. Order a free copy by visiting be.macmillan.org.uk or calling **0808 808 00 00**.





Partners, family and friends

Partners, family and friends are an important source of help and support when you are coping with advanced cancer. But it is common to find it upsetting or painful to talk about your illness with those close to you. Your family and friends may not be sure how much you want to talk about your illness and treatment. They may be waiting for you to bring up the subject.

If you find it difficult to talk about how you feel, our booklet **Talking about your cancer** has suggestions that can help.

When someone has a serious illness, many people are unsure how to respond. Some may try to avoid you rather than risk saying the wrong thing. Some people may avoid discussing your illness or may seem unsympathetic.

Our booklet **Talking with someone who has cancer** is written for family and friends, to help them feel more confident in supporting you. You can order a free copy by visiting **be.macmillan.org.uk** or calling **0808 808 00 00**.

'I felt that we actually drew closer together. We talked much more about what we meant to each other and the things that we'd enjoyed together. So that was a positive thing.'

Janet

Your partner

If you have a partner, you may find that the stresses of an uncertain future, any side effects of treatment, or other difficulties put a strain on your relationship. There may be times when you don't get on well together. Some couples find that problems are harder to resolve because they feel they have less time to consider them.

Talking about your feelings with your partner can help you both. Some people find their relationship becomes stronger if they can be open about feelings.

Having short breaks from each other may help relieve stress. Sometimes talking to someone outside of your situation also helps. They may be a relative, a friend or a counsellor.

Sexuality

When someone becomes ill, it can affect their ability to feel good about their sexuality. How advanced cancer affects you and your sexuality will depend on the type of cancer you have. Treatment and side effects can also have an impact. But having cancer doesn't have to mean an end to your sex life.

Sex life

Sex can still be part of your life if you have advanced cancer, but you may find that you and your partner need some time to adjust. Even if you don't feel like having sex or are unable to, there are intimate and affectionate ways of showing how much you care about each other.

Partners may sometimes mistakenly worry that having sex could harm you or make the cancer worse. Or they may worry that they could catch the cancer. Try talking openly with your partner about difficulties or concerns about your sex life. This can help sort out any misunderstandings.

Although it can be embarrassing to talk about at first, most 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.

There are also some organisations that can help couples who are having problems with their sex life. They have trained counsellors who specialise in this area. Your GP practice nurse or community Macmillan nurse may be able to help you find someone.

Depending on what treatment you are having, it can be important to avoiding getting pregnant or fathering a child.

Our booklet **Cancer, you and your partner** has tips to help people and their partners with common issues they may face when someone has cancer.

We also have two booklets about sexuality and cancer. One is for men and one is for women. Order free copies at be.macmillan.org.uk or by calling **0808 808 00 00**.

'Going through something like this is incredibly bonding. We've sat up in the middle of the night with pots of tea and tears, and we've laughed and cried together. It's made us value each other in a way we didn't know was possible.'

Betsy

Children and grandchildren

It can be difficult to talk to your children or grandchildren about cancer. Even very young children will sense when something is seriously wrong, so it's probably best to be honest with them and tell them your cancer has come back or spread. However much you want to protect them, if you pretend everything's fine, they may feel they have to keep their worries to themselves. Their fears may be worse than the reality.

How and what you tell them will depend on their age and how much they can understand. It may be a good idea to choose to tell them at a time when you and your partner, relatives or close friends can all be together. Then the children will know there are other adults they can share their feelings with and who will support them.

Children of any age may worry that you are going to die. If your cancer is likely to be controlled for a long time, it is important to tell them this. If the cancer is more advanced, it's helpful to sensitively prepare them for your death. This can be a difficult thing to do and you may need help and support. Our booklet **Preparing a child for loss** aims to support people having these conversations, to help prepare a child for the death of a parent or close family member. You can order a free copy by visiting **be.macmillan.org.uk** or calling **0808 808 00 00**.

Teenagers

Teenagers can have an especially hard time. At a stage when they want more freedom, they may be asked to take on new responsibilities and they may feel over-burdened. It's important that they can go on with their normal lives as much as possible and still get the support they need.

If they find it hard to talk to you, you could encourage them to talk to someone close who can support and listen to them, such as a grandparent, family friend, teacher or counsellor. They may also find it useful to look at the website **riprap.org.uk** which has been developed especially for teenagers who have a parent with cancer. It is often helpful to tell the teacher of your situation so they are aware and can look out for any signs of struggles.

Our booklet **Talking to children and teenagers when an adult has cancer** has helpful suggestions. Order a copy by calling **0808 808 00 00** or visiting **be.macmillan.org.uk**

Family support services

Some hospices have family support services, which offer support to the families of people with advanced cancer. Your community nurse, Macmillan nurse (see page 46) or GP may be able to refer your family, including any children, for family support offered by the hospice.

Friends and colleagues

Some friends and colleagues will feel unsure about how to talk to you. They may leave it up to you to make the first move.

You can tell them as much or as little as you want about your health. You may not want to talk about your cancer all the time, and you may rely on your friends to carry on as usual and distract you.

Your friends and colleagues will probably find it helpful if you can tell them what you want or need from them. For example, this might be help around the house or asking them to drive you to hospital appointments.

If you don't want to talk

There may be times when you don't feel like talking and want to be on your own. Don't feel that you have to see people if you don't want to or if you need time to yourself.

Allow other people to go to the door or answer the phone for you. If you are in hospital, you may want to limit the number of visitors you have. You can ask a relative or the nurses to help you with this.

There is no right or wrong way to face this situation. Each person has to try to deal with it in their own way and at their own pace.



Practical help

There may be times when you need a lot of help and support from doctors, nurses and other carers. For example, you may need extra support if you are having treatments like chemotherapy, or if you have symptoms that are worrying you. But at other times you may need very little help from your healthcare team, and you might only see them for check-ups.

Hospital care

If you are having treatment such as chemotherapy, targeted (biological) therapy, hormonal therapy or radiotherapy, you will be looked after by a cancer doctor. You will usually go to the hospital regularly for check-ups.

If you are no longer having treatment to control the cancer, you might be referred to a palliative care team. These are specialists who help you to manage symptoms such as pain. They are usually based in hospitals and hospices (see pages 50–52).

Home care

There is help and support for people being looked after at home, and also for their carers. It is not possible to get 24-hour nursing care at home and the amount of support available varies across the UK. Your GP or social worker can advise you on what is available in your area. The organisations listed on pages 73–79 will also be able to give you information.

Our booklet **Caring for someone with advanced cancer** has helpful information on the support available to you and the people caring for you. You can order a free copy by calling **0808 808 00 00** or visiting **be.macmillan.org.uk**

Over the next few pages we have listed the people who are most likely to be involved in your care when your cancer is advanced.

GP (general practitioner)

When you are being looked after at home, your GP has overall responsibility for your care. Your GP is also responsible for prescribing any drugs you need, and for arranging admission to a hospital or hospice if necessary. Along with the support of other community professionals, such as community or palliative care nurses, they will assess your nursing and medical care needs, and arrange the necessary help. Once home care arrangements have been set up, you will probably see the community nurse more regularly than your GP.



Nurses

- **Community or district nurses** can make regular home visits. They offer nursing care services, which may include changing dressings, giving medicines and supporting carers. They can also arrange practical aids, such as pressure-relieving mattresses or commodes.
- **Palliative care or symptom control nurses** are sometimes known as Macmillan nurses. They specialise in managing pain and symptoms. They are also specialists in giving emotional support to patients and their families. They may be based in hospitals or hospices (see pages 50–51), or they might visit people in their own homes. They don't usually provide daily nursing care, but they can call or visit you regularly to check on your symptoms and support you. For example, they can advise you about which medicines to take if pain is a problem. They may also be able to give you information about certain financial benefits you can apply for. Palliative care nursing services are free. Your GP or your doctor or nurse at the hospital can arrange a palliative care nurse for you.
- **Marie Curie nurses** are available in some parts of the UK. You can get one-to-one overnight nursing from a registered nurse or senior healthcare assistant in your home. The shifts are usually for eight or nine hours. In some parts of the UK, they also offer shorter shifts, evening shifts and day shifts. How much care they will be able to provide may differ. They will not usually be able to offer complete 24-hour cover. The services of Marie Curie nurses are free. They are usually arranged through the district nurse, who will talk to you and your carers to decide what hours of care you need.

Home care teams

These are usually based at a hospital or hospice, but they work with people at home. The teams usually include specialist nurses, who have had training in symptom control and emotional support. These are often palliative care nurses. Sometimes the team includes a doctor, who may share your care with your GP.

Other professionals

- **Clinical or counselling psychologists** are often part of the hospital cancer (oncology) services or the palliative care team. They are specialists in providing psychological and emotional support to people with advanced cancer. For example, they can help if symptoms of anxiety or depression become overwhelming, and with any relationship problems. Some psychological services will also offer support to carers and family members.
- **Occupational therapists** working in the community can help you keep your independence at home. After an assessment, they may be able to arrange for aids to be delivered, such as toilet frames, handrails or a wheelchair. They can also arrange for changes to be made to your home, such as fixing safety rails in bathrooms or making doors wider. If you have difficulty dressing, they may be able to suggest and arrange to have your clothes altered. Many occupational therapists may also be able to help you manage low moods, by changing daily routines and activities. Some therapists also get involved in managing anxiety.
- **Physiotherapists** can help keep you moving. They also offer treatment, massage and exercise programmes to help relieve pain. Your GP or community nurse can put you in touch with a physiotherapist.

Social services

Your hospital team, GP or district nurse can refer you to social services. Or you can refer yourself.

You are usually offered an assessment of your needs. A social worker, or sometimes an occupational therapist or nurse, will ask you questions about your daily routine and what you find difficult. They use this assessment to work out what your needs are and what support can be provided.

You usually have to pay towards the cost of services depending on your financial situation. But you may be entitled to extra benefits to help you get care.

Each local authority will have its own assessment procedure and information on their website. You can find what your local authority is by visiting [gov.uk/find-your-local-council](https://www.gov.uk/find-your-local-council)

Local authorities will also provide an up-to-date list of local providers and can signpost you to services.

The website [socialcareinfo.net](https://www.socialcareinfo.net) can also direct you to your local authority website and other sources of local support.

Care attendants or carers can come into your home to help with jobs around the house, such as cleaning and cooking. They can also help with some personal tasks, such as washing and dressing. Some care attendant schemes provide someone to be there at night.

This type of help can be arranged through private agencies, which must be registered with the Care Quality Commission. The UK Homecare Association can give you details of home care providers that follow its code of practice – call **020 8661 8188**. Your local adult social services department should be able to provide you with details of approved private agencies. You can also ask friends or relatives for recommendations.

Charities such as Age UK and Carers Trust (see page 78) can also provide home help and extra help around the house.

Other sources of help at home

- British Red Cross (see page 73) has volunteers that can help you with shopping and errands, like posting letters and changing library books. It also lends equipment, such as wheelchairs and commodes, and provides a service to take people to hospital.
- Lots of areas have **volunteer schemes** that can arrange for someone to visit your home, to provide company for you and give your carer a break. You can contact your local Community Volunteer Service or the Volunteer Bureau to find out what's available in your area. You could also check notice boards in your GP's surgery or your local library, community centre or church.
- For people needing a lot of health care or who are in the last few weeks of life, NHS Continuing Healthcare may fund and provide for all your care needs at home. This includes personal care from health care assistants. You can find more information about this by visiting **[nhs.uk/chq/Pages/2392.aspx](https://www.nhs.uk/chq/Pages/2392.aspx)**

Hospice care and care homes

If you have worrying symptoms, you may need extra support. Your doctor or nurse may refer you to a hospice or palliative care (symptom control) unit in a hospital.

Hospices

Hospices specialise in caring for people who have a life-limiting illness and may be approaching the end of their life.

They have doctors and specialist palliative care nurses who are experts in controlling symptoms, such as pain, and providing emotional support. They also have staff nurses or healthcare assistants who can visit and help care for people at home. Some have day centres for people living at home.

You can go into a hospice for a short time to have your symptoms controlled. In some hospices, you can go in for a period of respite care to give your carer a break. You may decide that you would like to die in a hospice. If so, you will need to discuss your wishes with your GP and the hospice team involved with your care.

Hospices offer a wide range of services for patients and their families. These include:

- counselling
- spiritual care
- complementary therapies
- psychological support
- bereavement support.

Accommodation and care in a hospice is always free of charge. There are a limited number of beds in each hospice and there will usually be a waiting list.

Some hospices run daycentres for people who do not need to be an inpatient, but who would benefit from spending a day or more each week at the hospice. They can get care from the specialist team and peer support from people living with illnesses similar to theirs.

You can find out more about your local hospice from your GP, district nurse or palliative care nurse. Hospice UK (see page 73) also has useful information about hospices and where they are located across the UK. If you are not sure about the idea of hospice care, you can ask to visit the hospice before making a decision. The staff will be able to show you around and chat through any questions or concerns you have.

Care homes

You or your family may think you would benefit by staying in a care home. Your GP, district nurse or social worker can arrange for you to stay in a residential care home, either with or without nursing care. They may offer short-stay or respite care, but usually also offer long-stay care. For someone with an advanced cancer it is important to consider future care needs. You may not have any nursing needs now. But thinking ahead can prevent moving into a residential home, and then needing to move again to somewhere that offers nursing care.

A residential care home provides living accommodation, meals and help with personal care. If you need nursing care some registered care homes can provide this. These are often referred to as nursing homes.

Private nursing homes and residential homes charge a fee. You may be able to get free care if you are eligible, following an assessment by a social worker or care manager.

Availability of care varies from area to area and can take a while to organise.

The details of registered residential care homes are available from your local social services department and your area health authority. You can get information about finding a residential care and nursing homes on the NHS Choices website – visit [nhs.uk/conditions/social-care-and-support-guide/pages/care-homes.aspx](https://www.nhs.uk/conditions/social-care-and-support-guide/pages/care-homes.aspx)

Help with pets

If you have a pet and are concerned about them while you are in hospital or having treatment, there are organisations that offer services such as dog walking. If you need to be away from your home for a while, some organisations may be able to foster your pet.

We have more information on our website about getting help with pet care when you are ill.

You can use the space on the opposite page to write down anything you need help with and where you can get support. It may be something we've talked about in this section, or another concern you have.



PLANNING AHEAD

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Why plan ahead?

Although the future may seem uncertain, for many people it is important to plan ahead. This is sometimes called advance care planning. It can help to consider important issues while you are well enough to do so. For example, you might want to decide where you want to be when you die, or choose who will look after your affairs if you are no longer able to do so. Some people choose to make an advance decision to refuse treatment. This is when you document your wishes to not have a particular treatment in certain circumstances.

Our booklet **Your life and your choices: plan ahead** can help you with advance care planning. We can send you a version for where you live. There is one version for England and Wales, one for Scotland and one for Northern Ireland. Visit [be.macmillan.org.uk](https://www.be.macmillan.org.uk) to order a copy.

You can discuss advance care planning with your palliative care team.

Putting your affairs in order

Part of advance care planning is putting your affairs in order. Sorting through some of your important documents and thinking about who will receive your possessions after you die can be upsetting. However, it may spare family or friends painful decisions and even financial difficulties that could happen if you don't make your wishes clear. Putting your affairs in order may also clear your mind of lots of worries, leaving you free to concentrate on the present.

Things you can do to put your affairs in order

- Make a will, or update your will if you have already made one. A will ensures that your wishes are carried out after your death, so you can make sure your possessions go to the people you want them to. You may find making a will upsetting. But once you have done it, you may feel satisfied and relieved that your affairs are sorted out. You might find our **Step-by-step guide to writing a will** useful.
- If you have children under 18, discuss arrangements for their future with their other parent. Appoint guardians who would look after them if you both died.
- Write a list of where you keep important documents, such as the title deeds of your house. Write down details of things like your bank accounts and insurance premiums.
- Write a list of the people who should be told when you die. For example, your employer, your solicitor and anyone who you have named to carry out the wishes in your will (executor).
- You might like to make plans for the sort of funeral you would like, or to discuss whether you would prefer cremation or burial.
- It may also be helpful to note down any everyday tasks that you have always done. For example, where you get the car serviced or how to turn the boiler on.

Our booklet **End of life: a guide** has more information about planning ahead and end-of-life care. You can order a free copy by calling **0808 808 00 00** or visiting **be.macmillan.org.uk**



FINANCIAL SUPPORT

Financial help and benefits

60

Financial help and benefits

Cancer can mean extra expenses, such as the cost of travelling to hospital, car parking charges and higher heating or food bills. If you can no longer work, your income may also be affected. This can cause more worries at a difficult time.

If your income is low or you are struggling to cope with the financial effects of cancer, you may be entitled to financial help. Call our cancer support specialists on **0808 808 00 00**. They can give you information to help you access benefits and financial support. Some other organisations can also offer help with financial issues (see pages 76–77).

If you can't work because you're ill, you may be able to get Statutory Sick Pay (SSP). Your employer will pay this for up to 28 weeks of sickness. If you qualify for it, they cannot pay you less.

Before your Statutory Sick Pay ends, or if you don't qualify for it, check whether you can get Employment and Support Allowance (ESA). This benefit is for people who can't work because they're ill or disabled.

There are two different types of ESA:

- Contribution-based – you can get this if you have paid enough National Insurance.
- Income-based – you can get this if your salary and savings are below a certain level.

Since October 2013, a new benefit called Universal Credit (see opposite page) is replacing income-related ESA. This is for people who are looking for work or on a low income.

Universal Credit

This is a new benefit that has started replacing income-based ESA, tax credits and other means-tested benefits in England, Scotland and Wales. It is for people of working age who are not working or don't earn much money.

Universal Credit is gradually being introduced to different areas. The benefit you should apply for will depend on where you live and your situation. There are plans to introduce Universal Credit in Northern Ireland in the near future.

In some areas, you may be able to claim tax credits instead of Universal Credit. This may be a better option for you. Call our welfare rights advisers on **0808 808 00 00**. They can help you find out which benefits you may be able to claim.

Personal Independence Payment (PIP)

This is a new benefit for people aged 16 to 64 in England, Scotland and Wales. It is for people who find it difficult to walk or difficult to look after themselves.

Disability Living Allowance (DLA)

This benefit is mainly for people living in Northern Ireland who are under the age of 65. It is for people who find it difficult to walk or difficult to look after themselves. At some point, it is expected that PIP will replace DLA in Northern Ireland. In England, Scotland and Wales, you can only make a new DLA claim for a child aged under 16.

Attendance Allowance (AA)

This is for people anywhere in the UK who are aged 65 or over and find it difficult to look after themselves. You may qualify if you need help with things like getting out of bed, having a bath or dressing yourself.

Our welfare rights advisers can help you find out which benefits you may be able to claim. Call them on **0808 808 00 00**.

If you have an urgent claim

If you are terminally ill and are expected to live for less than six months, you can apply for some benefits under special rules. Applying under special rules means your claim will be dealt with quickly and you will get the benefit you apply for at the highest rate. If you get benefits under special rules and then live for longer than six months, the benefits won't be affected.

This can be difficult to think and talk about. Usually a member of your healthcare team, such as a specialist nurse, will be able to help you fill in any forms.

Help for carers

Carer's Allowance is a weekly benefit that helps people who look after someone with a lot of care needs. If they don't qualify for it, they can apply for **Carer's Credit**. This helps them build up qualifying years for a State Pension.

More information

The benefits system can be hard to understand, so it is a good idea to talk to an experienced welfare rights adviser. You can call the Macmillan Support Line on **0808 808 00 00** to speak to a financial guide. Although we have listed some benefits here, there may be others you can get.

You can find out about state benefits and apply for them online at:

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

These websites have information about financial support, your rights, employment and independent living. You can also get information from the relevant Department for Work and Pensions helplines or Citizens Advice. In Northern Ireland, you can call the Benefit Enquiry Line Northern Ireland. See page 76 for details of these three organisations.

Our booklet **Help with the cost of cancer** has more detailed information about benefits. Call us on **0808 808 00 00** or visit **be.macmillan.org.uk** to order a free copy. We also have a useful video at **macmillan.org.uk/gettingfinancialhelp**

Direct payments

If your assessment says you need social services, you may be entitled to get direct payments from your local authority or health and social care trust. This means that you are given payments to organise the services yourself, rather than them organising and paying for them for you.

You can get information about direct payments at:

- **gov.uk/apply-direct-payments**, if you live in England, Wales or Scotland
- **nidirect.gov.uk/articles/direct-payments**, if you live in Northern Ireland.

Grants

We give one-off Macmillan grants to people with cancer. Contact our cancer support specialists on **0808 808 00 00** for information on how to apply. You need to apply through a Macmillan nurse if you have one, or a health or social care professional such as a district nurse or a social worker.

CLIC Sargent (see page 77) offers grants to anyone aged 24 and under. Grant applications need to be made through a health or social care professional. You may also be able to claim grants and benefits from other organisations or charities.

Insurance

People with cancer may find it hard to get certain types of insurance, including life and travel insurance. A financial adviser can help you look at your needs and find the best deal for you. You can find a financial adviser by contacting one of the organisations on pages 76–77.

Our booklet **Insurance** may also be helpful. Order a copy by calling **0808 808 00 00** or visiting **be.macmillan.org.uk**

Travel insurance

If you're feeling well enough, you may be thinking about planning a holiday. It can be difficult to get travel insurance if your cancer is advanced.

You may find our booklets **Getting travel insurance** and **Travel and cancer** helpful. You can order free copies by visiting be.macmillan.org.uk or calling **0808 808 00 00**.





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About our information

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

Order what you need

You may want to order more leaflets or booklets like this one. Visit [be.macmillan.org.uk](https://www.be.macmillan.org.uk) or call us on **0808 808 00 00**.

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

All of our information is also available online at [macmillan.org.uk/cancerinformation](https://www.macmillan.org.uk/cancerinformation). There you'll also find videos featuring real-life stories from people affected by cancer, and information from health and social care professionals.

Other formats

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

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

Find out more at [macmillan.org.uk/otherformats](https://www.macmillan.org.uk/otherformats)

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

Help us improve our information

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

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

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



Other ways we can help you

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

Talk to us

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

Macmillan Support Line

Our free, confidential phone line is open Monday–Friday, 9am–8pm. Our cancer support specialists can:

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

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

Information centres

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

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

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

Talk to others

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

Support groups

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

Online community

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

The Macmillan healthcare team

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

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

Mal

Help with money worries

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

Financial guidance

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

Help accessing benefits

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

Macmillan Grants

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

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants. We can also tell you about benefits advisers in your area. Visit [macmillan.org.uk/financialsupport](https://www.macmillan.org.uk/financialsupport) to find out more about how we can help you with your finances.

Help with work and cancer

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



Macmillan's My Organiser app

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

Other useful organisations

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

Advanced cancer and end-of-life care

British Red Cross

UK Office,
44 Moorfields,
London EC2Y 9AL
Tel 0344 871 11 11

Email

information@redcross.org.uk

www.redcross.org.uk

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

Hospice UK

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

Tel 020 7520 8200

Email

info@hospiceuk.org

www.hospiceuk.org

Provides information about living with advanced illness. Has a directory of hospice services and practical booklets available free from the website.

Marie Curie

89 Albert Embankment,
London SE1 7TP

Helpline 0800 090 2309

(Mon–Fri, 8am–6pm,
Sat, 11am–5pm)

www.mariecurie.org.uk

Marie Curie nurses provide free end-of-life care to people in their own homes, or in Marie Curie hospices, 24 hours a day, 365 days a year.

General cancer support organisations

Cancer Research UK

Angel Building,
407 St John Street,
London EC1V 4AD

Tel 0300 123 1022

www.cancerhelp.org.uk

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

Riprap

Maggie's,
The Stables,
Western General Hospital,
Crewe Road,

Edinburgh EH4 2XU

www.riprap.org.uk

Developed especially for teenagers who have a parent with cancer.

General health information

Health and Social Care in Northern Ireland

www.hscni.net

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

Healthtalk

Email

info@healthtalkonline.org

www.healthtalk.org

www.youthhealthtalk.org

(site for young people)

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

NHS Choices

www.nhs.uk

The UK's biggest health information website.

Has service information for England.

NHS Direct Wales

www.nhsdirect.wales.nhs.uk

NHS health information site for Wales.

NHS Inform

www.nhsinform.co.uk

NHS health information site for Scotland.

Patient UK

www.patient.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 and emotional support

British Association for Counselling and Psychotherapy (BACP)

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

Tel 01455 883 300

Email bacp@bacp.co.uk

www.bacp.co.uk

Promotes awareness of counselling and signposts people to appropriate services. You can search for a qualified counsellor at **itsgoodtotalk.org.uk**

Family Action

24 Angel Gate,
City Road,
London EC1V 2PT

Tel 020 7254 6251

www.family-action.org.uk

A leading provider of services to disadvantaged and socially isolated families. Provides practical, emotional and financial support through over 100 services based in communities across England.

Relate

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

Tel 0300 100 1234

www.relate.org.uk

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

Financial or legal advice and information

Benefit Enquiry Line Northern Ireland

Tel 0800 220 674

(Mon–Wed and Fri, 9am–5pm,
Thu, 10am–5pm)

Textphone 0800 243 787

[www.nidirect.gov.uk/
money-tax-and-benefits](http://www.nidirect.gov.uk/money-tax-and-benefits)

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

Citizens Advice

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

England and Wales

www.citizensadvice.org.uk

Scotland

www.cas.org.uk

Northern Ireland

www.citizensadvice.co.uk

You can also find advice online in a range of languages at www.citizensadvice.org.uk/resources-and-tools/Languages/

Department for Work and Pensions

Disability Benefits Helpline

08457 123 456

(Textphone 0845 722 4433)

Personal Independence Payment Helpline

0845 850 3322

(Textphone 0845 601 6677)

Carer's Allowance Unit

0845 608 432

(Textphone 0845 604 5312)

[www.gov.uk/
browse/benefits](http://www.gov.uk/browse/benefits)

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

The Law Society

113 Chancery Lane,
London WC2A 1PL

Tel 020 7242 1222

www.lawsociety.org.uk

Can provide details of solicitors in England and Wales.

The Law Society of Scotland

Atria One,
144 Morrison Street,
Edinburgh EH3 8EX

Tel 0131 226 7411

Email lawscot@lawscot.org.uk
www.lawscot.org.uk

Can provide details of solicitors in Scotland.

The Law Society of Northern Ireland

96 Victoria Street,
Belfast BT1 3GN

Tel 028 9023 1614

www.lawsoc-ni.org

Can provide details of solicitors in Northern Ireland.

Turn2Us

Hythe House,
200 Shepherds Bush Road,
London W6 7NL

Tel 0808 802 2000

(Mon–Fri, 8am–8pm)

Email info@turn2us.org.uk
www.turn2us.org.uk

The website lets you access information on the benefits and grants available from both statutory and voluntary organisations. In many cases, applications for support can be made directly from the website.

Equipment and advice on living with a disability

The National Federation of Shopmobility

2–4 Meadow Close,
Ise Valley Industrial Estate,
Wellingborough NN8 4BH

Tel 01933 229644

Email shopmobility@bhta.com
www.nfsuk.org

A nationwide scheme that hires out mobility vehicles. Its website has a search function to see what help is available in different areas.

Support for young people

CLIC Sargent

No.1 Farriers Yard,
Assembly London,
77–85 Fulham Palace Road,
London W6 8JA

Tel 0300 330 0803

www.clicsargent.org.uk

Provides clinical, practical, financial and emotional support to children with cancer.

Support for older people

Age UK

Tavis House,
1–6 Tavistock Square,
London WC1H 9NA

Helpline (England and Wales)

0800 169 2081

Helpline (Scotland)

0800 470 8090

Helpline (Northern Ireland)

0808 808 7575

(Daily, 8am–7pm)

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.

Age Scotland

Causewayside House,
160 Causewayside,
Edinburgh EH9 1PR

Tel 0800 470 8090

www.ageuk.org.uk/scotland

Age Cymru

Ty John Pathy,
13/14 Neptune Court,
Vanguard Way,
Cardiff CF24 5PJ

Tel 08000 223 444

www.ageuk.org.uk/cymru

Age Northern Ireland

3 Lower Crescent,
Belfast BT7 1NR

Tel 0808 808 7575

www.ageuk.org.uk/northern-ireland

Elderly Accommodation Counsel

3rd Floor,
89 Albert Embankment,
London SE1 7TP

Tel 0800 377 7070

Email

info@firststopadvice.org.uk

www.eac.org.uk

A national charity that aims to help older people make informed choices about meeting their housing and care needs.

Support for carers

Carers Trust

Email support@carers.org

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

(Mon–Fri, 10am–4pm)

Tel (Northern Ireland)

028 9043 9843

Email advice@carersuk.org**www.carersuk.org**

Offers information and support to carers across the UK. Can put people in contact with support groups for carers in their area.

Bereavement support**Winstons Wish**

3rd Floor,

Cheltenham House,

Clarence Street,

Cheltenham GL50 3JR

Tel 08452 03 04 05**Email**info@winstonswish.org.uk**www.winstonswish.org.uk**

Offers support guidance to bereaved children, families and professionals.

Complementary therapies**British Complementary Medicine Association**

PO Box 5122,

Bournemouth BH8 OWG

Tel 0845 345 5977**Email** office@bcma.co.uk**www.bcma.co.uk**

Holds a register of qualified complementary and alternative therapists who are all members and adhere to its code of ethics.

Complementary and Natural Healthcare Council

46–48 East Smithfield,

London E1 1AW

Tel 020 3668 0406**Email** info@cnhc.org.uk**www.cnhc.org.uk**

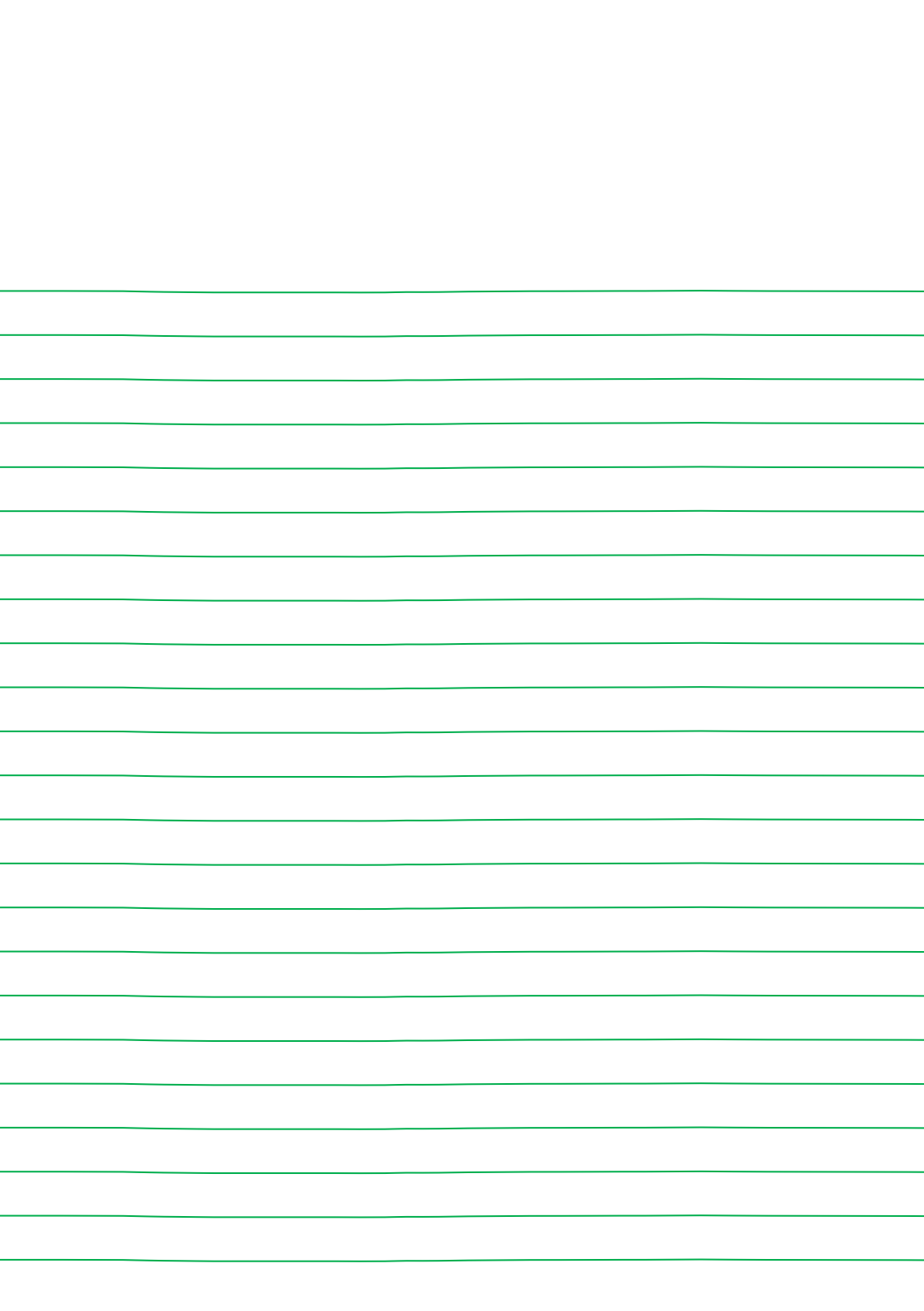
The UK regulator for complementary healthcare practitioners. You can search for accredited practitioners in your area who meet agreed levels of competence and practice.



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

YOUR NOTES AND QUESTIONS

A series of horizontal green lines spaced evenly down the page, providing a template for writing 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 our Chief Medical Editor, Dr Tim Iveson, Macmillan Consultant Medical Oncologist.

With thanks to: Suzanne Bridger, Macmillan Palliative Care CNS; Dr David Brookes, Macmillan Consultant in Palliative Care; Dr Judith Cave, Medical Oncologist; and Dr Dipti P Thakker, Senior Clinical Psychologist.

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

Sources

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

Berger, et al. *Principles and practice of palliative care and supportive oncology*. 3rd edition. 2006. Lippincott Williams and Williams.

Gardiner, et al. *Exploring the transition from curative to palliative care: a systemic review of literature*. *BMJ Supportive & Palliative Care*. 2011.

National Council for Palliative Care. *Planning for your future care*.

<http://www.ncpc.org.uk/publication/planning-your-future-care> (accessed March 2016)

NHS Scotland. *Palliative care guidelines*. 2009.

Can you do something to help?

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

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



Share your cancer experience

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

Campaign for change

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

Help someone in your community

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

Raise money

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

Give money

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

Call us to find out more

0300 1000 200

macmillan.org.uk/getinvolved

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £

(Please delete as appropriate)

I enclose a cheque / postal order /
Charity Voucher made payable to
Macmillan Cancer Support

OR debit my:

Visa / MasterCard / CAF Charity
Card / Switch / Maestro

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Don't let the taxman keep your money

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

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

I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. I understand Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, campaigning and services for people affected by cancer. If you would prefer us not to use your details in this way please tick this box.

In order to carry out our work we may need to pass your details to agents or partners who act on our behalf.



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

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

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

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

Together, we are all Macmillan Cancer Support.

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

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

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CANCER SUPPORT**