

**WE ARE
MACMILLAN.
CANCER SUPPORT**

A practical guide to living with and after cancer

THE CANCER GUIDE



About this booklet

This booklet aims to help you understand what cancer means and what to expect. It also explains where you can get more information and support. This booklet is for people living with cancer, and their family, friends and carers.

Being diagnosed with cancer can be a huge shock. You may be feeling lots of different emotions. But it doesn't mean you have to give up hope. Many people are now treated successfully or able to live with cancer for many years. There are lots of people and services that can support you.

We hope this booklet answers some of your questions and helps you cope with some of the feelings you may have.

How to use this booklet

We've divided the booklet into sections to help you find the information you need. You don't have to read it from start to finish. Different sections may be useful at different times, depending on your situation. You can use the contents list on pages 4–5 to help you.

We recommend that you read this booklet alongside our specific information about the type of cancer you have. You can order this information for free at **be.macmillan.org.uk** or by calling us on **0808 808 00 00**. All of our information is also available online at **macmillan.org.uk/cancerinformation**

Throughout the booklet, we've included some comments from people who have been affected by cancer. Some are from our online community (macmillan.org.uk/community) and some are from people who have chosen to share their stories with us. We hope you find these helpful.

On pages 84–95, you'll find details of how Macmillan and other organisations can help you. There's also space on pages 96–97 to write any notes or questions you may have for health and social care professionals.

If you'd like to discuss this information, call the Macmillan Support Line free on **0808 808 00 00**, Monday–Friday, 9am–8pm. If you're hard of hearing, you can use textphone **0808 808 0121**, or Text Relay. For non-English speakers, interpreters are available. Alternatively, visit macmillan.org.uk



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Information about cancer can be overwhelming. This section explains what cancer is and what the signs and symptoms can be. It also describes some of the health and social care professionals you might meet and how they can help you.

Diagnosing cancer (pages 19–23)

This section is about how cancer is diagnosed. It has information about some of the tests and scans that may be used to diagnose cancer, and how you might be feeling.

Treating cancer (pages 25–41)

Having the right information about different cancer treatments can help you make treatment decisions. This section has information about different treatment options and possible side effects.

Organising (pages 43–55)

Cancer can affect the practical things in your life. This section has information about managing work, travel and finances when you have cancer. It also looks at legal rights and how to plan ahead for your future care.

Coping (pages 57–69)

Cancer can have a huge emotional impact on you and the people you're close to. This section has information to help you cope with these feelings and explains where you can get support.

Medical terms (pages 71–81)

When you have cancer, you will come across lots of new medical terms. This section explains what these words mean. We've highlighted some of these in **bold** throughout the booklet.

Further information (pages 83–95)

This section has information about the different ways Macmillan can support you. It also has contact details of other organisations that can give you more information and support.



UNDERSTANDING CANCER

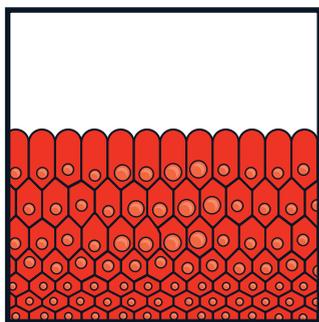
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What is cancer?

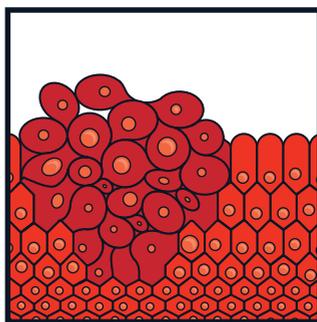
Cancer starts in cells in our body. Cells are tiny building blocks that make up the organs and tissues of our bodies. They divide to make new cells in a controlled way. This is how our bodies grow, heal and repair. Cells receive signals from the body telling them when to divide and grow and when to stop growing. When a cell is no longer needed or can't be repaired, it gets a signal to stop working and die.

Cancer develops when the normal workings of a cell go wrong and the cell becomes abnormal. The abnormal cell keeps dividing, making more and more abnormal cells. These eventually form a lump (**tumour**). Not all lumps are cancerous. Doctors can tell if a lump is cancerous by removing a small sample of tissue or cells from it. This is called a **biopsy**. The doctors examine the sample under a microscope to look for cancer cells.

Normal cells



Cells forming a tumour



A lump that is not cancerous (**benign**) may grow but cannot spread to anywhere else in the body. It usually only causes problems if it puts pressure on nearby organs.

A lump that is cancer (**malignant**) can grow into nearby tissue. Sometimes, cancer cells spread from where the cancer first started (**the primary site**) to other parts of the body. They can travel through the blood or **lymphatic system** (see page 77). When the cells reach another part of the body, they may begin to grow and form another tumour. This is called a **secondary cancer** or a **metastasis**.

Signs and symptoms of cancer

If you are a partner, friend, relative or carer, you may want to know more about how cancer is found. There are certain changes to the body that may suggest someone has cancer. These signs and symptoms don't always mean cancer, but a healthcare professional should check them as soon as possible.

Knowing how your body normally looks and feels can help you notice any early changes that could be caused by cancer. Always see your doctor if you have symptoms that are ongoing, unexplained or unusual for you. If it is cancer, the sooner it is found, the more likely it is to be cured.

Our leaflet **Signs and symptoms of cancer – what to be aware of** has more information. You can order this from **be.macmillan.org.uk** or call our support line on **0808 808 00 00**.

Who can get cancer?

Anyone can get cancer. It affects people from all backgrounds and lifestyles. It has been estimated that more than one in three people will get cancer at some point in their lives.

We don't know exactly what causes most cancers. But we know there are factors that can increase or influence someone's risk of getting cancer. These risk factors include your age and certain lifestyle choices. Cancer is most common in people over the age of 50, but it can happen at any age.

Because cancer affects so many people, there is a lot of support available. See pages 84–95 to find out how to get more information and support, for example from local support groups, or from organisations such as Macmillan.



'I was 26, and considered myself young and fit, so to get the news that I had cancer was difficult to deal with.'

Patrick



Who might I meet?

During your diagnosis and treatment, and in your life after treatment, you will meet lots of different health and social care professionals. Some work in the community and look after you at home. Others are based in hospitals or treatment centres.

You should have a **key worker** and be given their contact details. Your key worker should be your first point of contact for support and information. They can answer your questions or tell you who can help. If you have a **clinical nurse specialist** (CNS), they may be your key worker.

Your community team

Your **GP** looks after your healthcare while you're at home. They work closely with other members of your healthcare team. GPs can arrange for you to see specialists, and help with any ongoing symptoms and side effects from the cancer and its treatment. They can also:

- organise services to help you live at home
- help answer any questions you may have
- support you by talking through any decisions you may have to make about your treatment
- talk to family members about your illness (only with your permission)
- talk with you if you're unhappy with any part of your care.

Community and district nurses work closely with your GP. They are sometimes based at a GP practice. The nurses can visit your home (or residential care home) to give you care and support. They can also support anyone looking after you. Your GP can contact the nurses for you.

Some GP practices have **practice nurses**, who work alongside the GP. They can help explain things to you and may be involved in taking blood tests, dressing wounds or other areas of your care.

Your hospital team

A group of professionals will work together to manage your care. This is called a **multidisciplinary team (MDT)**. Depending on the type of cancer and how it's treated, your MDT may include a:

- **surgeon** – a doctor who is an expert in surgery and does operations
- **clinical oncologist** – a doctor who is an expert in treating cancer with radiotherapy and chemotherapy (see page 26)
- **medical oncologist** – a doctor who is an expert in treating cancer with chemotherapy
- **haematologist** – a doctor who is an expert in diagnosing and treating blood disorders
- **clinical nurse specialist** – a nurse who is an expert in an area of health, such as a specific cancer type
- **therapeutic radiographer** – an expert in giving radiotherapy
- **radiologist** – an expert in x-rays and scans
- **palliative care doctor or nurse** – an expert in relieving the symptoms of cancer when it can't be cured.

Many hospitals have specially trained information staff. Some hospitals have developed local information that is tailored to your situation. They can give you, and your family and friends, information about cancer.

Some hospitals, and charities like Macmillan, have set up cancer information and support centres. These offer free information about cancer, and you can talk to staff and volunteers face to face. They can help you get the support services you need. Some centres may be able to offer benefits advice and counselling services. Visit macmillan.org.uk/in-your-area to find out if there is a centre near you.

Other health and social care professionals

There are many specialists who can provide support and care, during and after you have been diagnosed. These may include dietitians, pharmacists, home carers, occupational therapists, physiotherapists, counsellors, and speech and language therapists. They may be based in the community or in the hospital.

Social services and voluntary organisations

You may have questions about getting support at home. For example, you may need help with:

- any care needs you have, such as getting washed or dressed
- practical things like shopping or cleaning.

If they think it's appropriate, your GP or a member of your healthcare team may refer you to a **social worker** for help with some of these issues. If you've been referred to social services, you can ask them about any practical issues you have. They can also help with financial issues.

There may also be voluntary organisations or charities in your area that could help with practical issues. Speak to your GP or key worker to find out more about these organisations.

Out-of-hours services

There may be times when you need non-emergency medical advice, when the GP surgery is closed. Out-of-hours healthcare services are usually open from 5pm to 8am on weekdays, and all day at the weekends and on bank holidays. Under recent UK government plans, some services may begin to open for longer and on more days in certain areas.

There are different services across the UK that can help you during out-of-hours periods:

- In England and Scotland, call **111**. This number is free to call.
- In Wales, call **0845 46 47**.
- In Northern Ireland, contact numbers vary but are listed at **nidirect.gov.uk/out-of-hours-service**

Sometimes you may be given specific out-of-hours and emergency contact numbers to call. For example, chemotherapy day units will have an out-of-hours number you can call if you need advice or become unwell after treatment.

Getting the most from your appointments

Appointments and other chances to speak with your healthcare team can be short. It's good to be prepared. The following tips may help.

- **Plan your questions.** Think of any questions you have about your diagnosis, treatment or anything else you are worried about. You could write these down on pages 96–97 and take them with you.
- **Keep notes.** You could use the Macmillan Organiser to record appointment notes. You can order this from be.macmillan.org.uk or download the My Organiser app if you have a smartphone.
- **Ask a friend or family member to join you.** They may be able to take notes, or remind you of what was discussed after the appointment.
- **Don't feel you have to ask everything at once.** There will be other chances to ask questions later on.
- **Remember that professionals are there to help.** They are very likely to have helped people with similar issues before, even if it is something you find embarrassing to ask about.

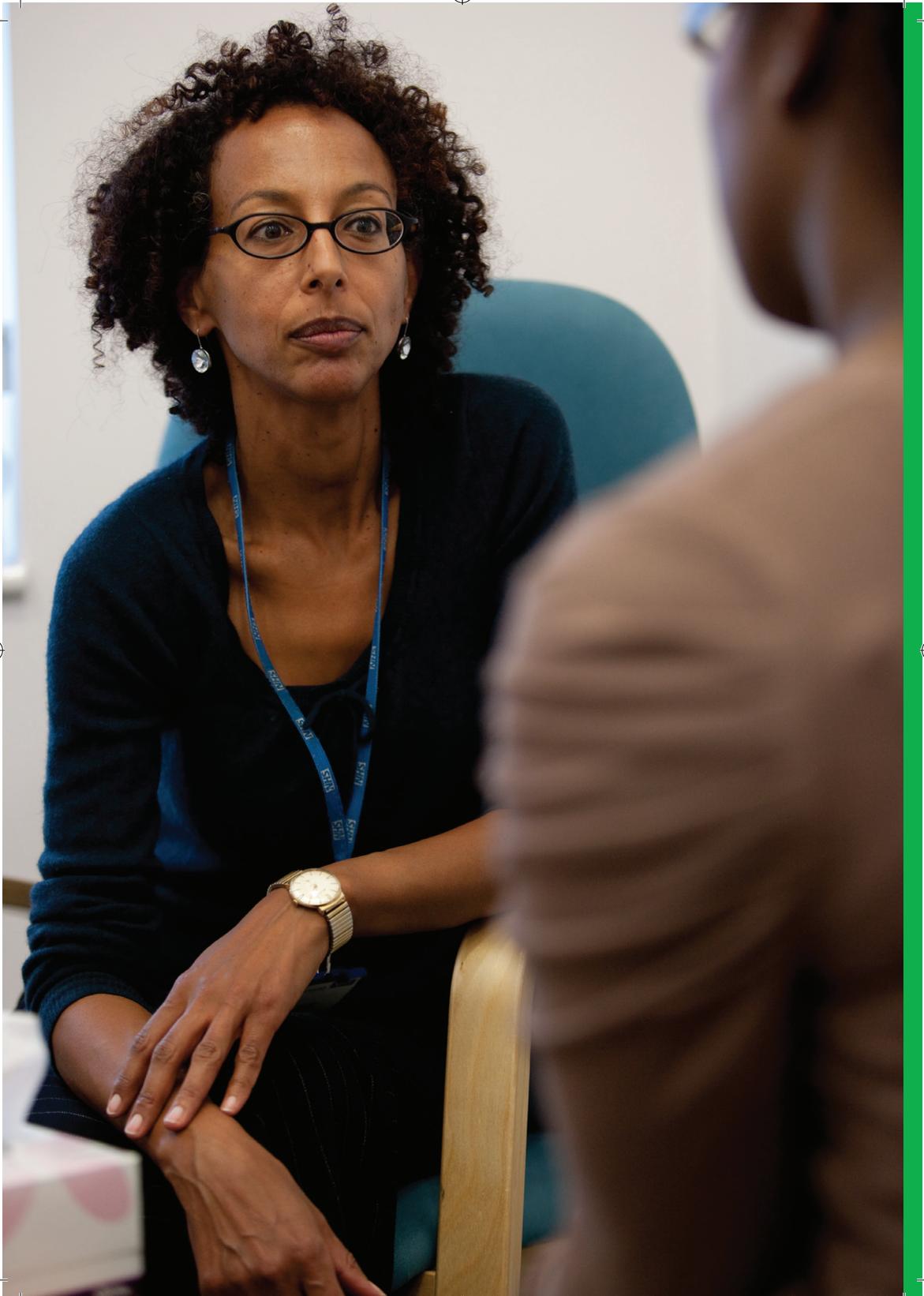
You may find our leaflet **Ask about your cancer treatment** helpful. It suggests questions you can ask your healthcare team, to help you understand your diagnosis and treatment options.

If you're a partner, relative or carer

Understanding more about cancer could help you support the person you're close to. Health and social care professionals, including the key worker, are there for you too. You can ask them questions about cancer. If you're caring for the person, you can also ask them questions about your caring role.

A **carer** is someone who provides unpaid support to a family member or friend who wouldn't be able to manage without this help. Caring can mean many things, including helping with personal care, providing transport, being a good listener or helping with everyday chores.

You can call our support line on **0808 808 00 00** for details of local and national support for carers. We can also send you our booklet **Looking after someone with cancer**, which is written by Macmillan and a group of carers. Or you can read our information for carers online, at **macmillan.org.uk/carers**



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How cancer is diagnosed

Some people are diagnosed with cancer after being referred for tests by their GP. Others are diagnosed after going into hospital for another health problem, or because a symptom gets so bad that it becomes an emergency.

It's important that people are diagnosed with cancer as early as possible. This is so the treatment has the best chance of working.

GP referral

If your GP thinks you may have cancer, they will make an urgent referral for you to see a specialist. This means tests should be arranged quickly.

GPs may also make a non-urgent referral. Non-urgent referral times can vary. This depends on where you live and what type of medical problem your GP thinks you have.

Having tests and scans

Medical teams use different tests and scans to find out if you have cancer. The tests also help give more information about the cancer. They may include:

- a **biopsy** – a small piece of tissue or a sample of cells is removed and examined under a microscope
- **blood tests** – to check your general health, check for infections and help diagnose cancer
- **scans and x-rays** – to check for changes inside your body.

There are many different types of tests and scans. Some are described on pages 72–81. The tests and scans you have will depend on the type of cancer and your situation.

After you have been diagnosed, your cancer specialist (see page 13) will often want to carry out further tests and investigations to learn more about the cancer. This will include tests to find out the **stage** and the **grade** of the cancer. Knowing the stage and grade helps doctors advise you about the best treatment for you. This means your treatment may not start straight away.

Waiting for test results

Waiting for test results can be a difficult time. It may take from a few days to a couple of weeks for the results of your tests to be ready. You may find it helpful to talk with your partner, your family or a close friend.

Your specialist nurse or one of the organisations listed on pages 86–95, can also provide support. You can also talk things over with one of our cancer support specialists on **0808 808 00 00**.

Your feelings about being diagnosed

When you're first diagnosed with cancer, the fear of what might happen next is sometimes the only thing on your mind. You may feel both sad and frightened, and wonder if you'll ever feel happy again.

Many people feel this way and it's natural to think that it will never change. However, there are things you can do to help come to terms with your diagnosis. As time goes by, many people find that they begin to get some control back in their lives and are able to carry on with their usual activities.

It can also be a very difficult time for family and friends. They may also need support.

Turn to pages 58–69 for more information about coping with difficult emotions.

'We've all had a huge life changing shock being diagnosed and it sometimes takes time for the full extent of what you've been through to present itself.'

Alison

What happens next?

Your healthcare team should ask you what support you need. They will tell you about your treatment options and give you an idea of when treatment will start.

If you were referred urgently by your GP (see page 20), your hospital team will aim to start treatment:

- within 31 days of you being diagnosed and a decision to start treatment, or
- within 62 days of the referral from the GP (whichever is sooner).

Not all cancers need treatment straight away. Some types of cancer are very slow-growing and unlikely to cause any problems for many years. If you are in this situation, you will be closely monitored. If there are signs that the cancer is beginning to progress, treatment options will be discussed with you. In these cases, delaying treatment until it is needed helps to avoid the potential side effects that it may cause.

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How cancer can be treated

The aim of treatment is to cure the cancer, or control it and relieve its symptoms.

The type of treatment you have will depend on the cancer and your situation. You may have more than one treatment.

Cancer treatments can include:

- **surgery** – the cancer is removed in an operation
- **radiotherapy** – high-energy x-rays are used to destroy cancer cells
- **chemotherapy** – anti-cancer drugs are used to destroy cancer cells
- **hormonal therapies** – treatment changes the hormones in your body, which can slow down or stop cancer from growing
- **targeted therapies** (sometimes called biological therapies) – treatment interferes with the way cancer cells grow.

We describe some of these types of treatment in more detail on pages 72–81.

We can also send you more detailed information about your type of treatment and any side effects it may cause. Call us on **0808 808 00 00**.

It's important to discuss your treatment options and what they may involve. For example, cancer treatment does not always mean staying in hospital. It may just mean visiting a hospital regularly.

Some people find that learning more about their treatment helps them feel prepared. It can also help you to plan any questions you may want to ask. For example, you may want to ask how you are likely to feel during and after treatment.

You can ask your healthcare team any questions. They are there to support you.

If you are a carer, finding out more information can help you plan ahead too. You can think about any extra help that you and the person who is ill might need, during and after treatment.

Clinical trials

You may be asked to take part in a cancer research trial. Research trials are carried out to try to find new and better treatments for cancer. Trials that are carried out on patients are known as **clinical trials**. If you decide not to take part in a trial, your decision will be respected and you don't have to give a reason.

Our booklet **Understanding cancer research trials (clinical trials)** describes clinical trials in more detail. We can send you a copy.

Treatment side effects

Different types of cancer treatment can cause different side effects. Your healthcare team will give you detailed information about any side effects you might have.

Side effects can often be reduced and managed. The team treating you will try to reduce your chance of getting them. For example, they may give you anti-sickness medication if they know **nausea** and vomiting are side effects of your treatment.

Other healthcare professionals will be involved if needed. For example, you may see a **dietitian** if your eating is affected, or a **lymphoedema** specialist if lymphoedema is a possible side effect of treatment. Lymphoedema is a condition that causes swelling in the body's tissues.

Most side effects gradually go away after treatment finishes. But some people have long-term or **late effects** after treatment (see page 39).

Contact your healthcare team if you are worried about any side effects.

Coping with changes to your body

Sometimes cancer treatment can affect the way parts of your body look and work. For example, chemotherapy can cause hair loss. Some of these changes can be temporary, while others may be permanent.

Body changes can sometimes be very difficult to come to terms with. Your healthcare team can help you cope with this.

We have more information about coping with body changes that you may find helpful. You can order our free booklets **Body image and cancer**, **Coping with hair loss** and **Feel more like you**.

'It's the uncertainty when they tell you what side effects you might get. But many people get very few side effects, some get none at all. Think of this as a short period of treatment to make things better in the long run! I know it's not easy.'

Mark



Making treatment decisions

Sometimes there are different choices about which treatment you could have. Your doctor will discuss these options with you.

If two treatments are equally effective for the type and stage of cancer you have, your doctors may offer you a choice. They can help you choose the best treatment for you.

It's important to understand what each treatment involves and the possible side effects, before you decide what is right for you. You will normally have time to consider the options and have another appointment to discuss your decision. It can help to make a list of the questions you want to ask and to take a relative or friend with you when you see the doctor again. Take notes about what has been said so you can refer back to them afterwards. You can use pages 96–97 for this.

Remember to ask questions about anything you don't understand or feel worried about. You may find it helpful to discuss the benefits and disadvantages of each option with your doctor, specialist nurse, key worker, or with our cancer support specialists on **0808 808 00 00**.

The benefits and disadvantages of treatment

Many people are frightened at the idea of having cancer treatment. This can be because of the side effects that can happen. However, these can usually be controlled with medicines.

Treatment can be given for different reasons. The potential benefits will vary depending on your situation. Your doctor can tell you if the aim of treatment is to cure the cancer, to control it, or to reduce symptoms and improve your quality of life. They can also tell you the possible side effects of each treatment and whether these are likely to last for a short time or be permanent.

In some situations, the impact of side effects could outweigh the benefits of the treatment. Your healthcare team will discuss this with you in detail. If you decide not to have the treatment, your healthcare team will make sure you are as comfortable as possible, and that any pain or symptoms are minimised.

We have a booklet called **Making treatment decisions**, which you might find helpful. Visit be.macmillan.org.uk to order a free copy.

'Everyone goes down different routes for various reasons. Keep positive, ask questions especially of your consultants, listen to everyone, and then make your own decision.'

Ann

Giving your consent

Before you have any treatment, your doctor will explain its aims. They will usually ask you to sign a form saying that you give permission (consent) for the hospital staff to give you the treatment. No medical treatment can be given without your consent. Before you are asked to sign the form you should be given full information about:

- the type and extent of the treatment
- its benefits and disadvantages
- any significant risks or side effects
- any other treatments that may be available.

If you don't understand what you've been told, let the staff know straight away, so they can explain again. Some cancer treatments are complex, so it's not unusual to need explanations repeated.

It's a good idea to have a relative or friend with you when the treatment is explained, to help you remember the discussion. You may also find it useful to write a list of questions before your appointment. You could use pages 96–97 to do this.

People sometimes feel that hospital staff are too busy to answer their questions, but it's important for you to know how the treatment is likely to affect you. The staff should be willing to make time for your questions.

You can always ask for more time if you feel that you can't make a decision when your treatment is first explained to you.

If you don't want treatment

You are free to choose not to have the treatment. Your healthcare team can explain what may happen if you don't have it. It's essential to tell a doctor or the nurse in charge, so they can record your decision in your medical notes. You don't have to give a reason for not wanting treatment. But it can help to let the staff know your concerns, so they can give you the best advice.

Getting a 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 cancer 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. You could have a list of questions ready, so that you can make sure your concerns are covered during the discussion.

Private healthcare

You can choose to pay for private healthcare. Private medical treatment for cancer is offered by private hospitals and clinics. Some specialist NHS hospitals that also treat private patients offer it too.

You can pay for treatment with private health insurance, or you can self-fund. This means you pay the hospital or clinic directly.



Living well during and after treatment

Eat well

Eating a balanced diet is one of the best choices you can make for your overall health. Keeping to a healthy weight will help you maintain or regain your strength, and have more energy. It can also reduce the risk of new cancer, heart disease, stroke and diabetes.

Making changes to your diet is not always easy. It may be more difficult if you are coping with cancer and having treatment. You could try making changes gradually.

Talk to your doctor or nurse. They can refer you to a **dietitian**, who can advise you about changes you should be making. A dietitian can help you if you're struggling to eat or have lost your appetite due to the cancer or its treatment.

We have more information about diet and cancer, including a range of booklets and videos. Visit **macmillan.org.uk**

Be active

Treatment can make you feel very tired. But it might help you feel a bit better to include some physical activity in your weekly routine. Even just spending less time sitting down and taking short walks can help.

Being active has many benefits and can help to:

- reduce tiredness and some treatment side effects
- reduce anxiety and depression
- improve your mood and quality of life
- strengthen your muscles, joints and bones
- look after your heart and reduce the risk of other health issues.

If you're not used to exercising or haven't exercised for a while, you may worry you're not going to be able to keep it going. Being active doesn't mean you have to exercise intensely. To start with, it can be as simple as going for short walks, doing things around the house or gardening.

Our **Move more** pack has more information to help you get active. You can order this from be.macmillan.org.uk or call our support line on **0808 808 00 00**.

Give up smoking

If you're a smoker, choosing to stop is a decision that will benefit your health. Smoking increases the risk of several types of cancer. It can also lead to heart and lung diseases. If you are coping with a cancer diagnosis, you may find it stressful to give up smoking. However, research has shown that non-smokers have fewer side effects during cancer treatment. If you are ready to stop, giving up smoking will help you feel better and be healthier.

Health and social care professionals, such as your pharmacist or GP, can help if you're trying to give up smoking.

You might also want to order our booklet **Giving up smoking**.

After treatment

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

When your treatment is over, it's important to give yourself time to adjust to any physical or emotional changes. Many people survive cancer. But the treatment can be very hard on the body and it may be some time before you're feeling fit and well again. Some of the tips on pages 36–37 about living well during and after treatment may help.

Our booklet **Life after cancer treatment** gives useful advice about keeping healthy and adjusting to life after treatment.

Follow-up care and support

After your treatment is over, you may have regular check-ups, and possibly scans or x-rays depending on your situation. Your cancer specialist or clinical nurse specialist will explain how often you'll need to come back to see them. Many people find that they get very anxious before their appointments. It may help to get support from family, friends or one of the organisations listed on pages 89–95.

If you have any problems, or notice any new symptoms between check-ups, let your doctor know as soon as possible.

Late effects of treatment

Most people have some side effects during and after cancer treatment (see page 28). These effects usually gradually get better and go away. But some people may have side effects that last for months after treatment and sometimes become permanent. Other people may develop delayed effects of treatment months or years later. These are called long-term or **late effects**.

Some people think that late effects are a price they have to pay for being free of cancer. But often this isn't the case. There are many things that can be done to manage or treat late effects. It's important that you don't feel you just have to put up with them.

Always let your cancer doctor or nurse know if side effects you developed during treatment aren't going away. You should also tell them if you develop new symptoms or problems after treatment is over.

People sometimes worry that their symptoms are caused by the cancer coming back. Your doctor or nurse will be able to reassure you. They may arrange for your symptoms to be checked if necessary.

Not everyone gets late effects, and many get better over time.

Worrying about cancer coming back

Many people worry that the cancer will come back. Feeling like this is natural. As time goes on, most people are less worried about this. It's not only the worry that eases over time, but the actual risk too. If cancer does come back, it often happens within a few years of treatment finishing. It may help to talk to your cancer specialist or clinical nurse specialist about the risk of your cancer coming back.

If you're worried about any unexplained symptoms, particularly any that last more than a week, it's a good idea to arrange a check-up with your GP.

You may find our booklet **Worrying about cancer coming back** helpful. It has information to help you cope with these feelings and how to get more support.

Coping if the cancer comes back

Sometimes the cancer comes back. Doctors call this **recurrence**.

Many cancers that come back can still be treated. It is sometimes possible to cure the cancer if it comes back. But in many cases, treatment will only be able to slow down the progress of the cancer.

If the cancer can't be cured

You may reach a stage when there are no more treatments available to cure the cancer. This can be a very difficult time. You may be referred to a **palliative care** team or to a Macmillan palliative care nurse. They support people when there is no longer a cure. They are specialists in relieving the symptoms of cancer to give you the best possible quality of life.

You may find it helpful to read our booklets **Coping with advanced cancer** and **End of life: a guide**. We also have a booklet for carers called **Caring for someone with advanced cancer**.

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Your rights

Being involved in decisions

You have the right to be involved in decisions about your care. This includes the right to:

- decide whether you want to have a particular treatment
- see your medical records
- information about services that can give the care you need.

Good healthcare and confidentiality

You have rights that aim to protect you against things going wrong. These include the right to:

- expect all your information to be kept confidential by the health and social care professionals who are treating you
- complain if you feel your healthcare isn't as good as it should be – visit macmillan.org.uk/makingacomplaint
- be protected against discrimination and harassment because of the cancer.

You are protected by the Equality Act 2010 in England, Scotland and Wales or the Disability Discrimination Act 1995 in Northern Ireland. These laws also offer protection against discrimination at work (see pages 48–49).

Good social care

If the cancer and treatment mean you cannot live as independently as before, you have the right to have your needs assessed by your local council. This is called a **community care assessment**. Some community support officers who do these assessments are based in hospitals, so they can assess you while you're there too.

You also have the right to make a complaint if you feel your social care isn't as good as it should be. To make a complaint about social care, contact your local council, or your social work department if you live in Scotland.

Getting enough information

You should be given enough information about the cancer and your treatment and care. This includes the right to:

- have your treatment options and side effects explained in words you understand (see pages 26–28)
- be offered written information that is easy to understand and specific to your needs (see page 14).

If you're a partner, relative or carer

If you're looking after someone with cancer, you have a right to a **carer's assessment** from your local council. This means a social worker can assess your needs, decide what support they can offer you, and agree a supportive care plan with you. They may be able to arrange help with caring for the person you're looking after, and give you respite breaks.

As a partner, relative or carer, you have the right to be given information and advice about any support the person with cancer may need (see page 17). If the person has given their permission, you also have the right to be involved in decisions about their treatment and their care plan.

You can speak to any member of your healthcare team about your rights. Or you can call the Macmillan Support Line on **0808 808 00 00** to talk to a cancer support specialist.



Work

You may need to take time off work during your treatment and for a while afterwards. It can be hard to judge the best time to go back to work. This will depend mainly on the type of work you do and how much your income is affected. It's important to do what's right for you.

Getting back into your normal routine can be very helpful, and you may want to go back to work as soon as possible. It can be helpful to talk to your employer about the situation – it may be possible for you to work part-time or job share.

On the other hand, it can take a long time to recover fully from cancer treatment, and it may be many months before you feel ready to return to work. It's important not to take on too much too soon. Your consultant, GP or specialist nurse can help you decide when and if you should go back to work.

Employment rights

The Equality Act 2010 protects anyone who has, or has had, cancer. Even if a person who had cancer in the past has been successfully treated and is now cured, they are still covered by the Act. This means their employer must not discriminate against them for any reason, including their past cancer. The Disability Discrimination Act protects people in Northern Ireland.

These laws also say employers must make 'reasonable adjustments' to make sure you are not at a disadvantage because of the cancer. This can mean different things depending on your work and the situation. For example, it could mean changing the tasks you do or your working hours.

Asking for a change in your working hours could help. Most employees in the UK now have the legal right to request flexible working from their employer.

People who are working and caring for someone with cancer are also protected from direct discrimination and harassment in the workplace. Carers also have the right to take unpaid time off work for people who depend on them in an emergency.

Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have more information that may be helpful. There's also lots more information at macmillan.org.uk/work

Financial help and benefits

If you are struggling to cope with the financial effects of cancer, help is available. Our booklet **Help with the cost of cancer** has more detailed information.

If you cannot work because you are ill, you may be able to get **Statutory Sick Pay**. 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 do not qualify for it, check whether you can get Employment and Support Allowance (ESA). This benefit is for people who cannot work because they are ill or disabled.

There are two different types of ESA:

- **contributory** – you can get this if you have made enough national insurance contributions
- **income-related** – you can get this if your income and savings are below a certain level.

Since October 2013, a new benefit called Universal Credit has started replacing income-related ESA in England, Scotland and Wales. This benefit is for people who are looking for work or on a low income.

Personal Independence Payment (PIP) is a new benefit for people under 65 who find it difficult to walk or look after themselves (or both). You must have had these difficulties for at least three months, and they should be expected to last for the next nine months. Since April 2013, PIP has started to replace a similar older benefit called Disability Living Allowance (DLA) in England, Scotland and Wales.

Attendance Allowance (AA) is for people aged 65 or over who 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. You don't need to have a carer, but you must have needed care for at least six months.

If you are terminally ill, you can apply for PIP, DLA or AA under the 'special rules'. This means your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate.

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 don't qualify for it, you can apply for Carer's Credit. This helps you to build up qualifying years for a State Pension.

More information

The benefits system can be hard to understand, so it's a good idea to talk to an experienced welfare rights adviser. You can speak to one by calling the Macmillan Support Line on **0808 808 00 00**. We've just listed some benefits here, but there may be others you can get.

You can find out about state benefits and apply for them online at **gov.uk** (England, Wales and Scotland) and **nidirect.gov.uk** (Northern Ireland). These websites have information about financial support, your rights, employment and independent living. You can also get information about these issues 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 93 for the contact details of these organisations.

Insurance

People who have, or have had, 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 page 94.

Our booklets **Insurance** and **Getting travel insurance** may also be helpful.

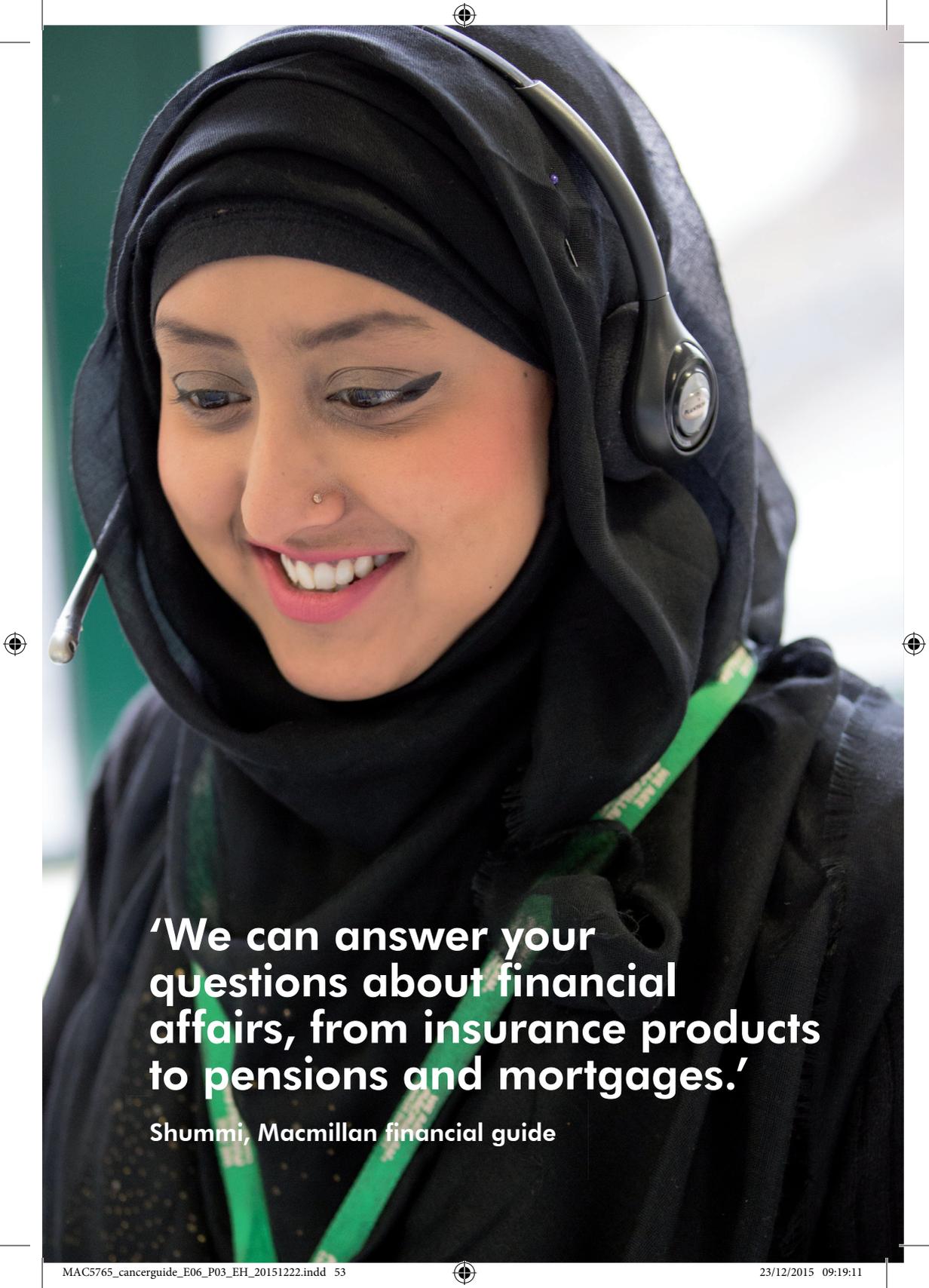
Macmillan Grants

These are small, mostly one-off payments to help people with costs caused by, or related to, their cancer.

Everyone's practical needs are different, so grants are available for a variety of things. Whether you need extra clothing, help paying heating bills or even a relaxing break, you may be entitled to a Macmillan Grant.

How much you can get will vary depending on your circumstances and needs. The average grant is less than £300. A grant will not affect the benefits you're entitled to. It's an extra help, not a replacement for other forms of support. You need to apply through a health or social care professional.

For more information on how to apply for a Macmillan Grant, visit **macmillan.org.uk/grants** or call **0808 808 00 00**.



'We can answer your questions about financial affairs, from insurance products to pensions and mortgages.'

Shummi, Macmillan financial guide

Travel

Travelling can be fun and fulfilling. But when you have cancer, you may have a few more things to think about if you're planning a trip.

It's important to check whether you're fit to travel. Your doctor can tell you if there is anything that could make travelling unsafe.

You may be advised to avoid flying if you:

- are breathless
- are anaemic
- are at risk of developing swelling in the brain
- have recently had surgery.

Some cancer treatments, such as radiotherapy and chemotherapy, can sometimes cause short-term physical problems. Some treatments can also make your skin more sensitive to the sun. These effects can limit the amount of travelling you can do – or the type of activities you do while you're away. If you want to travel abroad, it can also be more difficult to get travel insurance.

Being in the middle of treatment doesn't always mean you can't travel. Talk to your cancer specialist about the best time to go away. They should also be able to give you advice about supplies you need, or any dietary issues you should think about. With good planning, you can often avoid travel problems.

Planning ahead for your care

Planning for your future care (also called **advance care planning**) is important in case you ever become unable to make choices yourself. This could be because your health changed, and you became unconscious or lost the ability to make decisions about treatment.

There are lots of ways you can plan ahead. You could:

- **Record your wishes for your care.** These include how and where you would like to be cared for if you become seriously ill or are reaching the end of your life.
- **Create a Power of Attorney.** This is when you give someone you trust the power to make decisions on your behalf about your property and finances, or your welfare and healthcare, or both.
- **Create an Advance Decision to Refuse Treatment** (also known as an Advance Directive or Living Will). These are your decisions about specific treatments you don't want to have.

Other ways you can plan for the future include making a will and funeral planning.

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** to order a copy.



'My wife has been a big support. It's been hard for her, so she's been in touch with my Macmillan nurse. It's good that she's got somewhere to go for help too.'

Herbie

COPING

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Your feelings

It's common to feel overwhelmed by different feelings when you're told that you have cancer. We talk about some of these here. Partners, family and friends may also have some of the same feelings.

You might have different reactions to the ones we describe here. There is no right or wrong way to feel. You'll cope with things in your own way. Talking to people close to you or other people affected by cancer can often help.

Shock and disbelief

You may find it hard to believe it when your doctor tells you that you have cancer. It's common to feel shocked and numb. You may not be able to take in much information and find that you keep asking the same questions again and again. At first, you might find it hard to talk to family and friends about the cancer. This usually gets easier as the shock wears off and it becomes more real to you. You may find you can't think or talk about anything but the cancer. This is because your mind is trying to process what you're going through.

Fear and anxiety

People can be very anxious or frightened about whether treatment will work and what will happen in the future. This uncertainty can be one of the hardest things to cope with. It can help to try to focus on what you can control. You may want to find out more about the cancer, its treatment and how to manage side effects.

It can also help to talk about your feelings and to take time to do things that are important to you and that you enjoy.

Doctors often know roughly how many people can benefit from a type of treatment. But they can't be sure what will happen to an individual person. Although they may not be able to answer your questions fully, they can usually talk through any problems with you and give you some guidance.

Avoidance

Some people cope by not wanting to know very much about the cancer and by not talking about it. If you feel like this, let your family and friends know that you don't want to talk about it right now. You can also tell your doctor if there are things you don't want to know or talk about yet.

Occasionally, this avoidance can be extreme. Some people may not believe that they have cancer. This is sometimes called being in denial. It may stop them making decisions about treatment. If this happens, it's very important for them to get help from their doctor.

Sometimes, avoidance is the other way around. Family and friends may seem to avoid you and the fact that you have cancer. They may not want to talk about it or they might change the subject. This is usually because they are also finding the cancer difficult to cope with, and they may need support too. Try to let them know how this makes you feel and that talking openly with them about your illness will help you.

Being positive

Being positive can mean different things to different people. It could mean dealing with whatever situation you're in, being optimistic or finding ways of coping. People do this in different ways. What works for one person may not work for another.

Some people say they are able to find something positive about having cancer. For example, coping with cancer may have brought them closer as a family. They may have met new people, or feel they have a different outlook on life now.

A lot of people have periods of feeling low at some time in their lives, and this is quite natural. Sometimes being told to be positive when you feel low can be frustrating. It can feel as though the person isn't accepting how you really feel, even if they are just trying to help.

No one can be positive all the time. It's important that you don't feel you must always stay on top of things. Being positive doesn't mean having to feel happy and cheerful all the time. It's a positive thing to acknowledge and talk about it if you're feeling tired, worried, depressed or angry.

Anger

You may feel angry about your illness and sometimes resent other people for being well. These are normal reactions, especially when you feel frightened, stressed, out of control or unwell. You may get angry with the people close to you. Let them know that you are angry at your illness and not at them. Finding ways to help you relax and reduce stress can help with anger. This can include talking about or writing down how you feel, gentle exercise, breathing or relaxation therapy, yoga or meditation.

Guilt and blame

Some people feel guilty or blame themselves or others for the cancer. You may try to find reasons for why it has happened to you. Most of the time, it's impossible to know exactly what has caused a person's cancer. Over time, several different factors may act together to cause a cancer. Doctors don't fully understand all of these factors yet. Instead, try to focus on looking after yourself and getting the help and support you need.

Feeling alone

Some people feel alone because they don't have enough support. Family and friends may live far away, have other commitments or feel uncomfortable because of their own fears about cancer. Try to let your family and friends know how you feel and how they could support you more.

If you need more help

These feelings can be very difficult to cope with and sometimes people need more help. This happens to lots of people and doesn't mean you're not coping.

If you feel anxious, panicky or sad a lot of the time, or think you may be depressed, talk to your doctor or nurse. They can refer you to a doctor or counsellor who can help. They may also prescribe medicine to help with anxiety or an antidepressant drug.

Our booklet **How are you feeling? The emotional effects of cancer** discusses the feelings you may have in more detail, and has suggestions for coping with them.

'I did suffer and so I saw a counsellor, which was amazing. Before this I personally didn't believe in counselling! You may wish to try and speak to someone about how you're feeling as it can be a very lonely time.'

Emma



Getting support

You don't need to face cancer on your own. For many people, family and friends are likely to be one of the main sources of support. However, it's not always easy to tell people you care about how you're feeling, and you may find it easier to talk to someone outside the family.

Support groups

Self-help or support groups offer a chance to talk to other people who may be in a similar situation and facing the same challenges as you. Joining a group can be helpful if you live alone, or don't feel able to talk about your feelings with people around you. However, not everyone finds talking in a group easy, so it might not be for you. Try going along to see what the group session is like before you decide.

You can call us on **0808 808 00 00** or visit **macmillan.org.uk/supportgroups** to find a group near you.

Online support

Many people find 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 meet other people going through similar things, share your experiences and get advice.

You may find Macmillan's Online Community helpful. It is a social networking site. Visit **macmillan.org.uk/community** to find out more.

Cancer helplines

Some helplines are staffed by specialist nurses who can help you understand your cancer and answer any questions you may have. They can give advice on emotional, practical and financial difficulties. Some helplines have specially trained volunteers, who may have been treated for cancer themselves, while others have benefits advisers. The Macmillan Support Line is a good place to start. Call free on **0808 808 00 00**. Our phone service is open Monday–Friday, 9am–8pm.

Counsellors

Some people find it very hard to cope with the impact of a cancer diagnosis. In this situation it can help to have counselling. One-to-one counselling is when you meet with a trained counsellor who can listen to you and help you explore your feelings in a place where you feel safe. It's confidential and can be a great support during a difficult time.

Many GP practices and hospitals have a counsellor you can talk to or can put you in contact with one. Some support groups and cancer information and support centres offer free counselling services.

You may find our booklet **Talking about your cancer** helpful to read. There are also lots of charities and organisations you can turn to for support. Some of these are listed on pages 89–95.

Looking after yourself

It's important to look after yourself. If you're finding it difficult to manage your feelings, it can help to take things one day at a time and not look too far ahead. You may find that life gets easier to cope with as time passes.

Doing even the smallest tasks may help you feel better:

- Try to eat well (see page 36).
- Do some regular physical activity (see pages 36–37), even if it's only gentle exercise.
- Try to keep your social life active by staying in contact with family and friends. It may help to talk to them about how you're feeling.

If you can, make plans to do things you enjoy. It can help to keep up hobbies and interests that were part of your life before the cancer diagnosis.

Relaxation techniques can help you cope if you're feeling stressed. We have some tips on our website macmillan.org.uk

Looking after yourself if you're a carer

Try not to bottle up your emotions. Try talking to family, friends or one of the healthcare team. It can help relieve any stress you might be feeling. You may also find it helpful to join a support group or to speak to a counsellor. If you feel run down or stressed, your GP will be able to help. Relaxation techniques can also help.

Try to keep well by getting plenty of rest and eating healthily. Sometimes this isn't easy, especially if you're looking after someone who needs a lot of care at home, but there are organisations that can help (see page 95).

Our booklets **Looking after someone with cancer** and **Caring for someone with advanced cancer** have lots of useful information to help you look after your relative or friend. You can order this information from be.macmillan.org.uk or visit macmillan.org.uk/carers to read it online.

Complementary therapies

There are many types of **complementary** therapy that may help you feel better, including acupuncture, aromatherapy, meditation, visualisation, art therapy and reflexology.

Complementary therapists usually work with the person as a whole. This is called a holistic approach. A complementary therapist who listens and cares may help you cope with some of your difficult feelings, which can help you get back some control.

Some hospitals and hospices provide complementary therapies alongside conventional cancer treatments, such as chemotherapy or radiotherapy. Some support groups also offer complementary therapies.

Complementary therapies may help you:

- feel better and improve your quality of life
- feel less stressed, tense and anxious
- sleep better
- feel more in control
- cope with some cancer symptoms and treatment side effects.

You might be advised not to have complementary therapies. This is because it is not safe to have them if you have certain types of cancer or if you are having certain treatments. Your doctor will be able to give you more information about this. It is very important to tell your cancer doctor if you are thinking about having any complementary or alternative therapy.

If you have a complementary therapy, you should always use a registered therapist. And always let your complementary therapist know you have cancer. The British Complementary Medicine Association (see page 92) can give you the names of registered therapists and advice on what to look for. Remember to check the cost of treatment beforehand to make sure you're fairly charged.

We have more information in our booklet **Cancer and complementary therapies**. To order it, call our support line on **0808 808 00 00** or visit **be.macmillan.org.uk**



MEDICAL TERMS

When you have cancer, you will come across lots of new words and may not know what they mean. We've explained some of them here.

Remember, you can call the Macmillan Support Line free on **0808 808 00 00** if you need more information or support.

Abdomen is the part of your body that includes your stomach, intestines and other parts of the digestive system. It's often just called your tummy.

Adjuvant therapy is treatment given after your main cancer treatment. For example, your main treatment may be an operation to remove the cancer. You may then have chemotherapy to reduce the risk of the cancer coming back.

Advance care planning means planning for how you want to be looked after in the future.

Alopecia is a type of hair loss. It can happen to the hair on your head, eyebrows, eyelashes, and other areas of the body. Hair loss can be a side effect of some cancer treatments, such as chemotherapy. Your hospital team will talk to you about how to reduce the chance of this happening. They can also help you get a wig if you want one.

Anaemia means you have a low number of red blood cells in your blood. This can make you may feel tired and breathless. See **blood count**.

Benign tumour is a lump in the body that is not cancer. It usually grows slowly and doesn't spread.

Biopsy is when your doctor takes a small sample of tissue from your body and examines it under a microscope. This is to see if the cells are cancerous or not.

Blood count is a routine blood test to measure the number of red blood cells, white blood cells and platelets in your blood. It's also called a full blood count (FBC).

Carcinogen is a substance which can cause cancer, such as radiation, or the chemicals in cigarettes.

Carcinoma is a type of cancer that starts in epithelial cells. These cells cover the outside of our body and our organs. Most cancers are carcinomas.

Carcinoma in situ is cancer in the early stages of development which hasn't spread from the place it began.

Carer's assessment is a chance to talk to your local council or social services department about what help you need if you're caring for someone. If you care for someone over 18, you have the right to a carer's assessment and support. For more information contact your local council in England, Wales and Scotland, or your Health and Social Care Board in Northern Ireland. You can also contact Carers UK (see page 95).

Central line is a long, hollow tube made from silicone rubber. The line is put into one of the veins in your chest. It can be used to give chemotherapy treatment and other medicines. It can also be used to take samples of your blood for testing.

Chemotherapy is the use of anti-cancer (cytotoxic) drugs to destroy cancer cells, including leukaemia and lymphoma.

Clinical nurse specialist is a nurse who specialises in an area of health, such as a specific cancer type. They may also be your **key worker**.

Clinical oncologist is a doctor who is an expert in treating cancer with radiotherapy and chemotherapy.

Complementary therapies can be used alongside, or in addition to, conventional medical treatments. Examples include acupuncture and meditation.

CT (computerised tomography) scan uses x-rays to build a three-dimensional picture of the inside of the body. This scan takes 10 to 30 minutes and is painless.

Cytotoxic means toxic to cells. See **chemotherapy**.

Diarrhoea is having frequent and watery bowel movements. It can sometimes be a symptom of cancer or a side effect of some cancer treatments.

Dietitian is a health professional who is an expert in nutrition and diet. They can give advice on how to eat well, as well as help people who have eating problems.

Drip is a way of giving fluids or drugs, such as chemotherapy, into a vein. It is also called an **intravenous (IV)** infusion.

Fatigue is when you feel extremely tired most, or all, of the time. Cancer and some of its treatments can cause fatigue.

Fine needle aspiration is a test that uses a thin needle to take a small sample of cells from your body to be examined.

Grade of a cancer gives an idea of how quickly it may grow.

Someone having a CT scan



Haematologist is a doctor who is an expert in diagnosing and treating blood disorders.

Histology means the study of cells. Doctors look at cells under a microscope to see if they are normal or not. If there are cancer cells, they look to see what type of cancer it is. It's sometimes also called histopathology.

Hormonal therapies change the hormones in the body, which can slow or stop cancer cells from growing.

Hormones are substances produced naturally in the body. They act as chemical messengers and influence the growth and activity of cells.

Immune system is your body's natural defence system. It helps protect against infection and disease. See **lymphatic system**.

Incontinence is when you have trouble controlling your bladder or your bowel.

Inoperable is when cancer can't be removed by an operation. It might mean the cancer has spread to a part of the body where an operation is not possible or its removal would be too risky.

Intramuscular injection (IM) is an injection into a muscle.

Intravenous (IV) is when a drug or fluid is given into one of your veins.

Key worker is your first point of contact for support and information. This may be your **clinical nurse specialist**.

Local therapy is a treatment, for example radiotherapy and surgery, which only affects a particular area of your body.

Leukaemia is a cancer of the white blood cells. White blood cells fight and prevent infection.

Lumpectomy is an operation to remove a lump.

Lymph is a fluid that flows around your **lymphatic system**.

Lymphatic system helps to protect us from infection and disease. It also drains lymph fluid from the tissues of the body before returning it to the blood. The lymphatic system is made up of fine tubes called lymphatic vessels that connect to groups of **lymph nodes** throughout the body.

Lymphoedema is swelling that develops because of a build-up of fluid in the body's tissues. This happens when the lymphatic system, which normally drains the fluid away, isn't working properly. It can happen in any part of the body, but is most likely to affect an arm or a leg.

Lymphoma is a cancer of the lymphatic system.

Lymph nodes (lymph glands) are part of the **lymphatic system**. They are small and bean-shaped. They filter bacteria (germs) and disease from the lymph fluid.

Malignant tumour is a lump in the body that is cancer. It can spread to different parts of the body.

Metastasis is when the cancer has spread from one part of the body to another. Cancer that has spread is sometimes called metastatic disease or **secondary cancer**.

MRI (magnetic resonance imaging) is a scan that uses magnetism to build up a detailed picture of areas of your body.

Multidisciplinary team (MDT) is a group of professionals who work together to manage your treatment and care.

Nausea is feeling sick.

Negative result means something couldn't be found. For example, a negative lymph node biopsy means that cancer cells were not found in the lymph nodes.

Neo-adjuvant therapy is treatment given before the main treatment. For example, giving chemotherapy before surgery, to shrink the tumour and make the surgery easier or more effective.

Occupational therapist (OT) is a health and social care professional. They can help you with everyday things and looking after yourself. They can also recommend aids and equipment for the home if needed.

Oedema is the build-up of fluid in the body. It causes swelling.

Oncology is the study and practice of treating cancer.

Orally is when you take something by mouth. For example, a tablet.

Outpatient is when you go into hospital for an appointment and leave the same day. Outpatients don't stay in hospital overnight.

Palliative care is treatment that's given to help improve quality of life when the cancer can't be cured. Palliative treatment aims to meet the physical, spiritual, psychological and social needs of a person with cancer.

Pathology is the study and diagnosis of disease.

PET (positron emission tomography) scan is a test to measure the activity of cells in different parts of the body. It can be used to find out more information about a cancer and if it has spread to other parts of the body.

Physiotherapist is a health professional who helps you to stay mobile and free of pain, by teaching you how to exercise during and after your treatment.

Platelet is a type of cell found in your blood. They help your blood to clot to help stop bleeding. Chemotherapy can temporarily reduce the number of platelets in your blood, making you more likely to have bleeding and bruising.

Positive result means something has been found. For example, a positive lymph node biopsy means that cancer cells were found in the lymph nodes.

Pre-med (pre-medication) is a medication that you may be given before a test or treatment. For example, you may have a pre-med before having chemotherapy, to help prevent you feeling sick.

Primary cancer is a cancer that starts in one area of the body. Most cancers are primary cancers.

Prognosis is the likely outcome of your disease. The prognosis gives an idea of how long you might live.

Progression (or progressed) means that your cancer is still growing, or has continued to spread.

Pump is something that may be used to give you chemotherapy or fluids. The pump makes sure that the right amounts are given over the right amount of time. Some pumps are small and can be taken home, so that you don't have to stay in hospital.

Radiology is the use of imaging (x-rays and scans) to help diagnose cancer.

Radiotherapy uses high-energy x-rays to destroy cancer cells, while doing as little harm as possible to normal cells. It can help to shrink and control the cancer, and relieve symptoms.

Recurrence is when the cancer has come back. If it comes back in the same area of the body it is called local recurrence. If it has spread to other parts of the body it is called distant recurrence.

Remission is when treatment is controlling the cancer, or has made it temporarily disappear, but it may not have been cured.

Secondary cancers (or **secondaries**) are where the **primary cancer** has spread to another part of the body. See **metastasis**.

Social worker is a professional who can help people having difficulties with money, work or other problems.

Speech and language therapist is a health professional who can help you with any speech problems you have, or if you're finding it hard to chew and swallow.

Stage of a cancer means how big it is and whether it has spread from where it first started.

Subcutaneous injection (SC) is an injection given under your skin.

Systemic therapy is a treatment that treats the whole body. For example, chemotherapy.

Targeted therapies (sometimes known as **biological therapies**) interfere with cell processes that cause the cancer to grow.

Therapy is another word for treatment.

Tissue is the way your cells line up next to each other to form part of your body. For example, breast cells line up next to each other to make breast tissue.

Treatment cycle is the time between one round of treatment until the next one starts.

Tumour is a group of cells that are growing in an abnormal way. Tumours can be made up of cells that are **benign** (not cancer) or **malignant** (cancer).

Tumour markers are proteins produced by some types of cancer. They can be found in the blood and can help doctors to diagnose the cancer, and to see how well treatments are working.

Ultrasound scan is a way of using sound waves to create a picture of the inside of your body.

X-rays are used to take pictures of the inside of your body. They can show breaks or problems with your bones and joints. They can also show changes in other body tissues and organs, such as the lungs or breasts.



A practical guide to living with and after cancer

SEX AND RELATIONSHIPS

How to deal with sex and relationships affected by cancer

A practical guide to living with and after cancer

SIDE EFFECTS OF CANCER TREATMENT

We are proud to be a Macmillan Cancer Support

CANCER

UNDERSTANDING THYROID CANCER (FOLICULAR AND PAPILLARY)

YOUR RIGHTS WHEN TREATING

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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.

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

Other formats

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

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

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

Help us improve our information

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

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

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



Other ways we can help you

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

Talk to us

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

Macmillan Support Line

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

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

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

Information centres

Our information and support centres are based in hospitals, libraries and mobile centres.

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

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

Talk to others

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

Support groups

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

Online community

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

The Macmillan healthcare team

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

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

Mal

Help with money worries

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

Financial guidance

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

Help accessing benefits

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

Macmillan Grants

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

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

Help with work and cancer

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



Macmillan's My Organiser app

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

Other useful organisations

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

General cancer support organisations

Cancer Black Care

79 Acton Lane,
London NW10 8UT
Tel 020 8961 4151

Email

info@cancerblackcare.org.uk

www.cancerblackcare.org.uk

Offers information and support for people with cancer from ethnic communities, their friends, carers and families.

Cancer Focus Northern Ireland

40–44 Eglantine Avenue,
Belfast BT9 6DX

Helpline 0800 783 3339

(Mon–Fri, 9am–1pm)

Email hello@cancerfocusni.org

www.cancerfocusni.org

Offers a variety of services to people affected by cancer, including a free helpline, counselling and links to local support groups.

Cancer Support Scotland

The Calman Centre,
75 Shelley Road,
Glasgow G12 0ZE

Tel 0800 652 4531

Email [info@](mailto:info@cancersupportscotland.org)

cancersupportscotland.org

www.cancersupportscotland.org

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

Maggie's Centres

20 St. James Street,
London W6 9RW

Tel 0300 123 1801

Email [enquiries@](mailto:enquiries@maggiescentres.org)

maggiescentres.org

www.maggiescentres.org

Provides information about cancer, benefits advice, and emotional or psychological support.

Marie Curie

89 Albert Embankment,
London SE1 7TP

Helpline 0800 090 2309
(Mon–Fri, 9am–5pm)

Email supporter.relations@
mariecurie.org.uk

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.

Penny Brohn Cancer Care

Chapel Pill Lane,
Pill, Bristol BS20 0HH

Helpline 0845 123 2310
(Mon–Fri, 9.30am–5pm,
Wed 6–8pm)

Email
helpline@pennybrohn.org

**www.pennybrohn
cancercare.org**

Offers a combination of physical, emotional and spiritual support, using complementary therapies and self-help techniques.

Riprap

www.riprap.org.uk

Developed especially for teenagers who have a parent with cancer.

Tenovus

Head Office,
Gleider House,
Ty Glas Road,
Cardiff CF14 5BD

Helpline 0808 808 1010
(Mon–Sun, 8am–8pm)

Email info@
tenovuscancercare.org.uk

www.tenovus.org.uk

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

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@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.

National Cancer Institute –National Institute of Health – USA

www.cancer.gov

Gives information on cancer and treatments.

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.co.uk

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

British Complementary Medicine Association

PO Box 5122,
Bournemouth BH8 0WG

Tel 0845 345 5977

(Mon–Tue and Thu–Fri,
10am–5pm)

Email office@bcma.co.uk

www.bcma.co.uk

Has a code of conduct, and a list of registered practitioners who belong to member organisations. Can provide practitioners' telephone numbers.

Samaritans

Freepost RSRB-KKBY-CYJK,
Chris, PO Box 9090,
Stirling FK8 2SA

Helpline 116 123

Email jo@samaritans.org

www.samaritans.org

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

UK Council for Psychotherapy (UKCP)

2nd Floor, Edward House,
2 Wakley Street,
London EC1V 7LT

Tel 020 7014 9955

Email info@ukcp.org.uk

www.psychotherapy.org.uk

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

Financial or legal advice and information

Benefit Enquiry Line

Northern Ireland

Helpline 0800 220 674

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

Textphone 028 9031 1092

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

Provides information and advice about disability benefits and carers' benefits.

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 these 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 **adviceguide.org.uk**

Civil Legal Advice

Helpline 0345 345 4345

(Mon–Fri, 9am–8pm,
Sat, 9am–12.30pm)

Minicom 0345 609 6677

**www.gov.uk/
civil-legal-advice**

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

Department for Work and Pensions (DWP)

Personal Independence Payment Helpline

0345 850 3322

Textphone 0345 601 6677

Carer's Allowance Unit

0345 608 4321

Textphone 0345 604 5312

**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 benefits and public services in England, Scotland and Wales.

The Money Advice Service

Helpline 0300 500 5000

(Mon–Fri, 8am–8pm,
Sat, 9am–1pm)

Typetalk

18001 0300 500 5000

www.moneyadvice service.org.uk

Runs a free financial health check service and gives advice about all types of financial matters. Has an online chat service for instant money advice.

Money Advice Scotland

Helpline 0141 572 0237

www.moneyadvice scotland.org.uk

National Debtline (England, Wales and Scotland)

Tricorn House,
51–53 Hagley Road,
Edgbaston,
Birmingham B16 8TP

Tel 0808 808 4000

(Mon–Fri, 9am–9pm,
Sat, 9.30am–1pm)

www.nationaldebtline.org

A national helpline for people with debt problems. The service is free, confidential and independent.

NiDirect

www.nidirect.gov.uk

Has information about benefits and public services in Northern Ireland.

Personal Finance Society – ‘Find an Adviser’ service

www.findanadviser.org

Use the website to find qualified financial advisers in your area.

Unbiased.co.uk

Email contact@unbiased.co.uk

www.unbiased.co.uk

On the website you can search for qualified advisers who specialise in giving financial advice, mortgage, accounting or legal advice.

Support for carers

Carers Trust (Princess Royal Trust for Carers in Scotland)

32–36 Loman Street,
London SE1 0EH

Tel (England)

0844 800 4361

Tel (Scotland)

0300 123 2008

Tel (Wales)

0292 009 0087

Email info@carers.org

www.carers.org and

www.youngcarers.net

Provides support, information, advice and services for people caring at home for a family member or friend. 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

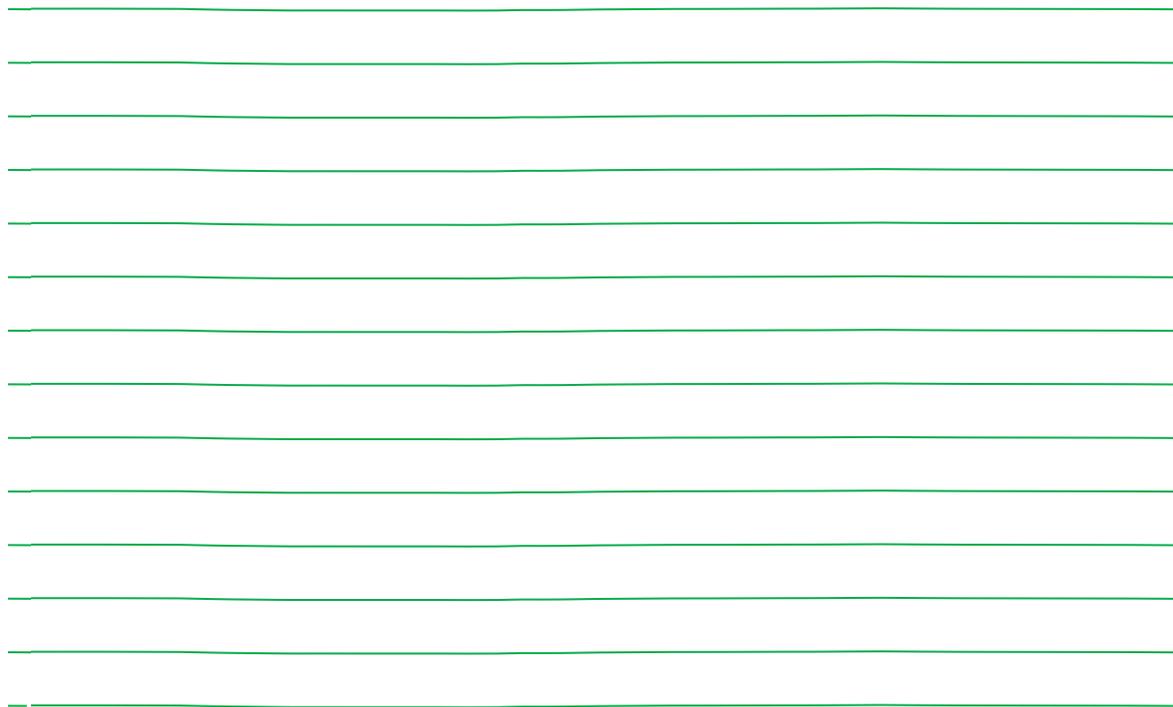
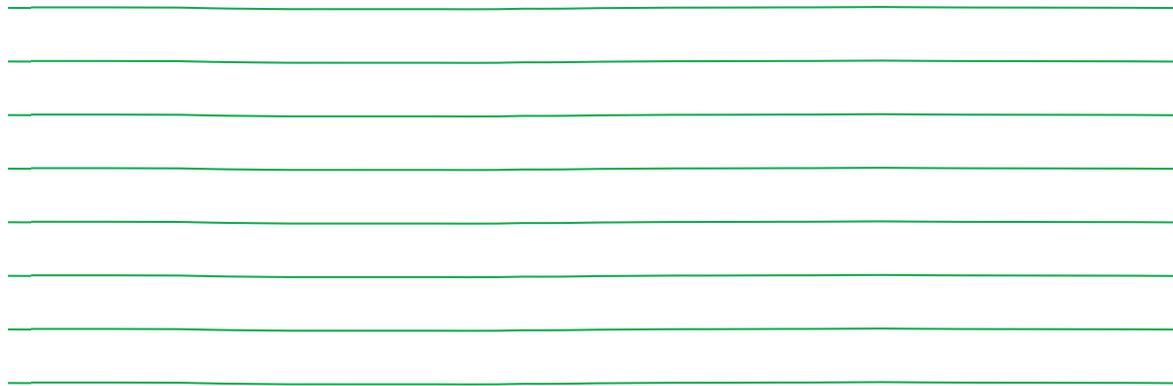
advice@carersuk.org

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.



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



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 photographs are of models.

Thanks

This leaflet 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: Dr Ingrid Haupt-Schott, Macmillan National Thyroid Cancer Clinical Nurse Specialist; Beverly Hurst, Macmillan Clinical Nurse Specialist, Gynaecology/Oncology; Dr Clifford Jones, Macmillan National GP Lead; Vikki Jones, Macmillan Gynae-Oncology Advanced Nurse Practitioner; Sue Llewelyn, Macmillan Information and Support Facilitator; Gerry Slade, Mesothelioma UK Clinical Nurse Specialist. Thanks also to the people affected by cancer who reviewed this edition, and those who shared their stories.

Sources

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

Ahmad A, et al. Trends in the lifetime risk of developing cancer in Great Britain: Comparison of risk for those born in 1930 to 1960. *British Journal of Cancer*. 2015. NHS Choices. *Carers' rights and the care act*. www.nhs.uk/conditions/social-care-and-support-guide/pages/carers-rights-care-act-2014.aspx (accessed September 2015).

Can you do something to help?

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

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



Share your cancer experience

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

Campaign for change

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

Help someone in your community

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

Raise money

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

Give money

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

Call us to find out more

0300 1000 200

macmillan.org.uk/getinvolved

Please fill in your personal details

Mr/Mrs/Miss/Other _____

Name _____

Surname _____

Address _____

Postcode _____

Phone _____

Email _____

Please accept my gift of £ _____

(Please delete as appropriate)

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

OR debit my:

Visa / MasterCard / CAF Charity
Card / Switch / Maestro

Card number

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Signature _____

Date / / _____

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 taxpayer and I would like Macmillan Cancer Support to treat all donations I have made for the four years prior to this year, and all donations I make in the future, as Gift Aid donations, until I notify you otherwise.

I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax in each tax year, that is at least equal to the tax that Charities & CASCs I donate to will reclaim on my gifts. I understand that other taxes such as VAT and Council Tax do not qualify and that 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

f

27530

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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**WE ARE
MACMILLAN.
CANCER SUPPORT**