

MACMILLAN
CANCER SUPPORT

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.

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.

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**.

How to use this booklet

The 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.

At the end of this booklet, there are details of other organisations that can help (see pages 81 to 86). There is also space to write down questions and notes for your doctor or nurse (see pages 87 to 88).

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.

Quotes

Throughout this booklet, we have included quotes from people who have advanced cancer. These are from people who have chosen to share their story with us. Quotes are from our Online Community at **community.macmillan.org.uk** Some names have been changed. To share your experience, visit **macmillan.org.uk/shareyourstory**

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FINDING OUT YOU HAVE ADVANCED CANCER

Finding out your cancer is advanced

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Finding out your cancer is advanced

It is common to have many different reactions and 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.

When you first find out your cancer is advanced, you may feel shocked and find it hard to understand. You may feel frightened about the future, or you may feel angry. These feelings usually become easier to manage with time, and as you start making decisions and plans.

We have information and tips to help you manage your feelings in our booklet **How are you feeling? The emotional effects of cancer** (see page 76).

It is not usually possible to cure an advanced cancer. But some people may live with it for a long time – sometimes for years. Sometimes you may need treatment to control the cancer.

But during this time, many people can continue with their day-to-day lives. They can still do the things that are important to them.

Knowing that your illness may not be curable can give you the chance to think about:

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

It may be good to focus on things you enjoy and what you want to achieve.

For some people, treatment may no longer be able to control the spread of the cancer. Or they may not be well enough to have treatment. Their cancer doctor (oncologist), specialist nurse or palliative (supportive) care specialist, will help with managing any symptoms they may have.

Some people may want to think about what they might want to happen if they 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 called advance care planning. Our booklet **Your life and your choices: plan ahead** has more information about advance care planning (see page 76).

Decisions about treatment

You may want to find out as much as possible about your treatment options before making any decisions. Your doctors and nurses will talk to you about what treatments may be suitable for you. These will depend on the type of cancer you have and where it is in your body. Your doctors will consider what is important to you and how treatment may affect you. This will help you both decide on the best course of treatment.

Treatment for advanced cancer usually aims to control the cancer and help you live longer. It may also aim to help improve your symptoms and quality of life. Treatment can shrink the size of the tumour or stop it from growing for a while.

You may also need other medicines to help manage symptoms.

You may be offered:

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

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. This is to assess the effect the treatment is having. If the scan results show that the treatment is working, you are likely to benefit from continuing with the treatment.

However, the treatment may no longer have an effect on the cancer after some time. You may start getting the side effects of the treatment without any of the benefits. In this case, you may want to think about whether to continue with treatment. Making treatment decisions in these circumstances is always difficult. It may help to talk with your cancer doctor, specialist nurse, family and friends before deciding what to do.

If you decide not to have treatment, you will be offered supportive (palliative) care to help control symptoms. This may include:

- medicines to manage pain or stop you feeling sick (nausea)
- radiotherapy, which is a cancer treatment that can also help reduce pain.

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 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 nurse specialist. 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 has been said. If you want to do this, ask them first. Recordings can also be helpful for family and friends to listen to, so 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 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 carry on working?
- Will I need to stay in hospital and, if so, for how long?
- Am I entitled to any financial benefits?

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 this question.

Your doctors cannot be certain about what will happen to an individual person or how long you might live. So they 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. Cancer affects people differently and it can be hard to say how quickly it might progress.

Some people may have times when the cancer is stable and is not causing too many problems. Some will live with their advanced cancer for many months and 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, it may depend on how the cancer responds to treatment and how quickly it grows. You may need to talk with your cancer doctor again about what the best treatment might be and if it needs to be changed.

Your healthcare 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 is okay 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 learn about your situation in more detail, tell your cancer doctor or 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. You may think of questions between appointments. If you do, you may have a key worker or specialist nurse who you can contact. It can help to write down any questions so you do not forget them.

Our cancer support specialists can also give you information and emotional support. Call them on **0808 808 00 00**. You may find it helpful to talk to someone you do not know and who is not emotionally involved in your situation. Your family or friends may find this helpful, too.

Second opinion

Your multidisciplinary team (MDT) uses national treatment guidelines to decide 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 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, so that 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 to treat cancer and manage its symptoms. One of the ways 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 check it is safe and effective.

Taking part in a trial

You may be invited to take part in a clinical trial. 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 is important to remember 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 will not have to give a reason. There will be no change in the way you are treated by the hospital staff. You will be offered the current standard treatment for your situation.

We have a booklet called **Understanding cancer research trials (clinical trials)** that you may find helpful (see page 76).

Complementary and alternative therapies

Complementary therapies are most often used with or in addition to conventional medical treatments such as chemotherapy and radiotherapy. They are not used to treat cancer, but they may improve well-being. For example, they may help to reduce anxiety, improve sleeping, and cope with other symptoms. Complementary therapies often include relaxation techniques (such as mindfulness) and breathing exercises.

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 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 because of false claims made about alternative therapies. 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.

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.

We have a booklet called **Cancer and complementary therapies** which has more information (see page 76).



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Managing symptoms and side effects

Some cancers can cause symptoms and cancer treatments can cause side effects. Your doctors and nurses will ask you if you are having any symptoms and side effects. It is important to tell your medical team about these so they can help.

For some people, treatment may no longer be able to control the cancer. If this happens, your doctor may suggest changing the aim of treatment. This might involve trying to manage symptoms rather than trying to shrink the cancer. 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, hospices or in the community. They are experts in helping manage symptoms, such as pain or nausea. Your GP or cancer specialist can refer you to a palliative care team.

We have a booklet called **Managing the symptoms of cancer** that has more information (see page 76).

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 you may need stronger pain relief medicines. Your medical team will work with you to decide the best way to manage your pain.

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, hypnotherapy, and relaxation techniques, can help relieve pain. There are specialist pain clinics which may offer these. Tell your nurse or doctor if complementary therapies have helped before.

Your GP may refer you to a specialist palliative care or pain clinic, or a community palliative care team.

We have a booklet called **Managing cancer pain** that has more information (see page 76).

Changes in appetite or eating habits

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

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.

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.

We have a booklet called **Eating problems and cancer** that has more information (see page 76).



Tips to help with eating difficulties

- Try having frequent snacks or small meals. These can be easier to manage than three large meals a day.
- If you do not feel like eating at meal times, you could try to eat again a couple of hours later.
- Do not worry if the food you feel like eating is not always healthy. It is your quality of life that is important. It is more important to eat foods you enjoy and ignore those that you do not like so much. You can try them again if your appetite improves or your sense of taste comes back.
- Eat whatever you feel you can manage. If you know you will not be able to eat a meal, do not agree to eat it to please other people.
- 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.
- You may want to keep a flask or cool bag with drinks and crackers nearby. This will make it easier to eat something whenever you feel hungry.
- If you do not feel able to eat any 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 can also prescribe or recommend supplement drinks and puddings for you.
- If you need more help at home with cooking or eating, talk to your GP or contact the dietitian at the hospital. They may be able to arrange meals on wheels or home help for you.

Our booklets **The building-up diet** and **Recipes for people affected by cancer** have more useful tips (see page 76).

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.

Tips to manage fatigue

- If you do not have much energy, save it for the things you really want to do.
- Organise your daily activities so you have some time to rest every day.
- Have regular rest periods to help you manage your energy levels.
- Try not to overdo things on a day when you have lots of energy. This may cause you to feel tired for several days afterwards. Listen to your body and try to pace yourself evenly throughout the day.
- 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 and use them when you want to. You could try sitting down when preparing food yourself.
- Physical activity can help improve energy levels and help reduce tiredness. It is quite safe to do some gentle physical activity when you have advanced cancer, if you feel able to.

Practical aids, such as walking sticks, walking frames or wheelchairs, can also be useful. 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. If they do not, you can check what is available in your local area on the National Federation of Shopmobility's website. Visit nfsuk.org

Our booklets **Coping with fatigue** and **Physical activity and cancer** have more information about how to manage fatigue (see page 76).

Difficulty sleeping

There are many reasons you may find it difficult to sleep. Sometimes cancer symptoms or treatment side effects can affect sleep patterns. For example, some medicines, such as steroids, can make you feel more awake and alert.

If you think any medicines might be affecting your sleep, speak to your doctor about it. They may be able to suggest ways to help. For example, you could take your medications earlier in the day so you do not feel wide awake at bedtime.

We have more information about difficulty sleeping and steroids on our website. Visit macmillan.org.uk

Tips for a better night's sleep

- Try to go to bed and get up at about the same time every day.
- Gentle exercise and keeping your mind busy with activities can help you feel naturally tired and ready for sleep. Walking, reading, playing games or doing puzzles may help.
- Try to get into a relaxing routine before bed. Have a warm bath or shower, with relaxing oils. Or try using essential oils such as lavender in a diffuser.
- Listen to an audio book, a relaxation exercise or music.
- Some people use a hypnotherapy CD or DVD to relax or calm them before bed.
- 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 late in the evening. Try having a warm, milky drink before bed.

Many people find they cannot sleep because of worry or anxiety. It can be helpful to write down your concerns or talk to someone about them. You may not be able to do anything immediately. But if you write them down, you can talk to someone or find out what might help the next day.

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

Our booklet **Managing breathlessness** has more information about these types of exercises (see page 76).

Other symptoms

Other symptoms you may have include:

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

Tell your GP, specialist doctor or nurse about any symptoms you have and if they are not being well controlled. They will look at the best ways to treat and manage them. We have a booklet called **Managing the symptoms of cancer** which has more information (see page 76).



Coping with day-to-day life

Being diagnosed with advanced cancer can mean living with doubt and uncertainty. You may worry about:

- your treatment, pain or other symptoms
- losing your independence or mobility
- the effect of the cancer on your family and friends
- how you will cope as the cancer develops.

You may be concerned about practical issues, such as your work or finances. It is understandable and natural to have these concerns.

Uncertainty can be one of the hardest things for you, your family and your friends to deal with. It may cause a lot of tension. You might feel irritable, angry or frightened. These feelings can make it difficult to live life the way you would like to.

It is difficult to make plans when you do not know what is going to happen. You can ask your healthcare team about this. But they may only be able to give you an idea of what will happen, because they do not know for sure.

'You want to get things done as time is precious. But things have to go on as usual. You make the most of the important things in life.'

Mary

Many people find they can learn to live with uncertainty. There are some things that can help.

What you can do

There may be times when you feel the cancer is all you can think about. It may feel as if many things are happening that are out of your control. You may find you feel more in control by:

- understanding what is happening to you
- making decisions about things you can do something about.

You may find that once you have dealt with some of your worries, you feel less anxious.

Ask for information and help

Some people feel very alone when they have been diagnosed with advanced cancer. But you do not have to cope with worries and fears on your own. There are people and places who can give you:

- 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. Just call **0808 808 00 00**.

You may be worried about things like how your cancer may affect your day-to-day life. Finding out more can help you feel better. Try to get the most out of appointments with your medical team.

It can help to think about and write down any questions you want to ask before you see them. Take a notepad to write down notes during your appointment so you do not forget what was discussed. You can use pages 87 to 88 to make notes. Your doctor or nurse at the hospital will do their best to answer your questions.

Help from family and friends

It can often help to talk about your situation with someone you trust. Try to think of a few key people you can talk openly with. This could be:

- your partner, if you have one
- parents
- your children, if they are older
- close friends
- colleagues.

Often neighbours or people from a local carers' or cancer support group can also help.

If you feel overwhelmed with jobs to do, try making a list of things you need help with. You could ask your family or friends whether they could help with anything. This might be housework, gardening, looking after a pet or going to appointments with you.

You may find it hard to ask people for help. But you will probably find people are happy to have specific things they can do for you. Accepting any offers of help can help to reduce stress and help you feel more in control.

Look after yourself

Medication

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

- treatment 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. Let any family, friends, or carers know where the list is. If you become unwell, they can tell health professionals what medications you are currently taking.



Healthy lifestyle

You may want to make some changes to your lifestyle. This can include trying to eat a healthy, balanced diet. This can help some people maintain or regain their strength. If your appetite is poor, you can ask your GP to refer you to a dietician. They can suggest what might help to build up your diet.

If you feel well enough, try doing some physical activity. It can improve symptoms such as tiredness (fatigue), pain, poor appetite, constipation and weak muscles. It can also help reduce stress and help you sleep better. You may not have been doing much physical activity because of treatment or symptoms. Start slowly and gradually increase the amount that you do.

Your doctor may suggest that you avoid certain types of physical activity. For example, this could be if the cancer is in your bones or you have bone thinning. Ask your doctor or palliative care team for advice before you start.

We have a booklet called **Physical activity and cancer** that has more useful tips (see page 76).

'I have to accept the reality that I cannot do everything that I thought I might do, but in general I try to get on with things.'

Ian

Complementary therapies

Some people find that complementary therapies are a good way of helping them cope with some of the stresses caused by the cancer and its treatments. A lot of the therapies are relaxing and enjoyable, and may improve your mood. Some can also help relieve any symptoms or side effects you have.

Many therapies, such as relaxation and visualisation, can be done at home using CDs or podcasts.

We have a booklet called **Cancer and complementary therapies** that has more information about complementary therapies and how they may be helpful (see page 76).

If you live alone

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

You may have people you can ask for help. People who care about you will want to help. They might be able to do practical things such as shopping or gardening. You could make a list of things that would make your life easier.

Some people may be better at listening. You could talk to them about any worries you might have.

If you do not have anyone to help you, tell your GP, social worker, or district or community nurse. They will be able to tell you what help and support is available in your area.

Coping with your feelings

It is natural to have a range of emotions when coping with advanced cancer. How often and how strong these feelings are will vary. It can be very physically and emotionally tiring when you are uncertain about your future. Most people find that over time they learn to cope with their feelings with support from family, friends and healthcare professionals.

Fear

Many people with advanced cancer feel frightened. You may 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 that talking puts your mind at rest. Talking to a professional can also help you plan around what might happen. This can help reduce fears.

Anger

It is natural 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. It may have affected your ability to work or your relationships. You may feel frustrated that you need to have tests and treatment, and that your long-term plans are less certain.

There may also be things about your healthcare that make you feel angry. For example, delays in getting test results or treatments may make you feel like this. Talk to your doctors if you feel like this.

Talking about feelings

We all express and manage our feelings in different ways. It may be clear how someone is feeling by their behaviour, what they say and how they say it. But sometimes, one emotion can cover another. For example, a person might be frightened but express this by being short-tempered or irritable. People close to them may not always realise how they are feeling and how much they might be struggling.

Talking about our feelings can help us understand the cause of our behaviour. This is not always easy, so it is important to talk to someone you trust. This could be a family member or friend. For some people, this will give them the support they need.

Some people find it easier to talk to someone outside of their family and friends. Your GP, palliative care nurse or doctors and nurses at the hospital will usually ask how you are feeling. This will give you the chance to talk to them about your feelings and emotions if you want to. You may already feel comfortable enough with them to do this. Or you could tell them that you are struggling with your feelings and would like to talk to someone. They may be able to refer you to someone who is trained to listen, such as a counsellor.

If you are finding it difficult to cope, you may need more specialised emotional support from a psychologist. Your GP or specialist can refer you to one.

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 is 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 will not give advice or answers, but will help you find your own answers. Talking one-to-one with a trained counsellor can help you express and understand your feelings. It can also help you find ways to cope with these feelings or the problems they relate to.

GP practices and hospitals often have their own counsellors. If they do not, they should be able to refer you to one. You can talk to one of our cancer support specialists on **0808 808 00 00** to find out about counselling in your area. The British Association for Counselling and Psychotherapy can also give you details of counsellors in your area. You can find their contact details on page 82.

If your family members or friends are finding it difficult to cope, they may find counselling helpful.

Psychological support

Sometimes strong emotions can feel overwhelming and difficult to cope with. These feelings can affect your thinking and behaviour. Some people may have physical symptoms of anxiety or depression such as pain, difficulty sleeping or breathlessness.

If symptoms of anxiety or depression become overwhelming and hard to manage, you may find it helpful to see a clinical psychologist.

Clinical psychologists are often part of the hospital cancer team or the palliative care team. They are specialists in providing psychological and emotional support to people with advanced cancer. Some psychological services will also offer support to carers and family members.

The palliative care team, your cancer doctors or your nurses will be able to make a referral.

Support and self-help groups

Your family and friends may be supportive. But you may find it useful to be with people who are going through a similar experience to you.

There are many support groups for people with cancer and their family and friends. 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 help 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 try a group to see what it is like and then make a decision.

You can search for groups in your area on our website. Or our cancer support specialists can help you find local groups. Just call **0808 808 00 00**.

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 our Online Community useful. Just visit community.macmillan.org.uk

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.

You may find it helpful to talk to a religious or spiritual leader or advisor. They can offer emotional and spiritual comfort, and help you feel more at peace with your situation. Even if you have not attended religious services regularly before or are not sure what you believe, you can still talk to someone. This may be a priest, rabbi, imam or other spiritual advisor, depending on your faith or preference. They are used to dealing with uncertainty and will not be shocked.

Hospices usually provide spiritual support to people of all faiths or no faith. This is often available through their day services.

You may prefer to talk to someone who is not religious. Humanist Care have volunteers who can provide non-religious pastoral support.

Being diagnosed with advanced cancer can make you think about how long you might live and when you will die. Dying is something that is certain for all of us. But it is not something that we talk about very much.

Some people feel calm about the fact that they are going to die. But others are frightened by the thought. Death cafes are opportunities to meet with other people to talk about death. Being with others who are having similar feelings and emotions can make it easier to talk about your own feelings.

Death cafes are led by someone who will help and support the conversation. They are held in different places throughout the country. Some hospices help with these and have dates of when and where they are being held locally. Visit **deathcafe.com** to find out more.

Medicines that can help

Sometimes feelings of anxiety and depression can affect your ability to cope with everything that is happening. 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 take effect. Medication is not likely to change how you think about things. But it might help you feel better so that you can talk to someone about it.

We have a booklet called **How are you feeling? The emotional effects of cancer** which has more information about the feelings and emotions you may have (see page 76).

Things you can do for yourself

There are 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. If people are struggling to understand your feelings, you could show them a section of the journal.

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 some of these 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 is available in your area.

Mindfulness is about learning to notice what is happening within and around you. It helps you learn to 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. 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 the meditation, yoga and 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 to recognise any unhelpful thoughts. It can help you manage your problems by changing the way you think and behave. There are a few centres in the UK that offer MBCT classes on the NHS. Talk to your healthcare team to find out where classes are available.

Partners, family and friends

Partners, family and friends can be an important source of 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. 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 talk about it.

If you find talking about your situation difficult, our booklet **Talking about cancer** may be helpful.

When someone has a serious illness, many people are unsure what to say. Some people may try to avoid you rather than risk saying the wrong thing. Some people may avoid discussing your illness or may seem insensitive. We have more information to help your family and friends talk about your illness and be able to support you in our booklet **Talking with someone who has cancer** (see page 76).

Your partner

If you have a partner, you may find that your relationship is affected by:

- the stresses of an uncertain future
- any side effects of treatment
- other difficulties.

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

Sometimes people avoid talking about how they feel as they do not want to upset the other person. But talking about what is happening and how you feel can help you both feel less alone. Some people find their relationship becomes stronger if they can be open about the situation and their feelings.

For some couples, having a short break from each other may help relieve stress. You may find that other ways to help relieve stress work better for you. For example, this may be doing some physical activity. Sometimes talking to someone outside of your situation can help. This may be a relative, a friend or a counsellor.

Sexuality

Having advanced cancer can affect how you feel about your sexuality. This will depend on the type of cancer you have. Treatment and side effects can also affect sexuality. But having cancer does not 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 to adjust to some changes. This adjustment may take some time. You may not feel like having sex, or you may be unable to. But there are still intimate and affectionate ways of showing how much you care about each other.

Partners may sometimes worry that having sex could harm you or make the cancer worse. Or they may worry that they could catch the cancer. But neither of these things are true. Try talking openly with your partner about difficulties or concerns about your sex life. This can help sort out any misunderstandings.

Our booklet **Cancer, you and your partner** has more information and tips (see page 76).

Although it can be embarrassing to talk about, 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. These include Relate and the College of Sexual and Relationship Therapists. You can find their contact details on page 83. Your GP, practice nurse, community nurse, Macmillan nurse or palliative care nurse may also be able to help you find someone.

It might be important to avoid getting pregnant or fathering a child. This depends on what treatment you are having. Ask your specialist doctor or nurse for advice if you are thinking about having a baby.

Our booklets **Cancer and your sex life – information for men** and **Cancer and your sex life – information for women** have more information (see page 76).

Family support services

You may find it hard to know what to say to your children or grandchildren. Many hospices have family support services, which offer support to families of people with advanced cancer. Your community nurse, Macmillan nurse or GP may be able to refer your family, including any children, for this service.

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. It is usually best to be honest with them and tell them your cancer has come back or spread. You may feel like you want to protect them. But if you pretend everything is okay, they may feel they are not able to talk about their worries. 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 tell them at a time when you are with other adults. This may be a partner, family or close friends. Then the children will know there are other adults they can talk to and who can support them. It is important they know who they can talk to if they have questions or need to talk.

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 is helpful to sensitively prepare them for your death. This can be a difficult thing to do and you may need help and support. It is usually a good idea to let the nursery or school know what is happening. That way they can support your child or children too.

We have a booklet called **Preparing a child for loss** that has more information (see page 76).

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 may feel over-burdened. It is 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. This might be a grandparent, family friend, teacher or counsellor. It can often help to tell the teacher about your situation so they know what is going on. They can look out for any signs of difficulties your child may be having. If your child is working, you can encourage them to tell their employer.

They may also find it useful to look at the website **riprap.org.uk**. It was developed for teenagers who have a parent with cancer.

Our booklet **Talking to children and teenagers** about cancer has more information and tips (see page 76).

Friends and colleagues

Some friends and colleagues will feel unsure about how to talk to you. They may wait for you to talk about it first before they say anything.

You can tell friends and colleagues as much or as little as you want about your health. You will probably not want to talk about your cancer all the time. You may find it helpful for your friends to treat you the same way as usual. For some people, having a standard answer can be helpful to direct the conversation in a way you would prefer.

Your friends and colleagues will probably find it helpful if you can tell them how they can help you. For example, this might include helping with housework or driving you to hospital appointments. Or you may want your friends to help to distract you, if your thoughts are focused on the cancer.

If you do not want to talk

There may be times when you do not feel like talking and want to be on your own. This is quite natural. So don't feel that you have to see people if you need time to yourself.

If you want to have some time alone, you could ask other people to answer the door or 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 your nurses to help you with this.

If you would still like to receive texts or emails from others, let them know. But explain that you might not always be able to reply.

There is no right or wrong way to face this situation. Each person has 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, this may be if you are having treatments like chemotherapy, or have symptoms that are worrying you. But at other times, you may need very little help from your healthcare team. You might only see them for check-ups.

Hospital care

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

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

'I always try to plan in something nice on any hospital visit day. I pass a National Trust property on the way to hospital, or sometimes go for a walk, coffee or lunch.'

Katrina



Care at home

Some people will need nursing care at home. There is help and support for people being looked after at home. This can help both you and your carers.

It is not possible to get 24-hour nursing care at home. The amount of support available is different across the UK. Your GP or social worker can tell you about what is available in your area.

We list here some of the people who are most likely to be involved in your care when your cancer is advanced.

GP

When you are being looked after at home, your GP has overall responsibility for your care. They are usually responsible for prescribing any drugs you need. They will also arrange for you to go into hospital or a hospice if needed.

Other healthcare professionals working in the community can also assess your nursing and medical care needs. This might include a community or palliative care nurse. Your GP and the community professionals can arrange help for you and your family.

Nurses

- Community or district nurses can make regular home visits. They can do 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 are sometimes called Macmillan nurses. They are often part of the homecare team (see opposite page). They specialise in managing pain and other symptoms. They are also experts in giving emotional support to patients and their families. Palliative care nurses may be based in hospitals or hospices (see pages 54 to 55) and work closely with other healthcare professionals to provide support. They can often visit people in their own homes. They usually call or visit you regularly to see how you are and make sure any symptoms are being managed. For example, they can advise you about which medicines to take if pain is a problem. They may also be able to tell you about certain financial benefits you can apply for. They can 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 arrange a palliative care nurse for you.
- Marie Curie nurses are available in some parts of the UK. They provide one-to-one nursing overnight from a registered nurse or senior healthcare assistant in your home. The shifts are usually for 8 or 9 hours. In some parts of the UK, they also offer shorter shifts, evening shifts and day shifts. There may be differences in how much care they provide. Marie Curie nursing services are free. Usually your district nurse will arrange a Marie Curie nurse for you. The district nurse will talk to you and your carers to help decide what care you need. You can find the contact details for Marie Curie on page 81.

Homecare teams

A homecare team provides care for you in your home. They usually include palliative care nurses. Sometimes the team includes a doctor who may share your care with your GP. Homecare teams are usually based at a hospital or hospice.

Other professionals

- Occupational therapists working in the community can help you keep your independence at home. They can assess your situation. Then 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. This might include fixing safety rails in your bathroom or making doors wider. If you have difficulty dressing, they may suggest and arrange to have your clothes altered. Many occupational therapists may also be able to change daily routines and activities to help you manage low moods. Some occupational therapists can also help you manage anxiety, fatigue and breathlessness.
- Physiotherapists can help keep you moving. They also offer treatment, massage and exercise programmes to help relieve pain. Your GP or community nurse can arrange physiotherapy for you.

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 about your daily routine and what you find difficult. They use this information to work out what your needs are and what support can be provided.

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

Each local authority has its own assessment procedure. You can find your local authority by visiting [gov.uk/find-local-council](https://www.gov.uk/find-local-council). 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. 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 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.

There also may be local organisations or charities that offer homecare, gardening, companionship or sitting services. Your GP or hospice staff usually have contact details of any in your area.

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

Charities such as Age UK and Carers Trust (see page 85) can also provide home help and extra help around the house.

Other sources of help at home

- British Red Cross (see page 84) has volunteers that can help you with shopping and errands, like posting letters and changing library books. It can also lend equipment, such as wheelchairs and commodes, and provides a service to take people to hospital.
- Some areas have volunteer schemes that can arrange for someone to visit you at home. This can provide company for you and give your carer a break. You could check notice boards in your GP surgery or your local library, community centre or church.
- NHS continuing healthcare may fund and provide for all your care needs at home. This is for people who need a lot of healthcare or are in the last few weeks of life.

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. They have a team of doctors, specialist palliative care nurses and other professionals. They are all experts in controlling symptoms and providing emotional support.

You can go into a hospice for different reasons. You may need to go into a hospice for a short time to help control your symptoms. Or you may go in for respite care to give your carer a break. Palliative care nurses may arrange this for you. They will visit you at home again once you are discharged. You may decide that you would like to die in a hospice. You will need to discuss your wishes with your GP and the hospice team involved with your care.

Hospices are very different to hospitals. They are quieter and aim to provide care to suit each person's situation. Visiting is usually much less restricted than in a hospital. They 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, so there may be a waiting list. But urgent admissions can usually be arranged within a couple of days.

Some hospices have day centres. People who are living at home can visit the day centre for a day or more each week. They can get care from the specialist team and peer support from people living with similar illnesses.

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 located across the UK. See page 81 for their contact details. If you are not sure about the idea of hospice care, you can ask to visit before you decide. The staff will be able to show you around and answer any questions or concerns you have.

Care homes

You or your family may think you might benefit by staying in a care home. These usually offer short-stay or long-stay 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. Your GP, district nurse or social worker can arrange for you to stay in a care home, either with or without nursing care.

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

A private care home charges for care. But if you have little or no savings, you can sometimes get help in paying this. It can sometimes take a while to organise care in a care home. There are not always places available.

nhs.uk has information about care homes and funding for care. You can get lists of local registered care homes (including ones with nursing) and their details from:

- your local social services department
- your area health authority.

You can also search for a care home by visiting **carehome.co.uk**

Help with pets

Many people are concerned about what will happen to their pet if they are going to be away from home. This includes going into hospital. Some organisations can offer services such as dog walking. If you need to be away from home for a while, some organisations may be able to foster your pet.

We have more information about getting help with pet care when you are unwell on our website. Visit **macmillan.org.uk**

Things I need help with

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 have talked about in this section, or another concern you have.



PLANNING AHEAD

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Ways to plan ahead

Many people want to plan ahead, even though the future may be uncertain. This is sometimes called advance care planning. There are different ways you can plan ahead and several documents you can use to record your wishes. Your healthcare team can tell you more about the forms you can use.

It is helpful to plan while you are well enough to do so and can make decisions. You might want to start thinking about:

- how you would like to be cared for when you become less well
- where you want to be when you are approaching the end of your life
- who will look after your affairs if you are no longer able to do so.

It is best to write down your wishes and preferences. That way your family and health and social care professionals will know what you would like. There is no guarantee that your wishes will be carried out. But the people looking after you will follow them as much as possible.

Some people choose to make an advance decision to refuse treatment. This is also known as an advance directive, advance decision, or living will. It means making a record of:

- any specific treatments you do not want to have
- the circumstances when you would refuse them.

You may also want to appoint someone who could make decisions on your behalf if you were unable to. This could be about your property or finances, or your health and welfare. This is called a power of attorney.

You can talk about advance care planning with your GP, specialist doctor or nurse, or palliative care team. It can also be helpful to speak with family and friends.

We have more information about planning ahead. There is separate information for England and Wales, Scotland and Northern Ireland in our booklet **Your life your choices: plan ahead** (see page 76).

Putting your affairs in order

Putting your affairs in order is part of advance care planning. Sorting through important documents and thinking about who will receive your possessions after you die can be upsetting. However, it may mean that family or friends do not have to make painful decisions after you have died. It may also prevent financial difficulties that could happen if you do not make your wishes clear. Putting your affairs in order may help relieve anxiety and leave you free to concentrate on the present.

Things you can do to put your affairs in order

- Make a will, or make sure your will is up to date, if you have one. A will makes sure that your wishes are carried out after your death. It also ensures that your possessions go to the people you want them to. A will is a legal document, so it may be best to use a solicitor to help you word it. 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.
- If you have children 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 friend. Decide on and appoint 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 (executor).
- You might want to make plans for the sort of funeral you would like. Or you may want to discuss whether you would prefer a cremation or a burial. If you tell your family and friends what you want, your funeral is much more likely to reflect your wishes.
- It may also be helpful to note down any everyday tasks that you have always done. For example, this might include where you get the car serviced or how to use the boiler.

Our booklet **End of life** has more information about putting your affairs in order. We also have a leaflet called **Your step-by-step guide to making a will** which may be helpful (see page 76).



Important documents

You may find it helpful to make a list of your important documents. This could include:

- your will
- an Advance Decision to Refuse Treatment
- your funeral plan.

It can also help to include:

- your bank and building society details
- any insurance policies you have
- the details of your accountant, solicitor and tax inspector.

Write on the list where to find this information. Make sure that your partner or the executor of your will knows where it is kept.



FINANCIAL SUPPORT

Financial help and benefits

68

Financial help and benefits

When you are affected by cancer, you might need help with extra costs. These might be travelling costs to and from hospital, car parking charges or higher heating or food bills. You might also need financial support if you have to stop working. This can cause more worries at a difficult time.

We have lots of information about the different types of financial help that might be available in our booklet **Help with the cost of cancer** (see page 76). You can call our cancer support specialists on **0808 808 00 00** for more information. Other organisations such as Citizens Advice can also offer help with financial issues.

If you work for an employer and take time off sick, you may be able to get Statutory Sick Pay. Your employer will pay this for up to 28 weeks.

Before your Statutory Sick Pay ends, or if you do not qualify for it, check whether you can get financial help from the government. You can find out about state benefits and apply for them at:

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

Here are some benefits that you might be able to get if you are affected by cancer.

Employment and Support Allowance (ESA)

This benefit is for people under State Pension age who cannot work because of illness or disability. There are different types of ESA:

- Contribution-based ESA may be available if you have paid enough National Insurance.
- Income-related ESA may be available if your income and savings are low, or if you cannot get contribution-based ESA. Income-related ESA is gradually being replaced by a new benefit called Universal Credit.

Personal Independence Payment

This benefit is for people aged between 16 and 64 who have problems moving around and looking after themselves. You must have had these difficulties for at least 3 months and expect them to last for at least 9 months.

Attendance Allowance

This benefit is for people aged 65 or over who have problems looking after themselves because of an illness or disability. This could mean getting out of bed, having a bath or getting dressed. You must have had these problems for at least 6 months.

Special rules

If you are terminally ill, and your doctor thinks you may be expected to live for less than 6 months, you can apply for some benefits using a fast-track process called special rules. Your doctor or specialist nurse will need to fill out a form for you.

Your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate. It does not matter if you live longer than 6 months.

Help for carers

Carer's Allowance is a weekly benefit that helps people who look after someone with a lot of care needs. If you do not qualify for it, you can apply for Carer's Credit.

Carer's Credit helps prevent gaps in your National Insurance record if you have to stop working while you are caring for someone else. You do not get money, but it protects your right to a State Pension later in life.

Direct payments

If you need social services, you may be entitled to get direct payments. These will be from your local authority or health and social care trust. So they give you payments to organise the services yourself, rather than organising and paying for them for you.

You can get information about direct payments at:

- [gov.uk/apply-direct-payments](https://www.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

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. A grant from Macmillan would not normally affect the benefits you are entitled to.

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 you can apply through a health or social care professional such as a district nurse or a social worker.

CLIC Sargent 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

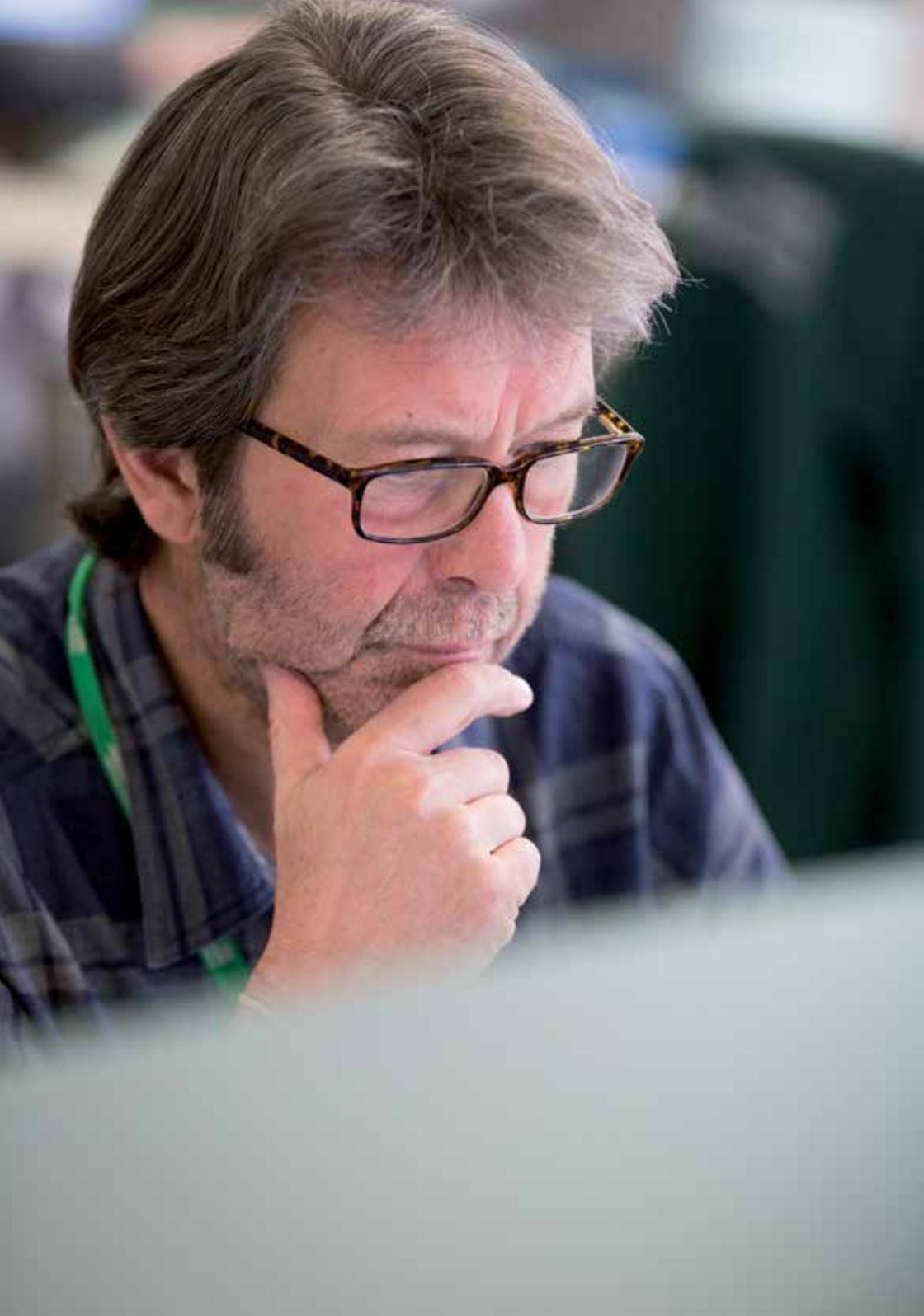
People with cancer may find it hard to get certain types of insurance, including life and travel insurance. A financial adviser can help you look at your needs and find the best deal for you. You can find a financial adviser by contacting a financial organisation. We have a booklet called **Insurance** that has more information.

Travel insurance

If you are feeling well enough, you may be thinking about planning a holiday. If your cancer is advanced, it can be difficult to get travel insurance to go abroad.

We have information about getting travel insurance and travel and cancer in our booklet **Travel and cancer** (see page 76).





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About our information

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

Order what you need

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

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

Online information

All of our information is also available at **macmillan.org.uk/information-and-support**

There you'll also find videos featuring real-life stories from people affected by cancer, and information from health and social care professionals.

Other formats

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

- audiobooks
- Braille
- British Sign Language
- easy read booklets
- eBooks
- large print
- translations.

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

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

Help us improve our information

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

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

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



Other ways we can help you

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

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. Our cancer support specialists 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.

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

Macmillan Grants

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

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants.

We can also tell you about benefits advisers in your area. Visit [macmillan.org.uk/financialsupport](https://www.macmillan.org.uk/financialsupport) to find out more about how we can help you with your finances.

Help with work and cancer

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

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 (Monday to Friday, 8am to 6pm).

Macmillan Organiser

This includes a records book to write down information such as appointments, medications and contact details. You can also download the app on IOS or Android.

Other useful organisations

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

Advanced cancer and end-of-life care

Hospice UK

Tel 020 7520 8200

Email info@hospiceuk.org

www.hospiceuk.org

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

Marie Curie

Helpline 0800 090 2309

(Mon to Fri, 8am to 6pm,
Sat, 11am to 5pm)

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 support organisations

Cancer Research UK

Helpline 0808 800 4040

(Mon to Fri, 9am to 5pm)

www.cancerresearchuk.org

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

Maggie's Centres

Tel 0300 123 1801

Email enquiries@maggiescentres.org

www.maggiescentres.org

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

General health information

Health and Social Care in Northern Ireland

www.hscni.net

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

Healthtalk

Email info@healthtalk.org

www.healthtalk.org

www.youthhealthtalk.org

Has information about cancer, and videos and audio clips of people's experiences. Also provides advice on topics such as making decisions about health and treatment.

NHS.UK

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

Helpline 0800 224 488

(Mon to Fri, 8am to 10pm,
Sat and Sun, 9am to 5pm)

www.nhsinform.scot

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)

Tel 01455 883 300

Email bacp@bacp.co.uk

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

College of Sexual and Relationship Therapists (COSRT)

Tel 020 8543 2707

Email info@cosrt.org.uk

www.cosrt.org.uk

Provides information and support on sexual problems.

Humanists UK

Tel 020 7324 3060

www.humanistcare.org.uk

Humanist Care is the pastoral arm of Humanists UK, providing support to people with non-religious beliefs.

Relate

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

Helpline 0800 022 4250

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

Textphone 028 9031 1092

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. Use their online webchat or find details for your local office in the phone book or by contacting:

England

Helpline 03444 111 444

www.citizensadvice.org.uk

Wales

Helpline 03444 77 2020

www.citizensadvice.org.uk/wales

Scotland

Helpline 0808 800 9060

www.citizensadvice.org.uk/scotland

Northern Ireland

Helpline 0800 028 1181

www.citizensadvice.co.uk

Department for Work and Pensions (DWP)

Personal Independence Payment (PIP) Enquiry Line

Tel 0800 121 4433

Textphone 0800 121 4493

NGT text Relay 18001

then 0800 121 4433

(Mon to Fri, 8am to 6pm)

Carer's Allowance Unit

Tel 0800 731 0297

Textphone 0800 731 0317

NGT text Relay 18001

then 0800 731 0297

(Mon to Fri, 8am to 6pm)

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.

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

Textphone 0207 562 2050

Email contactus@redcross.org.uk

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.

National Federation of Shopmobility

Tel 01933 229644

Email shopmobility@bhta.com

www.nfsuk.org

Brings together Shopmobility schemes, which give people access to mobility vehicles. You can search the website to see what help is available in different areas.

Support for young people

CLIC Sargent

Tel 0300 330 0803

www.clicsargent.org.uk

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

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.

Support for older people

Age UK

Helpline 0800 055 6112

(Daily, 8am to 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.

Support for carers

Carers Trust

Tel 0300 772 9600

(Mon to Fri, 9am to 5pm)

Email info@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 0808 808 7777

(Mon and Thurs, 10am to 4pm)

Email advice@carersuk.org

www.carersuk.org

Offers information and support to carers across the UK.

Has an online forum and can put people in contact with support groups for carers in their area.

Care homes

UK Homecare Association

Tel 020 8661 8188

Email enquiries@ukhca.co.uk

www.ukhca.co.uk

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

Carehome.co.uk

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.

Bereavement support

Child Bereavement UK

Tel 0800 02 888 40

Email [support@](mailto:support@childbereavementuk.org)

childbereavementuk.org

www.childbereavementuk.org

Supports families when a child is grieving or is facing bereavement.

Complementary therapies

Complementary and Natural Healthcare Council

Tel 020 3668 0406

Email info@cnhc.org.uk

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: Michelle Buono, Macmillan End of Life Education Nurse; Dr Faye Gishen, Consultant and Lecturer in Palliative Medicine; Louise Hines, Macmillan Community Specialist Nurse in Palliative Care; Dr Kiran Kaur, Consultant in Palliative Medicine; Matt Loveridge, Clinical Nurse Specialist; Dr Kathleen McHugh, Consultant Clinical Psychologist; Gina McRobb, Clinical Nurse Specialist; Dr Ollie Minton, Macmillan Consultant in Palliative Medicine; and Melanie Smith, Community Specialist Palliative Care Nurse.

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

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

Sources

We have listed a sample of the sources used in the booklet below. If you would like further information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

National Council for Palliative Care. www.ncpc.org.uk/ (accessed November 2018)

National Institute for Health and Care Excellence (NICE). End of Life Care for Adults.

www.nice.org.uk/guidance/qs13 Last updated March 2017 (accessed November 2018)

NHS Scotland. Scottish Palliative Care Guidelines. www.palliativecareguidelines.scot.nhs.uk/ (accessed November 2018)

Uptodate. Approach to symptom assessment in palliative care. www.uptodate.com/contents/approach-to-symptom-assessment-in-palliative-care (accessed November 2018)

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

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

We're here to help everyone with cancer live life as fully as they can, providing physical, financial and emotional support. So whatever cancer throws your way, we're right there with you. 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.

**MACMILLAN
CANCER SUPPORT**
RIGHT THERE WITH YOU

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 <p>The Information Standard</p> <p>Certified member</p>	<p>This organisation has been certified as a producer of reliable health and social care information.</p> <p>www.theinformationstandard.org</p>
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What's this logo? Visit **macmillan.org.uk/ourinformation**

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OR debit my:

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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