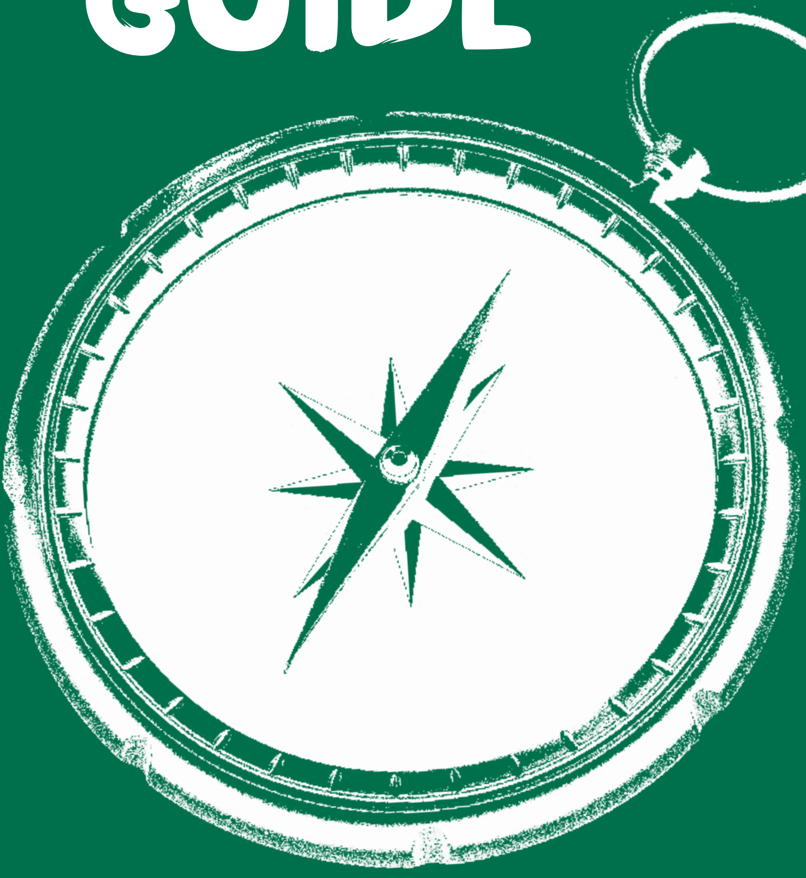
What to expect when you're
affected by cancer

THE CANCER GUIDE



WE ARE MACMILLAN.
CANCER SUPPORT

About this booklet

This booklet aims to help you, and those who care for you, get a feel for what cancer means and what to expect. It also tells you about organisations and services that can help.

Finding out that you have cancer can be a shock, even if you already suspected it. Cancer is a word that can stir up many fears and emotions. However, a diagnosis of cancer doesn't mean that you have to give up hope. These days, many people are cured of cancer or are able to live with it for many years.

You can ask your healthcare team about anything that is important to you. There are no right or wrong questions. We have put together some questions, asked by people who have had cancer, which may help. You'll find these listed throughout the booklet. There's also space to write down your own questions or notes on page 120.

Throughout the booklet we have included comments from people who have been affected by cancer, which you may find helpful.

You don't have to read this guide from start to finish. It's split into sections to make it easier to dip into when you feel like it. We hope that the information will help you feel more in control, and help you get the best care and support for you and those close to you.

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**

At the back of this booklet there is a glossary, which explains some medical terms you may come across (see pages 92–102). Turn to pages 107–119 for some useful addresses and websites.

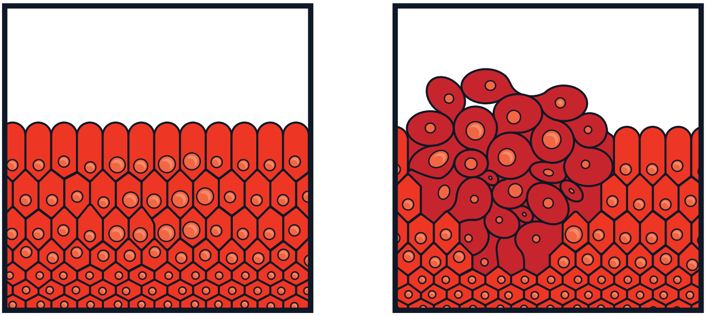
If you find this booklet helpful, you could pass it on to your family and friends. They may also want information to help them support you.

Contents

1 What is cancer?

The organs and tissues of the body are made up of tiny building blocks called cells. Cancer is a disease of these cells. Cancer isn't a single disease with a single cause and a single type of treatment. There are more than 200 different kinds of cancer, each with its own name and treatment.

Although cells in different parts of the body may look different and work in different ways, most repair and reproduce themselves in the same way. Normally, cells divide in an orderly and controlled way. But if for some reason the process gets out of control, the cells carry on dividing, and develop into a lump called a tumour. Tumours can be either **benign** (non-cancerous) or **malignant** (cancerous). Doctors can tell whether a tumour is benign or malignant by removing a piece of tissue (**biopsy**) and examining a small sample of cells under a microscope.



Normal cells

Cells forming a tumour

In a **benign tumour**, the cells do not spread to other parts of the body and so are not cancerous. However, they may carry on growing at the original site, and may cause a problem by pressing on surrounding organs.

In a **malignant tumour**, the cancer cells have the ability to spread beyond the original area of the body. If the tumour is left untreated, it may spread into surrounding tissue. Sometimes cells break away from the original (primary) cancer. They may spread to other organs in the body through the bloodstream or lymphatic system (see page 96).

When the cancer cells reach a new area they may go on dividing and form a new tumour. This is known as a **secondary cancer** or a **metastasis.**

We can send you information about the different cancer types. We have a video on our website of an oncologist explaining what cancer is and how it can be treated. Visit macmillan.org.uk/aboutcancer

2 Tests and investigations

After the diagnosis, your cancer specialist (see page 16) will usually 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, which helps doctors decide on the most appropriate treatment for you. This means your treatment may not start straight away.

The **stage** of a cancer describes its size and whether it has spread beyond its original site. Staging may involve further scans (see page 10) and biopsies (see page 9) and can take a few days to complete. Your cancer specialist will be able to tell you how long this will be.

The **grade** of a cancer gives an idea of how quickly it may develop. To find the grade of your cancer, your doctors will look at the cancer cells under a microscope.

Preparing for your tests

You may be sent some instructions that tell you what you need to do before your appointment. For some tests, you won't be able to eat or drink anything for a few hours beforehand. For others, you may need someone to take you home afterwards if possible.

It's important that you follow any instructions carefully. If you have a problem with the instructions, let the staff at the hospital know before your appointment. The hospital may also give you a map to help you find the department where you'll have your test.

Before each test or investigation, the cancer specialist or nurse will explain what will happen. This is a good time to ask any questions if anything is unclear or you don't understand.

Tests you may have

Biopsy

This is when a doctor removes a small sample of tissue from your body so that the cells can be checked. The cells will be examined under a microscope by a doctor called a pathologist (see page 17). They can see if there are any cancer cells, and if so, what type they are. There are different types of biopsy depending on which part of the body is affected. Your doctor or nurse can explain in detail what's involved.

Blood tests

These check the levels of blood cells, proteins and other chemicals in your blood. This can help provide information about your general health. A small number of cancers make proteins that can be detected in the blood (called tumour markers). A tumour marker can be used to help diagnose the cancer and check how well the cancer is responding to treatment.

Endoscopy

An endoscope is a thin, flexible tube with a light and a camera inside. It's used by doctors and nurses to look inside your body so they can see any problems you may have. Before an endoscopy you're likely to have a sedative, which can help you relax and reduce any discomfort. During the endoscopy, small samples of cells (biopsies) can be removed from any areas that look abnormal. These samples are then examined by a pathologist.

Scans

These are used to build up detailed images of the inside of your body. They can help doctors see what might be wrong.

Some scans work by using x-rays (CT scan) and others use magnetism (MRI scan), sound waves (ultrasound) or mildly radioactive chemicals (bone scan or PET scan). Before your scan you may need to drink, or have an injection of, a liquid dye. This helps to show up parts of your body more clearly on the scan. Scans are usually painless but may be slightly uncomfortable.

Not all scans are suitable for everyone, and some scans may have instructions that you must follow before they can be done. The doctor or nurse will discuss each scan with you.

X-rays

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

There are different types of x-rays. Some use film, a bit like a camera, while others are digital and create an image on a computer. Some x-rays involve the use of a chemical called barium, which is taken into the body as a liquid to show differences on the x-ray picture. Other x-rays are done after a dye is injected into a vein, which can show different areas of the body in detail.

Waiting for your results

Waiting for results can be a difficult time and you may need support from family, friends or one of our cancer support specialists on **0808 808 00 00**. You can also contact one of the organisations listed on pages 107–119.

Depending on the tests you're having, your results may be available on the same day. However, it's more common for the results to take a few days or even a week or two to be ready. Your cancer specialist, clinical nurse specialist (see page 16) or GP will let you know how long it will take. When you get your test results your cancer specialist will explain what they mean.

Remember, you can ask questions if you don't understand something and you can make notes to help you remember what was said when you're at home. It's a good idea to take a family member or friend with you for support. They may also be able to help you remember the things that were said.

Questions to ask about tests and investigations

- What tests and investigations will I need?
- Where will I go for these tests?
- How soon will I know the results?
- Who will explain what the results mean?

Questions to ask about your diagnosis

- What does my diagnosis mean?
- What stage is the cancer? How advanced is it?
- What happens next?
- What are my treatment options and the possible side effects?
- How successful will the treatment be?
- Can you explain this to a family member/friend?
- Is there any written information about the type of cancer I have and its treatment?

3 The healthcare team

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

The community team

Depending on your needs, you may meet social workers, district nurses and other professionals working in the community, as well as your GP.

GP (general practitioner)

Your GP is responsible for your healthcare while you're at home and they work closely with other members of your healthcare team. GPs can organise referrals to specialists and help with any ongoing symptoms and side effects from your 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

Community and district nurses work closely with your GP. They are sometimes based at a GP practice. They can visit your home (or residential care home) to provide care and support to you and your carer(s). Your GP can contact them for you.

Practice nurses

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

Social workers

Social workers can give you information about social services and other support that you may be entitled to. A social worker will be able to contact any specialist staff or organisations you may need, such as home helpers and meals on wheels. Some social workers are based in the hospital.

Key worker

To help keep things simple, one member of the healthcare team will usually be nominated as your key worker. They will be your first point of contact and will coordinate help and support from all the other members of the community team.

The hospital team

In most hospitals a team of specialists, called a **multidisciplinary team (MDT)**, work together to make sure your treatment and care is coordinated and organised.

Cancer specialist

This is the term used to describe doctors who are experts in diagnosing and treating cancer. Your cancer specialist will usually either be an oncologist or a surgeon.

Oncologist This is a doctor who is a specialist in the treatment of cancer. There are two types of oncologist. A medical oncologist is an expert in the treatment of cancer with chemotherapy and other drugs. A clinical oncologist is an expert in the treatment of cancer with both chemotherapy and radiotherapy.

Surgeon This is a doctor who carries out operations to remove all or part of the cancer. Your surgeon will be a specialist in carrying out operations for your type of cancer. Surgeons may also carry out operations to relieve any symptoms the cancer is causing.

Clinical nurse specialist

A clinical nurse specialist (CNS) is a nurse who is an expert in providing information, support and care for people affected by cancer. They help make sure you, and those who care for you, get the best possible support and care. Although they work mainly in hospitals, they can coordinate the support and care you need when you go home. If you don’t have a CNS, your hospital should still have someone you can talk to between visits.

Information and support staff

Many hospitals have specially trained staff who can give you, and your family and friends, information about any aspect of cancer. Some hospitals and charities, such as Macmillan, have set up cancer information and support centres. These offer free information about cancer and you can talk to staff and volunteers, who can help you get the support services you need.

We can give you details of your nearest cancer information and support centre. Call us free on 0808 808 00 00 or visit macmillan.org.uk/howwecanhelp

Other organisations that can give you support are listed on pages 107–119.

Pathologist

This is a doctor who looks at cells in the laboratory. They check to see if the cells are cancerous, and if so, what type of cancer it is and how it might behave. The pathologist provides information that can help determine the best kind of treatment for you.

Palliative care doctors and nurses

These professionals are experts in controlling the symptoms that cancer and its treatment can cause, such as pain and sickness. They also provide information, and emotional and psychological support. They work alongside your healthcare team. They can be based in hospitals, but can also work in hospices, nursing homes or visit you in your own home.

Radiologist

This is a doctor who is an expert in specialist tests including x-rays and scans. They work closely with your cancer specialist to decide what kind of treatment would be the best for you.

Diagnostic radiographer

Diagnostic radiographers work in radiology (imaging) departments and perform x-rays and scans to help diagnose cancer. They work closely with the radiologist.

Therapy radiographer

Therapy radiographers work closely with clinical oncologists to plan and organise radiotherapy treatment. If you're having radiotherapy treatment, you'll see the radiographer each time. They will be able to answer any questions you have, and give advice and information about the possible side effects of radiotherapy.

Allied health professionals and other specialist staff

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

We describe other types of healthcare roles at the back of this booklet. See pages 92–102.

4 Treatment

The main treatments for cancer are surgery, radiotherapy and chemotherapy (see pages 23–29). Other treatments such as hormonal therapy and targeted therapies (see pages 29–30) may also be used for certain cancers. Often a combination of more than one type of treatment is used.

We can send you more information about the different types of treatment.

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

> ‘It was to be almost a year of treatment involving chemotherapy, radiotherapy and surgery. It was a lot of information to take in, but with the help of my consultant and the specialist cancer nurse I gradually became aware of my circumstances and dealt with them as best I could.’
>
> **Tom**

Everybody's situation is different so it's not unusual for other people with the same type of cancer as you to be receiving different treatments.

> **We have information about making treatment decisions, which we can send you for free.**

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, and before you are asked to sign the form you should be given full information about:

- the type and extent of the treatment
- its advantages 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 the form on page 120 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 also free to choose not to have the treatment. The staff 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.

We have a leaflet with questions you can ask about your treatment.

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

Surgery

This is an operation to remove body tissue. It's one of the main treatments for cancer.

Surgery can be done for a number of reasons. It's often used to diagnose a cancer (a biopsy) or to help stage the illness (see page 8). It can also be used to remove the cancer, reduce the risk of developing cancer or for reconstruction after cancer treatment (such as breast reconstruction). Surgery may also be done to relieve symptoms (palliative surgery).

After an operation to remove the cancer, other cancer treatments may be given to reduce the risk of it coming back. Treatment, such as chemotherapy and radiotherapy, may also sometimes be given before surgery to shrink the cancer and make it easier to remove.

The doctor who carries out your operation is called a surgeon (see page 16). Your surgeon and nurse will explain what will happen, any side effects of the operation and how long you will need to stay in hospital. They should offer you some written information that you can take away and read.

After your operation, the tissue that has been removed will be sent to the laboratory to be examined. This helps the doctors know how successful the operation was and whether any other treatments may be needed.

Side effects

Sometimes surgery can affect the way parts of your body look and work. This can sometimes be very difficult to come to terms with. Clinical nurse specialists can help you to cope with any changes to your body. You can talk to your nurse or surgeon if you're worried about the possible side effects of surgery.

We have a booklet about coping with body changes that you may find helpful.

Radiotherapy

Many people with cancer will have radiotherapy as part of their treatment. Radiotherapy is the use of high energy x-rays and similar rays, such as electrons, to treat disease. It works by destroying the cancer cells in the treated area. Although normal cells can also be damaged by the radiotherapy, they can usually repair themselves.

Radiotherapy is sometimes given on its own, but it's often given in combination with other treatments, such as surgery or chemotherapy. Radiotherapy treatment can cure some cancers and can also reduce the chance of a cancer coming back after surgery. It may also be used to reduce cancer symptoms (palliative radiotherapy).

Your radiotherapy will be carefully planned by a clinical oncologist (see page 16). The treatment is given by therapy radiographers (see page 19).

We have a video of an oncologist explaining radiotherapy treatment on our website. Visit macmillan.org.uk/radiotherapy

Radiotherapy can be given in two ways – externally or internally.

External radiotherapy is normally given as a series of short, daily treatments in the radiotherapy department using equipment similar to a large x-ray machine. The treatments are usually given from Monday–Friday, with a break at the weekend. Each treatment is called a fraction. Giving the treatment in fractions ensures less damage is done to normal cells than to cancer cells.

A course of radiotherapy treatment may take between 2–7 weeks, depending on the type of cancer you have. Palliative treatments are often shorter and sometimes only a single treatment is necessary.

External radiotherapy doesn't make you radioactive, and it's perfectly safe for you to be with other people, including children, throughout your treatment.

Internal radiotherapy is given by either putting solid radioactive material (known as the source) close to or inside the tumour for a limited period of time (brachytherapy), or by using a radioactive liquid, which is given either as a drink, as capsules or as an injection into a vein (radioisotope treatment).

If you have internal radiotherapy, you may have to stay in hospital for a few days and special care will need to be taken while the radioactive material is in your body. With most types of internal radiotherapy, once the treatment is over, there's no risk of exposing your family or friends to radiation. Your cancer specialist or clinical nurse specialist can give you information about whether you need to take any precautions at home.

Side effects

These will depend on the part of the body that is being treated. The skin in the area that's been treated may become red, sore or itchy and you may feel more tired.

Staff in the radiotherapy department will be able to give you advice on how to look after your skin. Most side effects of radiotherapy will continue for about 10–15 days after treatment has finished and then gradually begin to get better. For some people however, they may continue for a few weeks.

Your cancer specialist and the radiographers will explain your treatment and its possible side effects. They can give you advice to help you cope with any side effects you develop and can answer any questions you may have.

There is more information about radiotherapy and the possible side effects in our booklet *Understanding radiotherapy*, which we can send you. Some hospitals will also have information that is written especially for the particular type of treatment you're having.

Chemotherapy

Chemotherapy – often called 'chemo' for short – is the use of anti-cancer (cytotoxic) drugs to destroy cancer cells. It can be given to cure a cancer, or after surgery or radiotherapy to reduce the risk of cancer coming back. Chemotherapy is also sometimes used before an operation to make it easier to remove the cancer or it can be given to relieve symptoms (palliative chemotherapy).

Chemotherapy drugs may be given:

- by drip (intravenous infusion) or injection into a vein (intravenously)
- as a tablet or capsule (orally)
- as a cream (topical chemotherapy)
- as an injection into a muscle (intramuscular) or just under the skin (subcutaneous injection)
- by injection into a body cavity (intracavitary chemotherapy), such as the bladder, or into the fluid around the spinal cord (intrathecal chemotherapy).

There are many different chemotherapy drugs. Some are given on their own but often several drugs are given together. This is known as **combination chemotherapy**.

Chemotherapy is often given over several different sessions of treatment. Depending on the drugs you're having, each treatment can last from a few hours to several days. Each treatment is usually followed by a rest period to allow your body to recover from any side effects. The treatment and rest period make up a cycle of treatment. Your cancer specialist will tell you how many cycles you'll need to have.

Side effects

Common side effects of chemotherapy include feeling or being sick (nausea or vomiting), increased risk of infection, bruising and bleeding, tiredness and hair loss.

The side effects can vary depending on which drugs you're having. Some side effects are mild and easily treated. Others can be harder to manage but they can often be reduced or helped in some way.

Some people may have very few side effects, while others will have more. Your reaction may not be the same as someone else having the same chemotherapy as you.

Your cancer specialist or chemotherapy nurse will explain the potential side effects of the chemotherapy you are having.

You may find it helpful to read our booklet *Understanding chemotherapy*, which has more information about the treatment and some of the possible side effects. We also have fact sheets about specific chemotherapy drugs.

Hormonal therapy

Hormones are substances that occur naturally in the body. They help to control how cells grow and what they do in the body. Hormones are produced by a number of different organs or glands, which together are known as the endocrine system.

Hormones can encourage some types of cancer cells to grow. Hormonal therapies work by lowering the level of hormones in the body or by preventing hormones from attaching to cancer cells. Hormonal therapies are mainly used to treat breast or prostate cancer.

Side effects

These can vary depending on the drug that is used. Your cancer specialist or clinical nurse specialist will explain the treatment to you and discuss any possible side effects and ways of coping with them.

We can send you fact sheets about the different hormonal therapies.

Targeted therapies

Targeted therapies (also known as biological therapies, immunotherapy or biotherapy) are a group of drugs that treat cancer cells but do little damage to normal cells. They target specific parts of the cancer, which is why they are known as targeted therapies. Each drug works in a different way but they all affect the way cancer cells grow or divide.

Side effects

The side effects of targeted therapies can be less severe than the side effects of chemotherapy, however in many situations both types of treatment are given at the same time.

We can send you fact sheets about many of the common targeted therapies.

High-dose treatment with stem cell support (autologous stem cell transplant)

This treatment may be used if you need to have very high doses of chemotherapy (or sometimes radiotherapy) to improve the chances of curing your cancer.

Chemotherapy is good at killing cancer cells, but it also destroys healthy cells. With lower doses of chemotherapy the body can replace the lost, healthy cells between treatments. But with higher doses, the bone marrow inside your bones may not be able to fully recover.

The bone marrow produces all your blood cells, which are made from cells called stem cells. Stem cells divide and grow to form fully-developed (mature) red blood cells, platelets and white blood cells. These types of blood cells are essential for the body to work properly.

Stem cell support is a way of replacing the stem cells in your bone marrow after high-dose treatment so that you can make blood cells again.

Before you have high-dose treatment some of your stem cells will be collected from your blood. You can have this done without having to stay in hospital overnight. The stem cells are then stored until they're needed.

Once you've had high-dose treatment you're given your stem cells back through a drip (intravenous infusion). This means your bone marrow will be able to make the blood cells you need again.

You can watch a video of David's story of having high-dose treatment with stem cell support. Visit macmillan.org.uk/highdosetreatment

Donor stem cell (allogeneic) transplant

Sometimes stem cells from another person whose bone marrow is a good ‘match’ for yours can be used. Siblings are usually the best match but some people can be given stem cells from a person not related to them.

This type of stem cell transplant is less common. It is most likely to be used to treat some types of leukaemia or some types of lymphoma that have come back after treatment.

Bone marrow transplant

Bone marrow transplants are similar to stem cell transplants. Instead of taking stem cells from the blood, some of your own or your donor’s bone marrow is collected. The liquid bone marrow contains stem cells and after you have high-dose treatment it can be given to you in a drip (intravenous infusion).

Side effects of stem cell and bone marrow transplants

There are many serious side effects with these types of treatment. While your bone marrow is recovering and the number of blood cells is very low, you’re at risk of infections and bleeding. High-dose treatment isn’t suitable for everyone and your cancer specialist can discuss with you whether it would be helpful in your situation. It’s useful to be aware of all the potential risks so that you can be sure that it’s the right treatment for you.

We can send you more information about these types of treatments.

Research – clinical trials

Cancer 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. These may be carried out to:

- test new treatments, such as new chemotherapy drugs or targeted therapies
- look at new combinations of existing treatments, or change the way they are given to make them more effective or reduce side effects
- compare the effectiveness of drugs used to control symptoms
- find out how cancer treatments work
- find out which treatments are the most cost-effective.

Trials are the only reliable way to find out if a different type of surgery, chemotherapy, hormone therapy, radiotherapy or other treatment is better than what is already available.

Taking part in a trial

You may be asked to take part in a research trial. You will be carefully monitored during and after the study.

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

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

Private healthcare

Private medical treatment for cancer is offered by private hospitals and clinics, and some specialist NHS hospitals that also treat private patients.

Payment for treatment can be made through private health insurance. You can also self-fund, which means you pay the hospital or clinic directly.

Questions to ask about your treatment

- What treatment do you recommend for me and why?
- Are there any other kinds of treatment that might be equally as effective?
- Where will I have to go for my treatment?
- How long will the treatment last?
- What are the benefits of each treatment option?
- What are the risks and side effects of each treatment?
- How experienced are you and your team in this kind of treatment?
- Will the treatment affect my daily routine or activities, for example work or education?
- Will I need some help to look after myself/my family?
- Will the treatment affect my sex life?
- Can I keep active or should I rest more?
- Will the treatment affect my fertility?
- How do I know I'm getting the best treatment?
- Are there any clinical trials I can take part in?
- Who can I contact for medical advice out-of-hours?

Questions to ask during your treatment

- How can I tell if the treatment is working?
- What follow-up will I have when the treatment finishes?
- What can I do to help myself?
- Is there anything, like certain foods or activities, I should avoid?
- Who can I talk to about getting psychological support or help with other issues, such as diet?

Questions to ask if you're a parent of a young person with cancer

- How can I make sure my child gets the best treatment and support?
- Where will my child be treated?
- Will my child be treated with older people or with young people?
- What should I tell my other children?
- Will our other children need help?
- Can I talk to other parents of young people with cancer?
- Can my child continue going to school/college?
- If not, are there other ways to continue with their education?

Questions to ask if you're a young person with cancer

- How can I get in touch with other young people with cancer?
- Where can I get more information and support for my age group?
- Can I talk to the doctor without my mum or dad?
- Is there somewhere I can be treated with people of my own age?
- Can I still go out and continue going to school/college?
- I think my mum and dad are finding it hard to cope. What support is available for them?
- I'm frightened of what my friends will say. How can I handle that?
- How might the treatment affect my future (such as my fertility and any long-term side effects)?

Macmillan has information written especially for teenagers and young people at macmillan.org.uk/teensandyoungadults

5 Talking to your healthcare team

Diagnosis and treatment can be a worrying and confusing time. Even after your treatment is over you may worry about what the future may bring or whether the cancer will come back.

Talking to your healthcare team can help. Many people feel better and more in control when they know what is happening to them and why.

People often feel that hospital staff are too busy to answer their questions, but it's important for you to understand what's happening and how the cancer and its treatment is likely to affect you. The staff should be willing to make time for your questions.

Your family and friends may also have questions to ask. Your healthcare team should be happy to answer their questions, if they have your permission to. They can also give your family and friends advice on how they can care for you. There's more information for people supporting someone with cancer on pages 65–73.

If you don't speak English

If you don't understand or speak English very well, the hospital can arrange an interpreter for you when you meet with your doctor or other members of the healthcare team.

Interpreters translate everything your doctor says to you and everything you want to say back. You may have to ask in advance for your hospital to arrange an interpreter.

There are also people called advocates who can talk on your behalf and make sure your healthcare team knows about any wishes you have.

The Macmillan Support Line has an interpretation service in over 200 languages. Call free on 0808 808 00 00.

If you have hearing or speech difficulties

You may want to bring someone with you to speak on your behalf or sign any conversation you have with your doctor. You can also ask your doctors or nurses to write things down for you. Action on Hearing Loss can give you further information and support (see page 114).

If you're partially sighted

If you're partially sighted you can ask for written information to be provided in large print. Some organisations, including Macmillan, can provide information in Braille or as an audio CD. You can also ask your doctor if it's okay to record their conversations with you.

You can get further information and support from RNIB (Royal National Institute of Blind People) – see page 115.

Planning for your appointments

Before you meet with your healthcare team, it may be helpful to think about the following:

- **Think about what matters to you.** Write your thoughts down and take them with you so you don't forget. Remember, it's important to tell your healthcare team what worries or concerns you have. This helps them understand what matters to you.
- **Think about any questions you want to ask** or use some of the suggested questions in this booklet. They may help put your thoughts into words.
- **Use your own words.** Although your doctors or nurses may use medical terms, you don't have to. It's okay to use your own words to describe the problem. In fact, using terms that you only partly understand may cause problems as your doctors and nurses may think you know more than you do.
- **Ask the doctor or nurse to explain any medical terms** you don't understand, even if they've explained them before. You'll also find a list of commonly used medical terms on pages 92–102.
- **Try not to feel rushed.** Ask for more time if you're confused or want to share any worries or concerns you have.
- **Take someone with you**, such as a relative or friend, who can listen to what is said and ask some questions on your behalf.

- **Write things down**, such as answers to your questions or test results. You can also ask to have copies of any letters, for example, letters that are sent to your GP by your cancer specialist (see page 16).
- **Ask questions** if you don't understand what is being said.
- **Record the conversations with your doctor.** Many doctors don't mind you taking a tape recorder to the appointment (or recording on your mobile phone), but check with them first. You can listen to the conversation when you go home so that you don't miss anything that is said.

6 Getting information and support

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 lots of things you can do to help come to terms with your diagnosis and treatment, and this can help change how you feel. 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.

Turn to pages 51–55 for more information about coping with difficult emotions.

Talking to people

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, like the nurses and doctors looking after you. They're there to listen and to talk to you about any worries you have. There are lots of charities and organisations you can turn to for support. Some of these are listed on pages 107–115.

We have a booklet called *Talking about your cancer*, which you may find helpful.

Information

Cancer can be a difficult disease to understand. Even if what you're hearing is straightforward, it can sometimes be hard to take everything in. Doctors and nurses may use medical words that you don't understand. It's important to ask your healthcare team to explain words you're not sure about. And don't worry if you have to ask more than once for an explanation. It's normal to feel confused when you don't know what is going on.

While your healthcare team is there to explain and answer any questions you have, once you're at home it's easy to forget what was said. Some people might not want to remember everything they've been told. But many people want to know about what's happening to them so they can feel a sense of control. One way to be less confused and more in control is to learn about your cancer, how it's treated and how to live with it after treatment finishes.

Written information

This can help you understand your cancer and reinforce what you've been told by your healthcare team.

Many cancer treatment centres have developed patient information for each stage of your care. Your healthcare team can provide you with written information that is tailored to your situation.

We have a range of cancer information booklets and fact sheets about the different types of cancer, the treatments, and many of the different aspects of living with cancer.

All our information is free and many hospitals and drop-in information centres have copies of our booklets and fact sheets. You can also get copies by calling the Macmillan Support Line free on **0808 808 00 00** or by visiting **be.macmillan.org.uk**

Information on the internet

A lot of information about cancer is available on the internet. However, finding websites that contain accurate and up-to-date information isn't always easy. It's a good idea to be careful when searching for information on the internet as it's not always written by trusted sources. We've listed some websites that are accurate and up-to-date on pages 117–119.

Information prescriptions

An information prescription is information that is tailored to your situation and includes contact details for further support.

You can create your own information prescription or you can discuss your information needs with your GP or healthcare team. To create your own information prescription, visit **nhs.uk/ips**

Cancer information and support centres

Many hospitals, and some GP practices and libraries, have their own cancer information and support centres. These are places where you can get free information about all aspects of cancer. Each centre provides a relaxing environment where you can look through information and talk to specially trained staff about any problems you and your family may have.

These centres often provide a range of support services. For example, some offer free counselling, benefits advice, complementary therapies, and some hold coffee mornings and social meetings where you can meet people with a similar experience to your own. The centres can also put you in contact with other sources of support and help.

We can give you details of your nearest cancer information and support centre. Call us free on **0808 808 00 00** or visit **macmillan.org.uk/howwecanhelp**

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. There are also helplines just for children and young people. The Macmillan Support Line is a good place to start. Call free on **0808 808 00 00**.

> ‘I called Macmillan just before I was due for the six-monthly consultation with my oncologist to talk about treatment options. The person I spoke to was so helpful and knowledgeable. I came off the phone confident that I had completely trustworthy information and it meant that at the consultation I was able to have a discussion informed with the facts.’
>
> **Claire**

Cancer support groups

Cancer support groups, or self-help groups, are groups of people affected by cancer who meet regularly to socialise and help each other. While some people may not feel comfortable discussing their situation with others, many find it very helpful to talk to those with similar issues.

Some support groups are specific to a particular type of cancer, for example a breast cancer support group. Others are more general and people with any type of cancer can go along. Some are open to family, friends and carers too.

Support groups provide the opportunity to talk with people who understand what you're going through and can also help you find out about other local services.

Online support groups, forums and blogs

If you have access to the internet, you can join an online support group or forum where you can read about other people's cancer experiences and their feelings. It's up to you whether you want to write anything or not – if you prefer, you can just read what others have written.

A blog is an online journal where you can share your feelings and thoughts. Many people find writing helps them to deal with their situation. It can also be helpful to find that other people are thinking similar things as you. Sometimes what other people say might express the feelings you've been struggling to put into words.

We have an online community with discussion forums at macmillan.org.uk/community

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. Other support organisations are listed on pages 107–115.

Spiritual care

Some people find that they become more aware of spiritual or religious feelings when they're under stress.

If you already have a strong faith, it may give you a lot of comfort and support. Some people find that they start to question their faith.

If you think that it would help you to talk to a religious leader or the hospital chaplain, don't be put off because you aren't sure what you believe or haven't worshipped anywhere regularly. They are used to dealing with uncertainty and are usually happy to talk to you and give whatever support and comfort they can. They can also speak with other religious and cultural groups in the community on your behalf.

7 Your feelings

Most people feel overwhelmed when they are told they have cancer, and have many different emotions. These are part of the process you may go through when dealing with your illness. Partners, family members and friends often have similar feelings and may also need support and guidance to help them cope.

> ‘“It can’t be true!” This was my initial reaction when I was told that I had cancer. For a while I was numb, unable to believe what was happening and express emotions.’
>
> **Asma**

Reactions differ from one person to another – there’s no right or wrong way to feel. We describe some of the common emotional effects of cancer here. However, reactions vary and people have different emotions at different times.

Our booklet *How are you feeling?* discusses the emotions you may have in more detail, and has suggestions for coping with them.

Shock and disbelief

Disbelief is often the immediate reaction when cancer is diagnosed. You may feel numb and unable to express any emotion. You may also find that you can only take in a small amount of information, and so you have to keep asking the same questions again and again. This need for repetition is a common reaction to shock. Some people find that their feelings of disbelief make it difficult for them to talk about their illness with family and friends. For others it may be the main topic of conversation as it's the main thing on their mind.

You may find our booklet *Talking about your cancer* helpful.

Fear and uncertainty

Cancer is a frightening word surrounded by fears and myths. One of the greatest fears people have is whether they will die.

Many cancers are curable if found at an early stage. When a cancer is not curable, current treatments often mean that it can be controlled for some time.

Many people are anxious about whether their treatment will work and have any side effects. It's best to discuss your treatment and possible outcomes in detail with your doctor.

You may find that doctors can't answer your questions fully, or that their answers sound vague. It's often impossible for them to say for certain how effective treatment will be.

Doctors know roughly how many people may benefit from a certain treatment, but they can't predict the future for a particular person. Many people find this uncertainty hard to live with, but your fears may be worse than the reality. Finding out about your illness can be reassuring. Discussing what you have found out with your family and friends can also help.

You might find it helpful to talk to other people in your situation. Call our cancer support specialists on **0808 808 00 00** to find out if there's a support group in your area. Or you can visit our online community at **macmillan.org.uk/community** to chat any time with people who know what you're going through.

Some people find some form of spiritual support helpful at this time, and you may like to talk to a spiritual or religious adviser.

Denial

Many people cope with their illness by not wanting to know much or talk much about it. If that's the way you feel, just let your family and friends know that you'd prefer not to talk about your illness, at least for the time being.

Sometimes, however, it's the other way around. You may find that your family and friends don't want to talk about your illness. They may appear to ignore the fact that you have cancer, perhaps by playing down your worries and symptoms or deliberately changing the subject. If this upsets or hurts you, try telling them. Perhaps start by reassuring them that you know why they're doing it, but that it will help you if you can talk to them about your illness.

Anger

People often feel very angry about their illness. Anger can also hide other feelings, such as fear or sadness. You may direct your anger at the people closest to you, or at the doctors and nurses caring for you. It's understandable that you may be very upset by many aspects of your illness, so you don't need to feel guilty about your angry thoughts or irritable moods.

Bear in mind that your family and friends may sometimes think that your anger is directed at them, when it's really directed at your illness. It may help to tell them this, or perhaps show them this section of the booklet.

Blame and guilt

Sometimes people blame themselves or others for their illness, trying to find reasons to explain why it has happened to them. This may be because we often feel better if we know why something has happened. In most cases it's impossible to know exactly what has caused a person's cancer. So there's no reason for you to feel that anyone is to blame.

Resentment

Understandably, you may feel resentful because you have cancer while other people are well. These feelings may crop up from time to time during the course of your illness and treatment. It usually helps to discuss these feelings, rather than keeping them to yourself.

Isolation and depression

There may be times when you want to be left alone to work through your thoughts and emotions. This can be hard for your family and friends, who want to share this difficult time with you. It may help them cope if you reassure them that, although you don't feel like discussing your illness at the moment, you'll talk to them about it when you're ready.

Sometimes, depression can stop you wanting to talk. If you or your family think you may be depressed, discuss this with your GP. They can refer you to a doctor or counsellor who specialises in the emotional problems of people with cancer, or prescribe an antidepressant drug for you.

We have a video at macmillan.org.uk/depression that you may find helpful.

8 After treatment

When your treatment is over, it's important to give yourself time to adjust to any physical or emotional changes.

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.

Your follow-up care and support

After your treatment is completed, 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 for a while they get very anxious before their appointments. This is natural. It may help to get support from family, friends or one of the organisations listed on pages 107–115 during this time. Sometimes, instead of routine appointments, people are asked to contact their doctor or specialist nurse if there's anything they're worried about.

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

Looking after yourself

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 people experience treatment side effects that gradually improve over time – others may have ongoing or delayed side effects.

Not everyone with cancer will experience specific side effects, but they may have a range of other effects, such as trouble sleeping or feeling weaker and more tired than usual. Some may have lost or gained weight, or have stiff muscles or joints.

Living a healthy lifestyle can help your body recover more quickly, and may help prevent the cancer from returning. Healthy living will also help to reduce the risk of other illnesses, such as heart disease and strokes.

A healthy lifestyle can include having a well-balanced diet, exercising, reducing stress and being involved in your healthcare. You will need to take any side effects of treatment into consideration when planning changes to your diet and exercise. Don’t try to do too much too soon.

> ‘Since joining the gym and doing a little basic yoga every morning, I find my moments of post-cancer depression far less frequent or severe.’
>
> **Richard**

If you’re thinking about making some major changes to your lifestyle, it’s a good idea to discuss your plans with your doctor or specialist nurse.

Our booklet *Life after cancer treatment* gives useful advice about keeping healthy and adjusting to life after treatment. We also have booklets about exercise, diet, giving up smoking and your feelings after treatment.

Worrying that the cancer will come back

Many people worry that the cancer will come back (recur). This is a normal reaction. As time goes on, most people become less worried about this. It's not only the worry that eases over time, but the actual risk too. When cancer does recur, in most cases it happens within the first two or three years after treatment has finished. It may help to talk to your cancer specialist or clinical nurse specialist about the risk of your cancer coming back.

If you're concerned 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.

Questions to ask after your treatment

- When will I know if my treatment has worked?
- How long will it be before I feel better and can get back to my normal routine?
- What follow-up will I have?
- What happens if the treatment hasn't worked?
- How will I know if the treatment has caused any long-term side effects?
- Who can provide help for me at home?
- Is there any financial help available for me?

If the cancer returns

Sometimes the cancer does come back. Doctors call this **recurrence**.

The cancer may start growing in the same place it was found originally (**local recurrence**) or somewhere else in your body (**metastatic** or **secondary cancer**).

Many cancers that come back can still be treated. Occasionally, if the cancer comes back it's still possible to cure it, but in many instances, treatment will only be able to slow down the progress of the cancer. Sometimes further cancer treatment isn't possible. When this happens, you can be given treatment to control any symptoms you may have.

You may also be referred to a palliative care team or to a Macmillan nurse. They are experts in supporting patients and families when there is no longer a cure but quality of life is very important.

Hospices

Many people affected by cancer like to be looked after at home, but you may be more comfortable being looked after in a hospice. Hospices specialise in the control of pain and other symptoms. It’s quite common for someone to go into a hospice for a short time so that their symptoms can be closely monitored and brought under control, and then to return home.

Hospices are smaller and quieter than hospitals and often work at a much gentler pace. Many have kitchens, sitting rooms and accommodation for relatives, and maybe even a bar. Accommodation and care in a hospice is always free of charge.

9 Complementary therapies

Complementary therapies are treatments people can use alongside conventional cancer treatments. Unlike conventional cancer treatments – such as radiotherapy, chemotherapy, surgery and hormonal therapy – complementary therapies don't treat the cancer. They're used to help you feel better and improve your quality of life. Complementary therapies may also:

- improve your general health
- give you a sense of control over what is happening to you
- reduce stress, tension, sleeplessness, anxiety and depression, and make you feel more relaxed
- help to reduce the symptoms of cancer, such as pain, feeling sick, breathlessness, constipation, diarrhoea, tiredness and poor appetite
- help to reduce some of the side effects of cancer treatment.

Complementary therapies are different to alternative therapies. Alternative therapies aim to treat cancer using unconventional treatments. Some people use alternative therapies alongside conventional treatments or complementary therapies. It's worth remembering that many alternative therapies have not been thoroughly tested or proven to have any health benefits in the same way that conventional medicines have.

Some complementary therapies may be available on the NHS in some areas. Some cancer information and support centres offer free complementary therapies for people affected by cancer.

Will they affect my treatment?

Most complementary therapies are unlikely to affect your treatment. However, some complementary therapies can interact with cancer treatments and may make them less effective. It's important to talk to your doctor about any other therapies you're thinking of having.

There's more information about different types of complementary therapies and choosing a therapist in our booklet *Cancer and complementary therapies*.

10 Caring for someone with cancer

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

You may not think of yourself as a carer, but rather as a partner, parent, relative, friend or neighbour. You may be 'just doing the right thing', but as a carer you're an important part of someone's life, and there are many organisations that can help you in this role.

Being a carer can be physically and emotionally exhausting so it's important to keep an eye on your own health as well. This section gives some tips to help you and the person you're caring for support each other.

Listening and understanding

The feelings that arise when someone close to you is ill can be very strong and hard to deal with. It can help to get them out in the open, if you can. If you can't do this with the person you're caring for, try talking to someone outside the situation who may be able to help you get things in perspective. Your feelings may be easier to deal with once you've discussed them.

Many people, however, find it difficult to be open together in this way, especially when they're faced with a new and stressful situation. Some people are uncomfortable about discussing their feelings with the person with cancer because they think they'll be a burden.

Others find it difficult to talk about it because they worry that they won't be able to console their friend or loved one, or that they'll break down and cry themselves. Some people just aren't used to talking to each other about important things like this.

As a relative or friend, it's not always what you say that matters most, but how you listen. Listening is a sign that you care about how they feel and helps a person be at ease when they talk. Try not to rush into talking. Just because someone is silent doesn't mean they aren't thinking about the situation. Let them know that you're there and ready to listen. When the moment is right for them, they will talk to you. Try to remember:

- Someone with cancer will have a range of emotions – shock, fear, anger, resentment, uncertainty and confusion. They may also be depressed. So it helps to be ready to listen to anything, however emotional or difficult.
- People with cancer can become frustrated. It's common for someone with cancer to direct their anger at those closest to them who mean the most.
- You may be asked difficult questions that you don't have the answers for. It's okay to say you don't know.

Our booklet *Lost for words* is written for relatives and friends of people with cancer. It looks at some of the difficulties people may have when talking about cancer and suggests ways of overcoming them.

Getting information and support

Many carers find it easier to understand what's going on and to cope better with their emotions when they have accurate information about the cancer, the treatment and its effects. The doctors and nurses who are looking after your relative or friend are also there for carers. They can give you information to help you understand what's happening and answer any questions you have.

Cancer helplines and cancer information and support centres are other good sources of information on all aspects of cancer. Other sources of information and support are discussed on pages 44–49.

You can ask doctors and nurses for advice if you're unsure about what you can do to help. They can arrange for a social worker to talk to you. The social worker may be able to organise financial and practical help for you and the person you care for.

We have a lot of information on our website for people caring for someone with cancer. Visit macmillan.org.uk/carers

> ‘After my wife was taken ill, I didn’t work for the next five months and became a full-time carer. We were plunged into the world of illness, hospitals and medicine. I quickly learned to understand and live in this world and I learned just how many wonderful people work in this world to care for the terminally ill.’
>
> **Patrick**

Looking after yourself

It’s impossible to do everything for your relative or friend all of the time. If you try to do too much, you may become exhausted and even ill. So it makes sense to look after yourself while you’re caring for someone else.

Be realistic about how much you can do and recognise what you can’t. You don’t need to feel guilty about accepting offers of help or asking other people (or organisations) to lend a helping hand. There are organisations, charities and support groups that can help – see pages 107–119.

Social workers and healthcare professionals, like clinical nurse specialists, specialise in offering support to the whole family from the moment someone is diagnosed.

Try not to bottle up your emotions. Talking to family or friends or one of the healthcare team 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 (see page 49). 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 pages 107–115.

Our booklets *Hello, and how are you?* and *Caring for someone with advanced cancer* have lots of useful information to help you look after your relative or friend.

Benefits and financial help

Carer's assessment

If you provide 'regular and substantial' care for someone over 18, you have the right to a carer's assessment from the social services department at your local council. This is a chance to discuss what help you need as a carer.

This is your right by law, under the Carers (Recognition and Services) Act 1995 and the Carers and Disabled Children Act 2000. You don't have to be living with, or related to, the person you care for to be assessed.

For more information about carer's assessments, contact your local council (social work department in Scotland) or Carers UK (see page 112).

Carer's Allowance

Carer's Allowance is the main benefit for carers. It's a weekly benefit for someone caring for a person who is in receipt of the care component of Disability Living Allowance (highest or middle rate) or Attendance Allowance.

Carer's Credit

Carer's Credit is a national insurance credit for carers of working age. It helps carers build up qualifying years for the State Pension so there are no gaps in your national insurance record if you're taking on caring responsibilities. It isn't a cash benefit.

There is more information about benefits and financial help in our booklet *Help with the cost of cancer*.

The benefits advisers on the Macmillan Support Line can also give you information about Carer's Allowance and other benefits you may be entitled to. Call free on **0808 808 00 00**.

Carer's rights

Flexible working and time off in an emergency

If you're caring for an adult who is a relative or lives at the same address as you, you have the right to ask your employer for flexible working hours under the Work and Families Act 2006. You also have the right to take unpaid time off work for dependants in an emergency. This right is covered by the Employment Rights Act 1996, as amended by the Employment Relations Act 1999.

In Northern Ireland, these laws are called the Employment Rights (Northern Ireland) Order 1996 and the Employment Relations (Northern Ireland) Order 1999.

Protection from discrimination and harassment

People with cancer and their carers are protected from direct discrimination and harassment under the Equality Act 2010. This applies to people living in England, Scotland and Wales.

The Disability Discrimination Act (DDA) protects people with a disability in Northern Ireland. Following the decision by the European Court of Justice in Coleman v Attridge Law (2008), carers who are also employees are protected under the DDA 1995 (as amended) from direct discrimination and harassment in the workplace in Northern Ireland.

We have a booklet called *Working while caring for someone with cancer*, which you may find useful.

If you want to help

If you're not the main carer but want to help in some way, these tips might be a good place to start:

- **Find out if your help is needed** by asking a close member of the family.
- **Ask yourself what help might be needed.** You could offer to sit with the person with cancer while their main carer is resting. You could pop in for a chat, do some laundry, make some meals (check which foods are best), pick up the children from school or do the food shopping.

- **Work out what jobs you can do.** If you’re a terrible cook, don’t agree to do the cooking. There will be lots of other things you are good at.
- **Offer to do things that you can easily do.** Sometimes the smallest things, like weeding the garden, mean the most. Offering to do everything can make people feel awkward and embarrassed.
- **Don’t visit too often.** Some people can be overrun with visitors. It’s well-meaning, but check when it is good to call by. Spending regular time with your relative or friend, and being reliable about your visits, could be the best way to show how much you care and how much they mean to you.


NZIMRT · World Radiography Day

11 Care standards and cancer services in the NHS

What is guidance?

Guidance is developed to help health and social care professionals deliver the best possible care based on the best available evidence.

It is about putting into practice what we know works well. To make this happen, the government in England set up the National Institute for Health and Clinical Excellence (NICE). NICE is an independent organisation that gives advice on which new drugs and treatments should be available on the NHS and how particular illnesses like cancer should be treated. NICE advises the NHS in England and Wales. But in Scotland and Northern Ireland, there are different organisations involved.

In Scotland, standards of care are regulated and developed by Healthcare Improvement Scotland and the Care Inspectorate. Guidance about treatment is developed by the Scottish Intercollegiate Guidelines Network (SIGN). Information about individual medicines is given by the Scottish Medicines Consortium (SMC).

In Northern Ireland, guidance about healthcare is the responsibility of the Department of Health, Social Services and Public Safety, which often uses guidance produced by NICE.

In Wales, the All Wales Medicines Strategy Group advises on the use of treatments that aren't evaluated by NICE.

These organisations were set up to help make sure that people have equal access to treatments and drugs wherever they live.

As well as providing guidance for healthcare professionals, NICE produces its information in a less technical, easier-to-understand format for the general public. This information can be found on the NICE website at **guidance.nice.org.uk**

How do governments plan healthcare?

Health policies are national or local government decisions or plans that aim to help people stay healthy, improve the way health and social care is delivered, and ensure that services are responsive, flexible and patient-centred. Examples of health policies include banning smoking in public places and the decision to create the NHS and make healthcare free for all.

Government policies around health and cancer are continually evolving across all four nations in the UK. Each nation has a different approach, based on different national context and strategies. If you would like to find out more about cancer policy in your nation, the following websites have up-to-date information:

Department of Health (England)
www.dh.gov.uk

Health and Social Care in Northern Ireland
www.healthandcareni.co.uk

Public Health Wales
www.wales.nhs.uk

Scotland's Health on the Web
www.scot.nhs.uk

What you should expect

As someone affected by cancer, you have the right to:

- have your treatment options and side effects explained in words you understand
- decide whether you want to have a particular treatment or not
- see your medical records
- 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 satisfactory (see pages 83–85)
- receive information on local services and those further away that can provide the care you need
- be offered written information that is easy to understand and tailored to your needs.

11

Your relatives and carers have the right to:

- be involved in decisions about your treatment and supportive care plan (with your permission)
- have information and advice about any support they may need.

If you're living at home, you have the right to:

- have your needs assessed by your local council (called a community care assessment – see page 88) – carers can make this request too (called a carer's assessment – see page 70)
- apply for services like home help or meals on wheels if your social worker thinks they're needed
- complain to your local council (social work department in Scotland) if the support it's providing isn't good enough. See pages 83–85 for more on making a complaint.

Cancer targets

Targets (set times when certain things should be done by) have been set to make sure everyone benefits from the best possible treatments, care and support at every stage of their cancer experience.

GP referrals

NHS services must see people within a certain time once their GP has referred them. The GP will examine the person and then determine (based on clinical guidance) if they need an **urgent referral** (called a red flag referral in Northern Ireland) to a specialist or whether they can be seen less quickly (called a **non-urgent referral**).

If your GP suspects you have cancer, you will be given an urgent referral and will be seen by a cancer specialist within two weeks of referral no matter where you live.

Non-urgent referral times can vary depending on which nation you live in and what type of medical problem your GP thinks you have.

Waiting times before seeing a specialist

Treatment times

There are then targets that set out how quickly people should begin cancer treatment in the UK. These are:

- a maximum of **31 days** between diagnosis/decision to treat and the start of your treatment
- a maximum of **62 days** between GP's urgent referral and the start of your treatment.

Maximum waiting times before starting treatment

Cancer services

The NHS is currently going through a period of change and some of the organisations mentioned below will change in the next few years.

Cancer networks, centres and units

To treat cancer in the best possible way, cancer services in the UK are organised into regional cancer networks. Each network is responsible for the planning and delivery of care for people with cancer in that area. Within each network there are one or more cancer treatment centres, usually based in a larger hospital. Cancer centres specialise in treating a variety of cancers, including some of the rarer types, and in giving specific cancer treatments, such as radiotherapy and chemotherapy. The cancer centre may not be your local hospital, so you may have to travel to be seen by a cancer specialist or to have treatment.

Throughout the cancer networks there are also smaller cancer units that are often based in local hospitals. The cancer units will treat people with the more common types of cancer and provide treatments, such as surgery and some chemotherapy treatments. Depending on your cancer and treatment plan, the cancer units allow you to be treated closer to your home. The units have very close links with the larger cancer centres and you'll still benefit from the care and support provided by the centre's multidisciplinary team.

Cancer networks in England are due to be replaced with 'strategic clinical networks' by April 2013. These will aim to improve health services for people affected by cancer.

Access to treatment in England

Primary care trusts (PCTs) are responsible for funding cancer drugs and treatment. They need to make sure the drugs and treatments they fund are of clear benefit to the people in their area. They also need to make sure they are spending their money wisely, helping as many people as possible. This means that they may decide that some drugs and treatments aren't available automatically.

Cancer drugs or treatments might not be automatically funded if it's not clear how effective they are, if they haven't been proven to be more effective than other treatments, or if the PCT decides that the possible benefits of the drug don't justify the costs.

The effectiveness of a drug or treatment may be decided after clinical trials have been done and when decisions are made by NICE (see page 75).

If you haven't been able to access a particular drug that would help control your cancer, you can apply to your PCT for it to be made available to you as an exception from their usual rules. PCTs usually call these applications individual funding requests (IFR). If you're still unable to get the drug and have tried all other funding options, you may be able to apply for funding through the Cancer Drugs Fund. This is a special fund for drugs that aren't routinely available on the NHS.

For information about access to treatment in Wales, Scotland and Northern Ireland, please call our cancer support specialists on **0808 808 00 00**.

PCTs will be replaced by Clinical Commissioning Groups (CCGs) in April 2013. CCGs will have similar responsibilities to the PCTs they're replacing.

We have more information about what to do if a treatment isn't available and about the Cancer Drugs Fund.

When your healthcare isn't as good as it should be

Most of the time treatment and care within the NHS goes well, but sometimes things go wrong. If you're not happy with the care or treatment you've received or you've been refused treatment for a condition, you have the right to complain, have your complaint investigated, and be given a full and prompt reply.

Your local hospital, trust or health board will have its own complaints procedure and can give you a copy. All complaints should be made as soon as possible and within 12 months of the date of the event that you're complaining about. You can make your complaint directly to the service you're unhappy with or through your local PCT if you live in England.

Your first step will normally be to speak with or write to the member of staff or department that you're unhappy with or the complaints manager. This is called local resolution, and most cases are resolved at this stage.

If you remain unhappy with the outcome, you can take your complaint further and seek an independent review. You may also be able take your case to the ombudsman – a person who investigates and settles complaints.

You can find more information about making complaints on the NHS Choices website (**nhs.uk**) by searching for 'complaints' or by calling NHS Direct (**0845 4647**), NHS 24 in Scotland (**08454 242424**) or NHS Direct Wales (**0845 46 47**).
For information about making a complaint about the Health Service in Northern Ireland, visit **nidirect.gov.uk/make-a-complaint-against-the-health-service** or contact your local health trust.

Making a complaint about your local council (social work department in Scotland)

To make a complaint about your local council or social work department, you must first complain to the council. If you're not satisfied with the outcome, you can then go to the Local Government Ombudsman (see page 110).

Getting advice

A good place to get free advice about making a complaint is your local Citizens Advice (see page 109). In England, you can talk to the Patient Advice and Liaison Service (PALS). All hospitals have access to a PALS department, which is there to help with any queries or issues you have about your healthcare. You can contact your local PALS by phoning the hospital where you were treated or searching at **pals.nhs.uk/officemapsearch.aspx**

The PALS can usually help solve problems or they can put you in contact with the Independent Complaints and Advocacy Service (ICAS), which can give advice.

Help and advice is also available in Northern Ireland from the Patient and Client Council on **0800 917 0222** or email **info.pcc@hscni.net**

In Scotland, you can contact your local NHS Board (**scot.nhs.uk/organisations**); and in Wales you can contact your Community Health Council (**wales.nhs.uk/sitesplus/899/home**). Its details are also in the phone book.

Healthwatch

Healthwatch is a new independent consumer champion created to gather and represent the views of the public in England. It will provide a complaints advocacy service from 2013 to support people who make a complaint about services.

We have a fact sheet about making complaints, which we can send you.

12 Financial help, benefits and employment

If you're struggling to cope with the financial effects of cancer, help is available.

If you're an employee and unable to work because of illness, you may be able to get **Statutory Sick Pay**. This is paid by your employer for up to 28 weeks of sickness, and if you qualify for it, your employer can't pay you less.

Before your Statutory Sick Pay ends, check whether you can claim **Employment and Support Allowance**. This benefit gives financial help to people who are unable to work due to illness or disability. It also provides some support to those who can work.

Disability Living Allowance (DLA) is for people under 65 who have difficulty walking or looking after themselves (or both). You need to have had these difficulties for at least three months to qualify, and they should be expected to last for the next six months. As part of the Welfare Reform Act 2012, DLA will be replaced by a Personal Independence Payment for people of working age from April 2013.

Attendance Allowance is for people aged 65 or over who have difficulty looking after themselves. You may qualify if you need help with personal care, such as getting out of bed, having a bath or dressing yourself. You don't need to have a carer to be eligible, but you must have needed care for at least six months.

If you've been diagnosed with cancer, you have the right to a **community care assessment** from your local social services department. This is to see whether you need services that the local authority should meet.

Help for carers

If you are a carer, you may be entitled to financial help as well. See pages 65–73 for more information.

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

> 'My benefits adviser dealt with all the paperwork and, with the extra money coming in, it took a weight off my shoulders and I could concentrate on getting better.'
>
> Kirsty

You can find out more about benefits from Citizens Advice, or by calling the Benefit Enquiry Line on **0800 882 200** (or **0800 220 674** if you live in Northern Ireland). The website **direct.gov.uk** (**nidirect.gov.uk** if you live in Northern Ireland) also has useful information.

See our booklet *Help with the cost of cancer* for more detailed information. Our video at macmillan.org.uk/gettingfinancialhelp may also be useful.

Financial guidance

We have a team of dedicated financial experts who can help you with financial issues, such as planning and managing finances, debt and borrowing, and insurance. You can speak to one for free by calling **0808 808 00 00**.

We can also send you our financial guide, *It all adds up,* or you can use the interactive financial tool on our website at macmillan.org.uk/financialguidance

Macmillan Grants

These are small, mostly one-off grants, to help people meet expenses that have arisen from, or are associated with, their cancer.

Whether you need extra clothing, help paying heating bills or even a relaxing break, you may be entitled to a Macmillan Grant.

Award amounts vary depending on circumstances and needs, but the average grant amount is £250. A grant from Macmillan won't affect your ability to claim benefits. It's an extra boost, not a replacement for other forms of support.

You need to apply through a health or social care professional, such as a social worker, district nurse, or a Macmillan nurse if you have one.

If you have any questions about Macmillan Grants or if you're having difficulty getting someone to fill in an application form with you, please contact us on **0808 808 00 00**.

Other grants

There are other grants available from a variety of sources, including occupational funds, utility companies (gas, electricity and water companies) and charities. For more information contact a local welfare rights adviser or our cancer support specialists on **0808 808 00 00**.

Employment

It may be difficult to decide whether or not to work during your treatment. It depends very much on your individual circumstances. Some people choose to carry on working, either full-time or part-time, during their treatment. Some people need to carry on working as much as possible for financial reasons. It's a good idea to talk to your doctor if you think your health may affect your ability to work.

Employment rights

As someone affected by cancer, you have the right to:

- carry on working
- not tell your employers about any tests you're having
- expect your employer to make 'reasonable adjustments' to your working environment or practices, if needed, for example allowing time off for appointments
- challenge your dismissal if you're sacked or made redundant because of your health, even if you work part-time.

Protection from discrimination

The Equality Act 2010 protects anyone who has, or has had, cancer. This means their employer must not discriminate against them in any way because of their illness or past cancer. People in Northern Ireland are protected by the Disability Discrimination Act 1995.

You can get further information about your rights at work from the Equality and Human Rights Commission, the Equality Commission for Northern Ireland, Community Legal Advice and your local Citizens Advice (see pages 109–115).

Our booklets *Work and cancer* and *Self-employment and cancer* give more information about employment rights, disability rights and financial issues for people with cancer.

Medical terms

While having cancer treatment, you will come across lots of new words and may be unsure of what some of them mean. Remember, you can always call the Macmillan Support Line free on 0808 808 00 00 if you're unsure about any of the words your doctor or nurse has used.

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

Adjuvant therapy is further treatment given after your main cancer treatment. For example, you might have an operation (the main treatment) to remove your cancer and then be given chemotherapy (adjuvant therapy) to reduce the risk of the cancer coming back. *See neo-adjuvant therapy.*

Alopecia means the loss of your hair, and can include the hair on your head, your eyebrows, eyelashes and other body hair. Hair loss can be a side effect of some cancer treatments, such as chemotherapy.

Anaemia means you have a low number of red blood cells in your blood. Red blood cells carry oxygen, and if you have too few, you may feel tired and breathless. *See blood count.*

Benign means not cancerous. Benign tumours usually grow slowly and don't spread.

Biological treatments/therapies are a group of drugs that treat cancer cells but do little damage to normal cells. They target specific parts of the cancer cell and so are sometimes called targeted therapies.

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

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

Bone marrow is the spongy material found inside the bones. It's where blood cells develop.

Bone marrow aspiration is a test that uses a thin needle to remove a small amount of bone marrow.

Bronchoscopy is a type of endoscopy test that looks at the inside of your lungs. *See endoscope.*

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

Carcinoma is the name given to cancers that begin to grow in the epithelium, which is the covering (or lining) of organs and of the body. Most cancers are carcinomas.

Carcinoma in situ means cancer cells in the very early stages of development that haven't spread beyond the place that they first began to grow.

Central line is a long, hollow tube made from silicone rubber that's put into one of the veins in your chest. It can be used to give you treatments such as chemotherapy, antibiotics and intravenous fluids. 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.

Colostomy is an opening of the large bowel (colon) on to the skin of the abdomen that is made after some types of surgery for bowel cancer. A bag is worn over the opening (stoma) to collect bowel motions.

Cytotoxic means toxic to cells. *See chemotherapy.*

Diagnosis is when the kind of disease you have is known.

Diarrhoea is 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 on nutrition and diet. They can give advice on how to eat well, as well as help people who have specific eating problems.

Drip is a way of giving fluids or drugs, such as chemotherapy, into a vein. Also called an intravenous infusion.

Endoscope is a thin, flexible tube with a light and a camera inside. It's used to look inside your body so the doctor can see any problems you may have. When this test is carried out it's called an endoscopy.

Fatigue is when you feel excessively tired or exhausted all or most 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.

Haematologist is a doctor that specialises in blood disorders.

Histology means the study of cells. Doctors look at cells under a microscope to see if they are normal or not. It's sometimes also called histopathology.

Hormonal therapies alter the production or activity of particular hormones in the body.

Hormones are substances that occur naturally in the body. They act as chemical messengers influencing the growth and activity of cells, and are produced by a number of different organs or glands, which together are known as the endocrine system.

Ileostomy is an opening of the small bowel (ileum) onto the skin of the abdomen that is made after some types of surgery for bowel cancer. A bag is worn over the opening (stoma) to collect the bowel motions.

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 (which holds urine) and/or bowel (which holds faeces).

Incurable means when the cancer can no longer be completely cured but may often be controlled or kept in remission for many months or years. *See remission.*

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.

Isotope scan is when you have an injection of a mildly radioactive liquid (isotope) before a scan. The isotope helps to show up parts of your body more clearly during the scan.

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

Lumpectomy is an operation to remove a lump.

Lymph is a fluid that flows around your lymphatic system.

Lymphatic system is part of the immune system – the body's natural defence against infection and disease. It's made up of organs such as bone marrow, the thymus, the spleen and lymph nodes. The lymph nodes throughout the body are connected by a network of tiny lymphatic tubes (ducts). The lymphatic system has two main roles – it helps to protect the body from infection and it drains fluid from the tissues.

Lymphoedema is a swelling caused by the build up of lymph. This can happen if cancer blocks the drainage of fluid through the lymphatic system. It can also occur when part of the lymphatic drainage system has been removed by surgery or damaged by cancer treatments such as radiotherapy.

Lymphoma is the name given to cancers that develop in the lymphatic system.

Lymph nodes (lymph glands) are part of the lymphatic system. They are shaped like a bean, fight infection and drain away waste fluid, waste products and damaged cells.

Malignant means cancerous. Malignant tumours have the ability to spread to different parts of the body.

Mammogram is an x-ray of the breast. It can help to spot cancers that may be too small to see or feel.

Mastectomy is an operation to remove the breast.

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

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 the name given to the team of people who will be looking after you. The MDT will include doctors, nurses and other healthcare professionals.

Nausea is the feeling of sickness.

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 professional who can give practical advice to help you live at home and look after yourself. They can also recommend aids and equipment for the home if you need them.

Oedema is the build up of a fluid in the cells, tissues or cavities of the body. It causes swelling in the part of your body where the fluid collects.

Oncology is the study and practice of treating cancer.

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

Orchidectomy is an operation to remove one of the testicles. When both testicles are removed it's known as a bilateral orchidectomy.

Outpatient is when you attend 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 but not to cure the cancer. 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 using low-dose radioactive glucose (a type of sugar) to measure the activity of cells in different parts of the body. They can be used to accurately define a cancer and find out 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 if you have a cut, or become bruised in some way. Chemotherapy can temporarily reduce the number of platelets in your blood, making you more prone to 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, before you have chemotherapy, you may be given a pre-med to help prevent any sickness (nausea).

Primary cancer is a cancer that starts in a single area of the body (site). Most cancers, other than leukaemias and lymphomas, are primary cancers. *See secondary cancer.*

Prognosis is the likely outcome of your disease. The prognosis tells you what will probably happen next, and how long you might live.

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

Prosthesis is a specially made replacement for a part of your body that has been removed. For example, an artificial leg or breast.

Pump is something that may be used to deliver chemotherapy or intravenous fluids. The pump makes sure that the right amounts are given over the prescribed amount of time. Some pumps are small and portable 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 treats cancer by using 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 comes back. This may be either at the site of the original primary cancer (local recurrence), or as a result of secondary spread of the cancer to other parts of the body (distant recurrence).

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

Secondary cancers (or secondaries) are cancers that have spread from the primary cancer, and are now growing in another part of your body. *See metastasis.*

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.

Staging is the process where doctors use tests and investigations to find out the size and position of a cancer and to see whether it has begun to spread. Knowing the stage of a cancer can help doctors to decide on the best treatment.

Stoma is an artificial opening made in your skin.

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

Syringe driver is a small pump that gradually delivers drugs either into your bloodstream or into the tissue just under your skin (subcutaneous).

Systemic therapy is a treatment, such as chemotherapy, that treats the whole body.

Terminal is when no more treatment can be given to control the cancer and the end of life is near.

Therapy is another word for treatment.

Thoracic means relating to the chest.

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.

Tracheostomy is an opening of the windpipe (trachea) on to the skin of the neck that is made after some types of surgery for cancer of the larynx. The opening (stoma) allows you to breathe.

Treatment cycle is a treatment session plus a rest period. Some cancer treatments, such as chemotherapy, are given in cycles. A cycle includes the time when you are given the chemotherapy followed by the rest period before you start the chemotherapy again. A course of treatment is made up of a number of cycles.

Tumour is a group of cells that are growing in an abnormal way. Tumours can be made up of cells that are benign (non-cancerous) or malignant (cancerous).

Tumour markers are proteins produced by some kinds of cancer. They can be detected 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.

Urostomy is an opening of the urinary system (bladder and kidneys) onto the skin of the abdomen that is made after some types of surgery. A bag is worn over the opening (stoma) to collect the urine.

How we can help you

Cancer is the toughest fight most of us will ever face. But you don’t have to go through it alone. The Macmillan team is with you every step of the way.

Get in touch

Macmillan Cancer Support
89 Albert Embankment,
London SE1 7UQ
Questions about cancer?
Call free on **0808 808 00 00**
(Mon–Fri, 9am–8pm)
www.macmillan.org.uk
Hard of hearing?
Use textphone
0808 808 0121 or Text Relay.
Non-English speaker?
Interpreters are available.

Clear, reliable information about cancer

We can help you by phone, email, via our website and publications or in person. And our information is free to everyone affected by cancer.

Macmillan Support Line

Our free, confidential phone line is open Monday–Friday, 9am–8pm. Our cancer support specialists provide clinical, financial, emotional and practical information and support to anyone affected by cancer. 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, and offer you the opportunity to speak with someone face-to-face. Find your nearest one at **macmillan.org.uk/informationcentres**

Publications

We provide expert, up-to-date information about different types of cancer, tests and treatments, and information about living with and after cancer. We can send you free information in a variety of formats, including booklets, leaflets, fact sheets, and audio CDs. We can also provide our information in Braille and large print.

You can find all of our information, along with several videos, online at **macmillan.org.uk/cancerinformation**

Review our information

Help us make our resources even better for people affected by cancer. Being one of our reviewers gives you the chance to comment on a variety of information including booklets, fact sheets, leaflets, videos, illustrations and website text. If you'd like to hear more about becoming a reviewer, email **reviewing@macmillan.org.uk**

Need out-of-hours support?

You can find a lot of information on our website, **macmillan.org.uk** For medical attention out of hours, please contact your GP for their out-of-hours service.

Someone to talk to

When you or someone you know has cancer, it can be difficult to talk about how you're feeling. You can call our cancer support specialists to talk about how you feel and what's worrying you.

We can also help you find support in your local area, so you can speak face-to-face with people who understand what you're going through.

Professional help

Our Macmillan nurses, doctors and other health and social care professionals offer expert treatment and care. They help individuals and families deal with cancer from diagnosis onwards, until they no longer need this help.

You can ask your GP, hospital consultant, district nurse or hospital ward sister if there are any Macmillan professionals available in your area, or call us.

Support for each other

No one knows more about the impact cancer has on a person's life than those who have been affected by it themselves. That's why we help to bring people with cancer and carers together in their communities and online.

Support groups

You can find out about support groups in your area by calling us or by visiting **macmillan.org.uk/selfhelpandsupport**

Online community

You can also share your experiences, ask questions, get and give support to others in our online community at **macmillan.org.uk/community**

Financial and work-related support

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. Some people may have to stop working.

If you've been affected in this way, we can help. Call the Macmillan Support Line and one of our cancer support specialists will tell you about the benefits and other financial help you may be entitled to.

We can also give you information about your rights at work as an employee, and help you find further support.

Macmillan Grants

Money worries are the last thing you need when you have cancer. A Macmillan Grant is a one-off payment for people with cancer, to cover a variety of practical needs including heating bills, extra clothing, or a much needed break.

Find out more about the financial and work-related support we can offer at **macmillan.org.uk/financialsupport**

Learning about cancer

You may find it useful to learn more about cancer and how to manage the impact it can have on your life.

You can do this online on our Learn Zone – **macmillan.org.uk/learnzone** – which offers a variety of e-learning courses and workshops. There's also a section dedicated to supporting people with cancer – ideal for people who want to learn more about what their relative or friend is going through.

Other useful organisations

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
Tel 0800 783 3339
(Mon–Fri, 9am–1pm)
Email
helpline@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
Shelley Court,
Gartnavel Complex,
Glasgow G12 0YN
Tel 0141 211 0122
Email info@cancersupportscotland.org
www.cancersupportscotland.org
Offers information and support to people affected by cancer. Also runs support groups, and provides counselling and complementary therapies.

Maggie's Centres
1st Floor, One Waterloo Street,
Glasgow G2 6AY
Tel 030 123 1801
Email
enquiries@maggiescentres.org
www.maggiescentres.org
Maggie's Centres provide information about cancer, benefits advice, and emotional or psychological support.

Marie Curie Cancer Care
89 Albert Embankment,
London SE1 7TP
Tel 0800 716 146
(Mon–Fri, 9am–5.30pm)
Email supporter.services@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
Tel 0845 123 2310
(Mon–Fri, 9.30am–5pm)
Email
helpline@pennybrohn.org
www.pennybrohncancercare.org
Offer a combination of physical, emotional and spiritual support, using complementary therapies and self-help techniques.

Tenovus
Head Office,
Gleider House, Ty Glas Road,
Cardiff CF14 5BD
Tel 0808 808 1010
www.tenovus.org.uk
Provides a range of services to people with cancer and their families, including counselling and a freephone helpline.

Equipment and advice on living with a disability

Assist UK
Redbank House,
4 St Chad's Street,
Manchester M8 8QA
Tel 0161 832 9757
Email
general.info@assist-uk.org
www.assist-uk.org
A UK-wide network of Disabled Living Centres. Staff can give advice about the products that are designed to make life easier for people who have difficulty with daily activities.

Disability Rights UK
12 City Forum,
250 City Road
London EC1V 8AF
Tel 020 7250 3222
Email enquiries@disabilityrightsuk.org
www.disabilityrightsuk.org

Provides information on social security benefits and disability rights.

Disabled Living Foundation (DLF)
380–384 Harrow Road,
London W9 2HU
Tel 0845 130 9177
(Mon–Fri, 10am–4pm)
Email helpline@dlf.org.uk
www.dlf.org.uk
Provides free, impartial advice about all types of disability equipment and mobility products.

Financial or legal advice and information

Benefit Enquiry Line (England, Wales, Scotland)
Warbreck House,
Warbreck Hill Road,
Blackpool FY2 0YE
Tel 0800 882 200
(Mon–Fri, 8.30am–6.30pm)
Email BEL-Customer-Services@dwp.gsi.gov.uk
www.direct.gov.uk/disability-money
Provides advice and information for disabled people and carers on the range of benefits available.

NI Direct (Northern Ireland)
Tel 0800 220 674
www.nidirect.gov.uk/money-tax-and-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 the following websites:

England and Wales
www.citizensadvice.org.uk

Scotland
www.cas.org.uk

Northern Ireland
www.citizensadvice.co.uk

You can also find advice online in a range of language at **adviceguide.org.uk**

Community Legal Advice
Tel 0845 345 43 45
www.communitylegaladvice.org.uk
Has a list of legal advice centres in England and Wales and solicitors that take legal aid cases.

Institute of Financial Planning
Whitefriars, Lewins Mead,
Bristol BS1 2NT
Tel 0117 945 2470
Email enquiries@financialplanning.org.uk
www.financialplanning.org.uk/consumers
A not-for-profit group that authorises financial planners and keeps a check on their professional activities.
Can help you find a financial planner in your area.

Local Government Ombudsman
PO Box 4771,
Coventry CV4 0EH
Tel 0845 602 1983
(Mon–Fri 8.30am–5pm, closed 9.30–10.30am, Tues–Fri)
www.lgo.org.uk
Investigates complaints about local authorities and certain other bodies in England, including all types of adult social care providers.
The service is independent, impartial and free. You can also text 'call back' to 0762 480 3014.

The Money Advice Service
Holborn Centre, 120 Holborn,
London EC1N 2TD
Tel 0300 500 5000
Email enquiries@moneyadviceservice.org.uk
www.moneyadviceservice.org.uk
Runs a free financial health check service and gives advice about all types of financial matters.

Money Advice Scotland
Tel 0141 572 0237
www.moneyadvicescotland.org.uk

Public Services Ombudsman for Wales
1 Ffordd yr Hen Gae,
Pencoed CF35 5LJ
Tel 0845 601 0987
www.ombudsman-wales.org.uk

Scottish Public Services Ombudsman
Freepost EH641,
Edinburgh EH3 0BR
Tel 0800 377 7330
(Mon–Fri, 9am–5pm
and Tues, 10am–5pm)
www.spso.org.uk

Northern Ireland Ombudsman
Tel 0800 34 34 24
Email ombudsman@ni-ombudsman.org.uk
www.ni-ombudsman.org.uk

Personal Finance Society – 'Find an Adviser' service
42–48 High Road, South
Woodford, London E18 2JP
Tel 020 8530 0852
www.findanadviser.org
Use the website to find qualified financial advisers in your area.

Unbiased.co.uk
1 Sekforde Street,
London EC1R 0BE
Email
contact@unbiased.co.uk
www.unbiased.co.uk
Search online for qualified advisers who specialise in giving financial, mortgage, accounting or legal advice.

Support for carers

Crossroads Caring for Carers (Northern Ireland)
7 Regent Street,
Newtownards,
Northern Ireland BT23 4AB
Tel 028 9181 4455
Email
mail@crossroadscare.co.uk
www.crossroadscare.co.uk

Carers Direct
PO Box 4338,
Manchester M61 0BY
Helpline 0808 802 0202
(Mon–Fri, 9am–8pm,
Sat–Sun, 11am–4pm)
www.nhs.uk/carersdirect

Carers Trust (Princess Royal Trust for Carers in Scotland)
32–36 Loman Street,
London SE1 0EH
Tel 0844 800 4361
Email info@carers.org
www.carers.org
www.youngcarers.net
Provides support, information, advice and services for everyone caring at home for a family member or friend. You can find details for UK offices on the website.

Carers UK
20 Great Dover Street,
London SE1 4LX
Tel (England, Scotland, Wales) 0808 808 7777
Tel (Northern Ireland)
028 9043 9843
(Wed–Thurs, 10am–12pm
and 2–4pm)
Email
adviceline@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.

Carers Scotland
The Cottage,
21 Pearce Street,
Glasgow G51 3UT
Tel 0141 445 3070
Email info@carerscotland.org
www.carersuk.org/scotland

Carers Wales
River House,
Ynsbridge Court,
Gwaelod-y-Garth,
Cardiff CF15 9SS
Tel 029 2081 1370
Email info@carerswales.org
www.carersuk.org/wales

Carers Northern Ireland
58 Howard Street,
Belfast BT1 6PJ
Tel 028 9043 9843
Email info@carersni.org
www.carersuk.org/northernireland

Young Carers Initiative (part of The Children's Society)
The Children's Society,
Edward Rudolf House,
Margery Street,
London WC1X 0JL
Tel 0300 303 7000
Email supportercare@childrenssociety.org.uk
www.youngcarer.com
Promotes good practice for young carers and their families. From the website you can search for local young carers projects in the UK, and also access information for young carers.

Young Carers Net (YCNet)
Head Office Carers Trust,
32–36 Loman Street,
London SE1 0EH
Tel 0844 800 4361
Email
youngcarers@carers.org
www.youngcarers.net
Young Carers Net (part of Carers Trust) provides advice and support for young people aged 18 and under in the UK, who help to look after someone in their family who has an illness, disability, drug/alcohol addiction or mental health condition.

Support for older people

Age UK
Tavis House,
1–6 Tavistock Square,
London WC1H 9NA
Tel (England and Wales)
0800 169 6565
Tel (Scotland)
0845 125 9732
Tel (Northern Ireland)
0808 808 7575
(Daily, 8am–7pm)
www.ageuk.org.uk
Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

Age Cymru
Ty John Pathy,
13/14 Neptune Court,
Vanguard Way,
Cardiff CF24 5PJ
Tel 0800 169 6565
www.ageuk.org.uk/cymru

Age Northern Ireland
3 Lower Crescent,
Belfast BT7 1NR
Tel 0808 808 7575
www.ageuk.org.uk/northern-ireland

Age Scotland
Causewayside House,
160 Causewayside,
Edinburgh EH9 1PR
Tel 0845 125 9732
www.ageuk.org.uk/scotland

Support for young people

CLIC Sargent
Horatio House,
77–85 Fulham Palace Road,
London W6 8JA
Tel 0300 330 0803
www.clicsargent.org.uk
Provides clinical, practical, financial and emotional support to children with cancer.

Teenage Cancer Trust
3rd Floor, 93 Newman Street,
London W1T 3EZ
Tel 020 7612 0370
www.teenagecancertrust.org
A charity devoted to improving the lives of teenagers and young adults with cancer. Run a support network for young people with cancer, their friends and families.

Other support organisations

Action on Hearing Loss
19–23 Featherstone Street,
London EC1Y 8SL
Information line
0808 808 0123
Textphone 0808 808 9000
Email informationline@hearingloss.org.uk
www.actiononhearingloss.org.uk
Offers a variety of services for people who are deaf or hard of hearing, and provides information and support on all aspects of deafness, hearing loss and tinnitus. Has offices in Wales, Scotland and Northern Ireland.

Equality and Human Rights Commission
Tel 0845 604 6610 (England)
0845 604 8810 (Wales)
0845 604 5510 (Scotland)
www.equalityhumanrights.com
Challenges discrimination, and protects and promotes human rights.

Equality Commission for Northern Ireland
Equality House,
7–9 Shaftesbury Square,
Belfast BT2 7DP
Tel 028 90 500 600
Textphone 028 9089 0890
www.equalityni.org
Promotes equality of opportunity, encourages good relations and challenges discrimination through promotion, advice and enforcement.

RNIB (Royal National Institute of Blind People)
105 Judd Street,
London WC1H 9NE
Tel 0303 123 9999
Email helpline@rnib.org.uk
www.rnib.org.uk
Offers information, support and advice to almost two million people with sight loss.

Further resources

Related Macmillan information

You may want to order some of the resources mentioned in this booklet. These include:

- *Ask about your cancer treatment*
- *Cancer and complementary therapies*
- *Caring for someone with advanced cancer*
- *Coping with body changes after cancer*
- *Getting the best from your cancer services*
- *Hello, and how are you?*
- *Help with the cost of cancer*
- *How are you feeling?*
- *It all adds up*
- *Life after cancer treatment*
- *Lost for words*
- *Self-employment and cancer*
- *Talking about your cancer*
- *Understanding allogeneic (donor) stem cell transplants*
- *Understanding chemotherapy*
- *Understanding cancer research trials (clinical trials)*
- *Understanding high-dose treatment with stem cell support*
- *Understanding radiotherapy*
- *Work and cancer*
- *Working while caring for someone with cancer*

To order, visit **be.macmillan.org.uk** To order the fact sheets mentioned in this booklet, call **0808 808 00 00**.

All of our information is also available online at **macmillan.org.uk/cancerinformation**

Audio resources

Our high-quality audio materials, based on our variety of booklets, include information about cancer types, different treatments and about living with cancer.

To order your free CD, visit **be.macmillan.org.uk** or call **0808 808 00 00**.

Macmillan videos

There are many videos on the Macmillan website featuring real-life stories and information from health and social care professionals.

Useful websites

A lot of information about cancer is available on the internet. Some websites are excellent; others have misleading or out-of-date information. The sites listed here are considered by nurses and doctors to contain accurate information and are regularly updated.

Macmillan Cancer Support
www.macmillan.org.uk
Find out more about living with the practical, emotional and financial effects of cancer. Our website contains expert, accurate, up-to-date information about cancer and its treatments, including:

- all the information from our 100+ booklets and 350+ fact sheets
- videos featuring real-life stories from people affected by cancer and information from medical professionals
- how we can help, the services we offer and where to get support
- how to contact our cancer support specialists, including an email form to send your questions
- local support groups search, links to other cancer organisations and a directory of information materials

- a huge online community of people affected by cancer sharing their experiences, advice and support.

www.cancer.gov (National Cancer Institute – National Institute of Health – USA)
Gives comprehensive information on cancer and treatments.

www.cancer.org (American Cancer Society)
Nationwide community-based health organisation dedicated to eliminating cancer. It aims to do this through research, education and advocacy.

www.cancer buddiesnetwork.org (Cancer Buddies Network)
An online support group for anyone affected by cancer.

www.cancerhelp.org.uk (Cancer Research UK)
Contains patient information on all types of cancer and has a clinical trials database.

www.healthtalkonline.org
www.youthhealthtalk.org (site for young people)
Both websites contain information about some cancers and have video and audio clips of people talking about their experiences of cancer and its treatments.

www.intelihealth.com (drug and medicine information)
Has health news, disease and condition information, tools and risk assessments. Easy-to-use and free from medical jargon.

www.macmillan.org.uk/ cancer voices (Macmillan Cancer Voices)
A UK-wide network that enables people who have or have had cancer, and those close to them such as family and carers, to speak out about their experiences of cancer.

www.nhs.uk
(NHS Choices)
NHS Choices is the online 'front door' to the NHS. It is the country's biggest health website and gives all the information you need to make decisions about your health.

www.nhsdirect.nhs.uk
(NHS Direct Online)
NHS health information site for England – covers all aspects of health, illness and treatments.

www.nhs24.com
(NHS 24 in Scotland)

www.nhsdirect.wales.nhs.uk
(NHS Direct Wales)

www.n-i.nhs.uk
(Health and Social Care in Northern Ireland)
The official gateway to health and social care services in Northern Ireland.

www.patient.co.uk
(Patient UK)
Provides people in the UK with good-quality 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.

www.riprap.org.uk
(Riprap)
Developed especially for teenagers who have a parent with cancer.

Your notes and questions

You could use this page to write down any questions you want to ask your doctor or nurse, and then to write down the answers you receive.

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

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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.

5 WAYS YOU CAN HELP

SOMEONE WITH CANCER

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 £

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

OR debit my:
Visa / MasterCard / CAF Charity Card / Switch / Maestro

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Expiry date
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Issue no
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Security number
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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.

FRSB give with confidence

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

27530

Cancer is the toughest fight most of us will ever face. If you or a loved one has been diagnosed, you need a team of people in your corner, supporting you every step of the way. That's who we are.

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 supporting you online, any time. The fundraisers who make it all possible.

You don't have to face cancer alone.
We can give you the strength to get through it.
We are Macmillan Cancer Support.

Questions about living with cancer?
Call free on 0808 808 00 00 (Mon–Fri, 9am–8pm)
Alternatively, visit macmillan.org.uk

Hard of hearing? Use textphone
0808 808 0121, or Text Relay.
Non-English speaker? Interpreters available.

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