The cancer guide

About this booklet

This booklet is about cancer. It is for anyone who has been diagnosed with cancer. There is also information for carers, family members and friends.

How to use this booklet

The booklet explains what cancer is and what to expect when you have been diagnosed. It has information to help with emotional, practical and financial issues. It also explains where you can get more information and support.

Being diagnosed with cancer can be a huge shock. You may be feeling lots of different emotions. But many people are treated successfully or able to live with cancer for many years. There are lots of people and services that can support you.

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

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

The Macmillan organiser

The cancer guide is available on its own, or as part of the **Macmillan organiser**. The organiser is an easy-to-use folder that has a copy of this booklet, and a booklet called **My records** in it. You can use the organiser to store information and documents relating to your treatment, so that you can keep everything in one place.

We refer to the **My records** booklet often in this information, because many people have both booklets as part of the organiser.

My records can be used to write down important information about your diagnosis, treatments, emotions and symptoms. Some people find it a helpful tool to use when talking to their healthcare team. If you do not have the **Macmillan organiser**, you can order it for free. Or you can order a copy of **My records** on its own.

Call **0808 808 00 00** or visit **be.macmillan.org.uk** to order what you need.

Quotes

In this booklet, we have included quotes from people living with cancer, which you may find helpful. Some are from our Online Community (**macmillan.org.uk/community**). The others are from people who have chosen to share their story with us. To share your experience, visit **macmillan.org.uk/shareyourstory**

For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, 7 days a week, 8am to 8pm, or visit **macmillan.org.uk**
If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

If you are deaf or hard of hearing, call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app. We have some information in different languages and formats, including audio, eBooks, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call **0808 808 00 00**.

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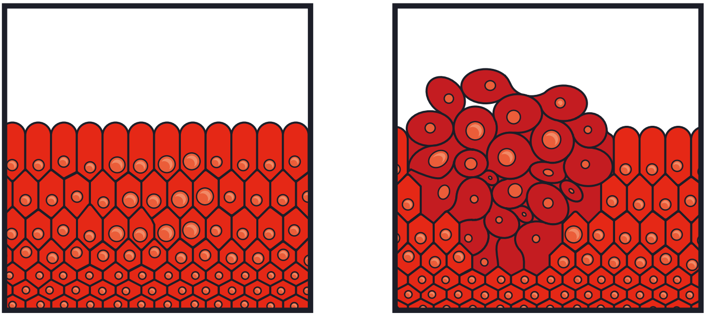
UNDERSTANDING CANCER

What is cancer?

Cells are tiny building blocks that make up the body's organs and tissues. Cells receive signals from the body, telling them when to grow and when to divide to make new cells. This is how our bodies grow and heal. These cells can become old, damaged or no longer needed. When this happens, the cell gets a signal from the body to stop working and die.

Sometimes these signals can go wrong, and the cell becomes abnormal. The abnormal cell may keep dividing to make more and more abnormal cells. These can form a lump, called a tumour.

Cells forming a tumour



Normal cells

Cells forming a tumour

Not all tumours are cancer. Doctors can tell if a tumour is cancer by taking a small sample of cells from it. This is called a biopsy. The doctors examine the sample under a microscope to look for cancer cells.

A tumour that is not cancer (a benign tumour) may grow, but it cannot spread to anywhere else in the body. It usually only causes problems if it grows and presses on nearby organs.

A tumour that is cancer (a malignant tumour) can grow into nearby tissue.

Sometimes cancer cells spread from where the cancer started (the primary site) to other parts of the body. They can travel around the body in the blood or through lymph fluid which is part of the lymphatic system (see page 98). When these cancer cells reach another part of the body, they may grow and form another tumour. This is called a secondary cancer or a metastasis.

Some types of cancer start from blood cells. Abnormal cells can build up in the blood, and sometimes the bone marrow. This is where blood cells are made. These types of cancer are sometimes called blood cancers.

Signs and symptoms of cancer

Certain symptoms may suggest you have cancer. It is important you are aware of any:

- changes to your body
- new symptoms that do not go away.

Knowing how your body normally looks and feels can help you notice any early changes that could be caused by cancer. Cancer can cause different symptoms, but common symptoms include:

- a lump or swelling
- unexplained pain
- unexplained bleeding
- unexplained weight loss
- changes to your bowel function
- a persistent cough and coughing up blood.

These symptoms do not always mean you have cancer. But you should get them checked by a healthcare professional as soon as possible.

Always see your GP if you have symptoms that are ongoing, unexplained or unusual for you. If it is cancer, the sooner it is diagnosed and treated, the more likely it is that treatment will be successful. There is more information in our **Signs and symptoms** z-card (see page 108).

Who can get cancer?

Anyone can get cancer. It affects people from all backgrounds and lifestyles. Cancer is most common in people over the age of 50, but it can happen at any age. It is estimated that more than 1 in 2 people will get some type of cancer during their life. But cancer survival is improving all the time. Survival rates in the UK have doubled in the last 40 years.

We do not always know what has caused a cancer, but there are things that can increase your risk. These are called risk factors. They include:

- your age
- smoking
- drinking alcohol
- eating an unhealthy diet
- sun exposure
- certain viruses, such as the human papilloma virus (HPV).

Having risk factors does not mean you will get cancer. And not having any risk factors does not mean you will not get cancer.

Most of us have family who have had cancer. People often worry that a history of cancer in their family increases their risk. But it is estimated that less than 1 in 10 cancers (3 to 10%) are linked to a strong family history of cancer. If you are worried, you may find our booklets **Are you worried about cancer?** and **Cancer genetics – how cancer sometimes runs in families** helpful (see page 108).

Because cancer affects so many people, there is a lot of support available (see pages 82 to 86).

Who might I meet?

You will meet lots of different health and social care professionals. Some work in hospitals or clinics. Others work in your community or look after you at home.

You should be given a main point of contact in your healthcare team. This is often a clinical nurse specialist (CNS). They may be called a key worker or link worker. You will be given their name and contact details. If you have questions or need advice about your treatment, they will be able to help.

Your community team

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

- answer any questions you may have
- talk 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 are unhappy with any part of your care
- organise services to help you at home.

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

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

Hospital multidisciplinary team (MDT)

A team of specialists meet to talk about the best treatment for you. They are called a multidisciplinary team (MDT).

The MDT look at national treatment guidelines or the latest evidence for the type of cancer you have. If you have any treatment preferences, your doctor will tell them about this.

The MDT may include the following:

- Consultant – an expert doctor who is in charge of a team of doctors when you are having treatment in hospital.
- Oncologist – a doctor who treats people who have cancer.
- Clinical nurse specialist (CNS) – a nurse who gives information about cancer, and support during treatment.
- Pathologist – a doctor who looks at cells or body tissue under a microscope to diagnose cancer.
- Radiologist – a doctor who looks at scans and x-rays to diagnose problems.
- Haematologist – a doctor who diagnoses and treats blood disorders and cancers.
- Surgeon – a doctor who does operations (surgery).
- Palliative care doctor – a doctor who helps with symptom control.

If you are involved in a clinical trial, you may meet also meet research staff. We have more information about clinical trials on page 31.

Other health and social care professionals

There are many specialists who can provide support and care, during and after you have been diagnosed. They may be based in the community or be part of your hospital MDT.

These may include the following:

- Counsellor – someone who is trained to listen to people's problems and help them find ways to cope.
- Dietitian – someone who gives information and advice about food and food supplements.
- Occupational therapist (OT) – someone who gives information, support and aids to help people with tasks such as washing and dressing.
- Pharmacist – someone who gives out medicines and gives advice about taking medicines.
- Phlebotomist – someone who is trained to take blood samples.
- Physiotherapist – someone who gives advice about movement, physical activity and mobility.
- Psychologist – someone who gives advice about managing feelings and behaviours.
- Social worker or social prescribing link worker – someone who can help support you with practical and financial problems.
- Speech and language therapist (SLT) – someone who gives information and support to people who have problems talking and swallowing.
- Support worker – someone who works as part of a cancer care team to provide information and support for people living with cancer.
- Therapy radiographer – someone who treats certain types of cancer with radiotherapy and provides information about the management of side effects.

Further support in hospital

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

Some hospitals and charities like Macmillan have cancer information and support centres (see pages 110 to 112). These offer free information about cancer, and you can often talk to staff and volunteers face to face. They can help you get the support you need. Some centres may be able to offer benefits advice and counselling services.

Social services and voluntary organisations

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

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

Your GP or a member of your healthcare team may refer you to a social worker to help with some of these issues. A social worker is a professional who can help you and your family with money or work issues, or any other problems. If you have been referred to social services, you can ask them about any practical issues you have. They can also help with financial issues.

You may want to get advice from a benefits adviser. Benefits advisers are sometimes called welfare rights advisers. They can help people get money from the government if they need it. These payments are called benefits. They can also help you apply for grants from other organisations and charities (see page 63).

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

Out-of-hours services

There may be times when you need non-emergency medical advice when the GP surgery is closed. Out-of-hours healthcare services are usually open from 6.30pm to 8.00am on weekdays and all day at weekends and on bank holidays.

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

- In England and Scotland, call **111** – this number is free to call.
- In Wales, call **0845 46 47**.
- In Northern Ireland, visit **nidirect.gov.uk/articles/gp-out-hours-service** to find contact numbers.

Sometimes the hospital may give you their own out-of-hours and emergency contact numbers. For example, chemotherapy day units will have an out-of-hours number you can call if you need advice or become unwell after treatment.

Getting the most from your appointments

Appointments with your healthcare team can sometimes feel short, so it is good to be prepared. The following tips may help:

- Plan your questions before the meeting. Write down any questions you have about your diagnosis and treatment, or anything else you are worried about.
- Write notes during the appointment. This may help you remember what was said.
- Ask in advance if you can have a friend or family member with you. They may be able to take notes, or remind you of what was said after the appointment.
- Ask if you can record the audio of your appointment on a mobile device. Always check before doing this.
- Do not feel you have to ask everything at once. You will have lots of chances to ask questions.
- Remember that professionals are there to help. They are used to talking to people with similar issues. Do not feel embarrassed to ask any questions you may have.

If you have a **Macmillan organiser**, you can use pages 22 to 30 of the **My records** booklet to plan your questions and keep appointment notes. You can also use pages 14 to 21 to record the contact details of key members of your healthcare team. If you do not have the organiser, you can order a copy for free (see page 108). Or you can write your own notes (see pages 126 to 128).

You may find our leaflet **Ask about your cancer treatment** helpful (see page 108). It suggests questions you can ask your healthcare team, to help you understand your diagnosis and treatment options.

If you are LGBTQ+

If you are LGBTQ+, you may have different or additional needs. Your healthcare team are there to support you and treat you in a way you feel comfortable.

Sometimes it can help you feel better supported if your healthcare team know your sexual orientation or gender. And it may help your healthcare team give the right information and support to you and the people closest to you.

If you are trans (transgender) or non-binary, talking to a health professional about your body may be especially difficult and complicated. Sometimes, diagnosis or treatment of cancer may involve parts of the body that do not reflect your gender identity. You may find this uncomfortable or upsetting to talk about. You may also have specific questions if you take hormones or have had gender-affirming surgeries.

You may find it helps to have someone you trust with you at appointments. They can listen and help you cope with what is happening. It may also help to talk to others in a similar situation. Live Through This (see page 122) runs a peer support group for LGBTQ+ people affected by cancer. This can be a good way to meet and share with others, hear how others have coped, and talk about what you are going through.

If you are a partner, family member or carer

As a carer, you provide unpaid help and support to someone with cancer who could not manage without your help. This could be a:

- partner
- family member
- friend
- neighbour.

Caring can mean many things, including:

- helping with personal care
- helping with everyday tasks.
- driving them to hospital
- giving emotional support.

Understanding more about cancer could help you support the person you care for. Health and social care professionals, including the clinical nurse specialist, are there for you too. With permission from the person with cancer, you can ask the healthcare team any questions you might have. This includes questions about your caring role. We have more information you may find useful in our booklets **Looking after someone with cancer** and **A guide for young people looking after someone with cancer** (see page 108). Or you can visit **macmillan.org.uk/carers**

Finding out more information about the cancer and treatment (see page 30 to 31) can also help you plan ahead. You can think about any extra help that you and the person with cancer might need, during and after treatment.

> ‘After mum’s diagnosis I emailed Macmillan and heard back from a nurse within 24 hours. She sent loads of really personalised information. They took the time to understand and look after your case. They really put me at ease and answered questions that I didn’t want to ask my mum.’

Daniella

DIAGNOSING CANCER

How cancer is diagnosed

Some people are diagnosed with cancer after their GP refers them for tests. Others are diagnosed after going into hospital for another health problem. Or because a symptom gets so bad that it becomes an emergency. In general, the earlier a cancer is diagnosed, the better the chances are that treatment will be successful.

GP referral

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

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

Having tests and scans

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

- a biopsy – where a small piece of tissue is removed and looked at under a microscope to check for cancer cells
- blood tests – to check your general health, check for infections and help diagnose cancer
- scans and x-rays – to look for signs of cancer inside your body.

There are many different types of tests and scans. The tests and scans you have will depend on the type of cancer and your situation. We have more information on our website, visit **macmillan.org.uk/testsandscans**

After you have been diagnosed, your cancer specialist will often want to do further tests. This may include tests to find out the stage of the cancer. The stage of a cancer usually means how big it is and whether it has spread from where it first started. Knowing more about the cancer helps doctors advise you about the best treatment for you.

Waiting for test results

Waiting for test results can be a difficult time. It may take from a few days to a couple of weeks for the results of your tests to be ready. You may find it helpful to talk with your partner, your family or a close friend. Your specialist nurse or a support organisation (see pages 113 to 125) can also provide support. You may find it helpful to talk to one of our cancer support specialists on **0808 808 00 00** (7 days a week, 8am to 8pm).

Your feelings about being diagnosed

When you are first diagnosed with cancer, it is natural to have many different thoughts and feelings.

Fear about what might happen next is sometimes the only thing you can think about. You may feel sad, frightened or angry. There are things you can do to help you cope with your diagnosis (see pages 82 to 86).

With time, people often find they start to feel in control of their lives and can carry on with many of their usual activities.

We have more information about coping with difficult emotions (see pages 70 to 77). Family and friends may also need support.

> **In a sense I'd say cancer turned my world upside down. Macmillan turned it the right way up.**
>
> **Philomena**

Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you, your cancer diagnosis and your treatment is collected in a cancer registry. This is used to plan and improve health and care services. Your hospital will usually give this information to the registry automatically. There are strict rules to make sure the information is kept safely and securely. It will only be used for your direct care or for health and social care planning and research.

Talk to your doctor or nurse if you have any questions. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out.

What happens next?

Your healthcare team will talk to you about your treatment options and when treatment will start. They can also talk to you about any support you need.

If you were referred urgently by your GP, your hospital team will aim to start treatment as soon as possible. This will either be:

- within 31 days of you being diagnosed and agreeing a plan to start treatment
- within 62 days of the referral by your GP.

They will aim for whichever one of these is sooner.

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

If you have this booklet as part of a **Macmillan organiser**, you can use pages 40 and 45 of the **My records** booklet to record your diagnosis and any updates to your diagnosis. If you do not have a **My records** booklet, you can order one for free (see page 108).

Checklist for transport

You may need to travel to a hospital for appointments and treatment. Although having some appointments by phone or video call is becoming more common.

- If you need to travel for healthcare, it is good to have a plan for how to get there. You might find it helpful to use this checklist to make sure you can get there and back easily:
- If you can, ask family or friends if they can drive you to and from the hospital.
- If you have problems with mobility and using public transport, you may be able to get a Blue Badge. A Blue Badge allows you, or the person driving you, to park in parking spaces that are closer to where you need to go.
- If you are worried about getting to the hospital, ask your GP or nurse about other options. They may be able to arrange a volunteer driver.
- If you are travelling to the hospital on public transport, ask your transport provider about discounts. There are special rates for bus, coach and train travel for eligible older people and people with disabilities.
- Ask at the hospital if they can help with travel and parking costs.
- Travel safely. If wearing a seat belt is uncomfortable, there are comfort aids that can help. If you cannot wear a seat belt for medical reasons, you can get a medical exemption certificate from your doctor.

TREATING CANCER

How cancer can be treated

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

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

Cancer treatments can include:

- surgery – the cancer is removed during an operation
- radiotherapy – high-energy x-rays are used to destroy cancer cells
- chemotherapy – anti-cancer drugs are used to destroy cancer cells
- targeted therapies – these interfere with the way cancer cells grow
- hormonal therapies – these change the activity of certain hormones in the body, which can slow down or stop cancer from growing.

You may have a combination of these treatments. This is quite common. We have more information about treatment types in our booklets **Understanding chemotherapy** and **Understanding radiotherapy** (see page 108)

It is important to discuss your treatment options and what they may involve with your healthcare team. For example, you may want to know if a treatment would mean staying in hospital, or if you would need to visit a hospital regularly.

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

You can ask your healthcare team any questions you have. They are there to support you. We have more information about cancer types, treatments and any side effects treatments may cause on our website. Visit **macmillan.org.uk**

Clinical trials

Clinical trials are medical research studies involving people. Doctors may use cancer clinical trials to:

- test new treatments to see if they work better than current treatments
- find which treatments have fewer side effects
- find new ways to combine treatments to see if they work better
- test new cancer drugs to find out more about them and their side effects
- improve the way treatments are given to try to reduce side effects.

Results from clinical trials can improve cancer treatments and help people live longer. Trials can also look at improving things like diagnosis and symptom management. We have more information at **macmillan.org.uk/clinicaltrials**

Making treatment decisions

You and your doctor can decide together on the best treatment plan for you. Your doctor is an expert in the best treatments. But you know your preferences and what is important to you. You can decide how involved you want to be in your treatment plan.

Sometimes doctors need to review a treatment plan. This may be when more information about the cancer becomes available – for example, when the doctor knows the results of surgery to remove the cancer. It may mean making more decisions with your doctor.

There may be more than one treatment that is effective for the type and stage of cancer you have. Your doctors may offer you a choice. They can help you choose the best treatment for you. Before you decide what is right for you, it is important to understand:

- what each treatment involves
- the possible side effects.

The benefits and disadvantages of treatment

You will normally have time to consider your options and have another appointment to discuss your decision. You may find it helpful to discuss the benefits and disadvantages of each option with your doctor, clinical nurse specialist, or with our cancer support specialists on **0808 808 00 00**. We have more information in our booklet **Making treatment decisions** (see page 108)

It can help to make a list of the questions you want to ask. If you can, you may want to take a family member or friend with you when you see the doctor again. Write notes about what has been said so you can look at them afterwards.

If you have this booklet as part of a **Macmillan organiser**, you can use the notes pages in the **My records** booklet to do this. If you do not have a **My records** booklet, you can order one for free (see page 108).

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

Treatment side effects

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

Side effects can often be reduced and managed. The team treating you will also try to reduce your chance of getting them. For example, they may give you anti-sickness medication if they know you may have nausea and vomiting from your treatment. Or they may advise you about ways to be more active if they know that tiredness (fatigue) is a side effect of your treatment.

Some healthcare professionals specialise in supporting people with certain side effects. For example, you may see a dietitian if you are having problems with eating. Or if you have lymphoedema (swelling in body tissue), you may see a lymphoedema specialist (see page 98).

Most side effects gradually go away after treatment finishes. But some people have long-term or late effects after treatment. Your healthcare team can help with these too. For more information visit **macmillan.org.uk/late-effects-of-treatment**

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

Changes to your body

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

Body changes can sometimes be difficult to accept. Your healthcare team can help you cope. You may also find support groups or online forums helpful (see page 83 to 85). We have more information in our booklets **Coping with hair loss** and **Body image and cancer** (see page 108).

Giving your permission (consent)

Doctors need your permission (consent) before you have any treatment. They will give you all the information you need to make your decision. We explain this in our section on talking about your treatment plan (see page 32 to 33).

You can give consent in writing when you sign a form that your doctor gives you, agreeing to a treatment. Or it can be a spoken (verbal) agreement with your doctor. Your doctor records your consent in your patient notes.

You may decide not to have treatment even when your doctor advises you to have it. If you refuse treatment, your decision must be respected. But your doctor needs to make sure you have all the information you need to make your decision. You need to understand all your treatment options and what will happen if you do not have the treatment. Always talk to your doctor about any concerns you have, so they can give you the best advice.

Second opinion

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

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

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

We have more information about getting a second opinion – visit **macmillan.org.uk/getting-a-second-opinion**

Private healthcare

You may choose to pay for private healthcare. You are entitled to free NHS healthcare even if you choose to pay for additional private healthcare. Private treatment for cancer is mainly offered by private hospitals and clinics. But some specialist NHS hospitals also treat private patients.

If you are having private and NHS healthcare for the same condition, your NHS and private treatment should be managed by one healthcare team. You may have different treatments from the NHS and private healthcare. But you cannot mix different parts of the same treatment between private and NHS healthcare. There must be as clear a separation as possible between your private treatment and your NHS treatment.

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

Living well during and after treatment

Your healthcare team can offer you different types of support. But there are also things you can do yourself to feel better. Making some lifestyle changes and recording your emotions can help you feel more in control of your situation.

Always ask for help if you need it.

Prepare for life at home

Think about how you will manage around the house if you become unwell or less able. Planning ahead can help reduce any future problems. You might find the following checklist helpful. These are things to do before, during and after treatment:

- Let your friends and family know you may need their help with things around the house during treatment. It is okay to ask for and accept help.
- If you have a child, think about your childcare options. Tell the school or nursery so they can support you and your child. For more information visit, **macmillan.org.uk/childcare**
- If you have a pet, think about your pet care options. For more information, visit **macmillan.org.uk/pet-care**

- Arrange for someone to water your plants or check on your home if you are going to be in hospital for a longer time.
- Plan your grocery shopping for times you are most likely to feel well. Online shopping may be a good option too. Make sure you have nutritious and easy-to-prepare meals. You could also make food in advance and freeze it.
- Keep a fatigue or activity diary to help track your energy levels and use this to plan your days. You can find these diaries in the **My records booklet** (see page 108).
- If you are worried about managing at home, your GP, cancer doctor or specialist nurse can tell you what equipment and support is available, and how to access it.

Keep a treatment record

You may find it useful to keep a record of which treatments you have had, so you can look back at it if you need to. If you have a **My records** booklet, there is space to record your treatments and medicines (see page 108).

You may take some medications on a regular basis, as part of your treatment. Or you may take medications when needed, for example to help with side effects. You might have to take several types of medication at one time. It can be difficult to remember what each of your medicines are for and any special instructions for taking them. Writing these things down will help you remember.

You might find it helpful to use a dosette box to keep your tablets in. This is split into sections which are labelled with the days of the week. Sometimes the section also has the time of day on it. A box like this can help you keep track of when to take your medicines. If you are not able to make up the dosette box yourself, ask your GP or pharmacist if they can help.

It can also be helpful to write down your symptoms and side effects and how severe they are. If you have a **My records** booklet, you can use the symptom diary there. This can help you see whether they are getting worse or improving. You can show this to your healthcare team to see if the doses of any of your medicines need changing.

A dosette box

Eat well

When you have cancer, you may find you need to change your diet. The cancer or its treatment may cause you to lose or gain weight. Or you might have a specific problem that makes eating difficult.

Making changes to your diet is not always easy. You could try making some simple changes slowly. It may help to eat small amounts often. Talk to your doctor or nurse if you have any concerns. They can refer you to a dietitian, who can help you if you are struggling to eat or have lost your appetite.

If you have a **My records** booklet, there are pages to write down what you think helps your appetite and what does not (see page 108).

We have more information in our booklets (see page 108):

- **Healthy eating and cancer**
- **Eating problems and cancer**
- **The building-up diet**
- **Managing weight gain after cancer treatment**.

Manage tiredness

Fatigue is a very common problem for people with cancer. Fatigue means feeling very tired or exhausted all or most of the time. It may be caused by the cancer itself, or by symptoms of the cancer. It can also be a side effect of treatment. Fatigue affects everyone differently. We have more information in our booklet **Coping with fatigue (tiredness)** – see page 108. If you find reading tiring, you can listen to this booklet as an audiobook. Visit **macmillan.org.uk/fatigueaudio**

There is good evidence that doing some physical activity can help you feel a bit better. Even just spending less time sitting down and going for short walks can help. Resting afterwards will help you save energy.

It can also be helpful to keep a record of your energy levels on different days, to share with your healthcare team. If you have a **My records** booklet, you can use the fatigue diary inside (see page 108).

Be active

Being active has many benefits. It can help to:

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

We have more information in our booklet **Physical activity and cancer** (see page 108).

Stop smoking

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

Health and social care professionals, such as your pharmacist or GP, can help if you are trying to give up smoking. The NHS has a lot of information and support to help you give up smoking. Look on the NHS website for the country where you live (see page 115).

After treatment

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

When the cancer treatment finishes, it is important to give yourself time to adjust to any physical or emotional changes. Many people survive cancer. But treatment can be very hard on the body and it may be some time before you feel fit and well again. We have more information in our booklet **Life after cancer treatment** (see page 108).

Follow-up care and support

After your treatment is over, you may have regular follow-up appointments. Your cancer doctor or clinical nurse specialist will explain how often you need to see them. Depending on your situation, you might need to have tests, such as:

- blood tests
- scans
- x-rays.

Many people find they feel very anxious before their appointments. It may help to get support from family and friends. Or we have a list of organisations that may be able to help (see page 113 to 125).

If you have any problems or notice any new symptoms between appointments, tell your doctor as soon as possible.

Late effects of treatment

Most people have some side effects during and after cancer treatment (see page 34 to 35). Usually, these improve and eventually disappear. But sometimes they continue, or develop months or years later. These are called late effects and include:

- long-term effects that continue after treatment
- late effects that start months or years after treatment.

There are many things that can be done to manage or treat late effects.

Always tell your cancer doctor or nurse if side effects that developed during treatment are not going away. You should also tell them if you develop new symptoms or problems after treatment has finished.

People sometimes worry that their symptoms are caused by the cancer coming back (see page 46). Talk to your doctor or nurse if you are worried about this. They can advise you and arrange for your symptoms to be checked if necessary.

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

Worrying about cancer coming back

Many people worry that the cancer will come back. Feeling like this is normal. As time goes on, most people become less worried about this. The risk also goes down over time. If cancer does come back, it often happens within a few years of treatment finishing.

It may help to talk to your cancer doctor or clinical nurse specialist about the risk of your cancer coming back.

If you are worried about any unexplained symptoms, particularly any that last for more than a week, get them checked by your GP. We have more information in our booklet **Worrying about cancer coming back** (see page 108).

If the cancer cannot be cured

Treatable but not curable

Some people live for many years with cancer that cannot be cured but can still be treated. At least 130,000 people in the UK are living with treatable but not curable cancer. This is cancer that can very rarely be cured, but can be treated to help manage symptoms or slow the progression of the cancer and extend people’s lives. Visit **macmillan.org.uk/treatable-but-not-curable**

End of life

Sometimes, people reach a stage where treatment is no longer able to control the cancer. This can be very difficult to hear and understand. If you are told you are reaching the end of your life, you may have lots of questions. You can talk to your healthcare team, carer, partner, family or friends about how you would like to be cared for towards the end of your life. Together, you can plan your care.

You will still have treatment to manage any symptoms. This is called supportive or palliative care. Your doctor might refer you to a specialist palliative care team or nurse, or a community care team. Palliative care aims to reduce symptoms, such as pain or tiredness. It can also give emotional, social and spiritual support to you and your family. Palliative care does not aim to cure the cancer, but it can help give you the best possible quality of life.

We have more booklets (see page 108) that you might find helpful:

- **A guide for the end of life**
- **Coping with advanced cancer**
- **Caring for someone with advanced cancer**
- **Planning ahead for the end of life: England and Wales**
- **Planning ahead for the end of life: Scotland**
- **Your life and your choices: Plan ahead Northern Ireland**

ORGANISING

Your rights

Most people are happy with the treatment and care they get from healthcare professionals. If you feel there is a problem, it is important to know what your rights are.

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

Being involved in decisions

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

- understand all your treatment options, and their risks and benefits
- see your medical records
- decide which treatment you wish to have.

Confidentiality

Your information should be kept confidential, unless you give permission for it to be shared.

If you think your information has been shared without your permission, you can make a complaint to the organisation involved. If you are unhappy with the response, contact the Information Commissioner's Office at **ico.org.uk**

Good health and social care

If the cancer and treatment mean you cannot live as independently as before, you have the right to have your needs assessed by your local council. This is called a needs assessment or a community care assessment. Sometimes you can also be assessed while in hospital.

Give as much detail as you can about all the tasks you need help with, even small things.

The needs assessment is free and anyone can ask for one.

Discrimination

You have the right not to be discriminated against because you have cancer. You are protected by:

- the Equality Act 2010 if you live in England, Scotland or Wales
- the Disability Discrimination Act 1995 if you live in Northern Ireland.

These laws also protect against discrimination at work (see pages 56 to 59). If you think you are being discriminated against, contact Citizens Advice (see page 117). Or you can call our Work Support Service on **0808 808 00 00**.

Complaints

If you have a problem with your healthcare, you have the right to make a complaint.

Many issues can be resolved before making a complaint, by talking to the relevant person. In hospital this could be a Patient Advice and Liaison Service (PALS) member. They will try to help you resolve issues before you make a complaint.

If you decide to make a complaint, it should be made within 12 months of the event, or as soon as you find out about the problem.

If the complaint is about your GP or NHS Trust, you can make a complaint to the NHS. The NHS must respond to your complaint and keep it confidential. How you complain depends on where you are being treated in the UK. Citizens Advice (see page 117) and the NHS website (see page 115) have information on how to complain.

You have the right to make a complaint if you feel your social care is not as good as it should be. To make a complaint about social care, contact your local council or service provider.

You can also make a complaint about your health and social care to your local public services ombudsman:

- If you live in England, contact the Local Government and Social Care Ombudsman at **lgo.org.uk**
- If you live in Scotland, contact the Scottish Public Services Ombudsman at **spso.org.uk**
- If you live in Wales, contact the Public Services Ombudsman for Wales at **ombudsman.wales**
- If you live in Northern Ireland, contact the NI Ombudsman at **nipso.org.uk**

Getting enough information

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

- have your treatment options and side effects explained using words you understand
- be offered written information that is easy to understand and specific to you
- be offered an interpreter if English is not your first language
- ask family members or friends to attend appointments with you, to help you understand what you are told.

If you are a partner, family member or carer

If you are looking after someone with cancer, you have a right to a carer's assessment from your local council. This means a social worker can:

- assess your needs
- decide what support they can offer you
- agree a supportive care plan with you.

They may be able to arrange for you to have help with your caring responsibilities or breaks from caring. If the person you care for is having a needs assessment (see page 51), you can ask to have your carer's assessment at the same time.

You can have an assessment regardless of:

- whether you care for the person full-time
- the type of care you provide
- your financial situation
- your level of need
- whether you live with the person you care for.

If the person with cancer gives their permission, you have the right to be:

- given information and advice about any support they need
- involved in decisions about their treatment and care plan.

We have more information in our booklets **Looking after someone with cancer** and **Working while caring for someone with cancer** (see page 108).

Work

You may not know how cancer will affect your work, now or in the future.

It is a good idea to talk to your manager soon after you are diagnosed. If your workplace has a human resources (HR) or personnel department, contact them as soon as you can. If they know how the cancer or treatment may affect your ability to work, they can support you better.

Some people stop working during cancer treatment and for a while after, until they feel ready to go back. Others keep working, perhaps with reduced hours or other changes to their job.

Some people may decide not to go back to work. Or they may choose to do something different. Others may not be able to go back to work because of the effects of cancer on their health. Going back to work may depend on the type of work you do or how much your income is affected.

It is important not to do too much, too soon. Your cancer doctor, GP or specialist nurse can help you decide when and if you should go back to work.

Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have more information that may be helpful (see page 108). There is also lots more information at **macmillan.org.uk/work**

Employment rights

If you have, or have ever had, cancer, the law considers this as a disability. This means you cannot be treated less favourably than people who do not have cancer because you have cancer, or for reasons connected to the cancer. That would be discrimination.

The law also says your employer must make reasonable adjustments (changes) to your workplace and their work practices to help you stay at work or return to work.

If you live in England, Scotland or Wales, you are protected by the Equality Act 2010. If you live in Northern Ireland, you are protected by the Disability Discrimination Act 1995.

Our booklet **Your rights at work when you are affected by cancer** has more information (see page 108).

Checklist for work

You may need to take time off work during your treatment and for a while afterwards. Having the right conversations with your employer can help set expectations at work. You might find it helpful to use this checklist:

- Ask your doctor how your ability to work will be affected by cancer treatment.
- Check your company's sickness absence and sick pay policies.
- If you cannot work for more than a few days, ask your doctor for a fit note. You need this to get sick pay and claim benefits.
- Plan your finances. Check to see if you are eligible for sick pay or benefits, including Employment and Support Allowance. You may also be eligible for free prescriptions.

- It is a good idea to tell your employer you have cancer, so they can support you.
- Remind your employer to keep the information you give them confidential or agree with them who can be told.
- If you are taking time off work, agree a communication plan with your employer. For example, you might have a phone call every 2 weeks. This is an opportunity for you to update your manager about your progress, and for them to update you about work.
- Talk to your employer about making reasonable adjustments to help you continue working or return to work. These may include time off for treatment, changes to working hours and extra breaks.
- When you are ready, agree a flexible or phased return-to-work plan with your manager.

We have lots more information about work and cancer, including information for people who are self-employed or carers. You might find the following booklets helpful (see page 108):

- **Work and cancer**
- **Self-employment and cancer**
- **Questions to ask about work and cancer**
- **Working while caring for someone with cancer**
- **Questions for carers to ask about work and cancer**
- **Your rights at work when you are affected by cancer.**

Financial help and benefits

When you are affected by cancer, you might need help with extra costs. Or you might need financial support if you have to stop working.

Statutory Sick Pay

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

Benefits

Benefits are payments from the government to people who need financial help. You can find out more about benefits and apply for them online. Go to **gov.uk** if you live in England, Wales or Scotland, or **nidirect.gov.uk** if you live in Northern Ireland.

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

Employment and Support Allowance (ESA)

This benefit is for people under State Pension age who have an illness or disability that affects how much they can work. There are different types of ESA, so it is a good idea to speak to a welfare rights adviser to see if you can make a claim.

Universal Credit

Universal Credit (UC) is a benefit for people under State Pension age who are either:

- out of work – for example, because of an illness or because they are caring for someone
- on a low income.

UC can include money for basic living costs, looking after children and housing.

Personal Independence Payment

This benefit is for people aged 16 to State Pension age who have problems moving around or looking after themselves. You must have had these problems for 3 months and expect them to last for at least 9 months, unless you are terminally ill.

Attendance Allowance

This benefit is for people at or over State Pension age who have problems looking after themselves because of an illness or disability. This could mean problems getting out of bed, having a bath or getting dressed. You must have had these problems for at least 6 months, unless you are terminally ill.

Special rules

If you are terminally ill, you can apply for some benefits using a fast-track process called special rules. You can apply if your doctor thinks you may be reasonably expected to live for less than 6 months. Your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate. It does not matter if you live longer than 6 months. Your doctor or specialist nurse will need to fill out a form for you.

Help for carers

Carer’s Allowance is a weekly benefit to help people who look after someone with a lot of care needs. If you do not qualify for it, you may still be able to apply for Carer’s Credit.

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

Macmillan Grants

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

If you need things like extra clothing, help paying heating bills or even a relaxing holiday, you may be able to get a Macmillan Grant.

How much you get will depend on your situation and needs. A grant from Macmillan does not normally affect the benefits you are entitled to. It is an extra bit of help, not a replacement for other support.

Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance. This includes life and travel insurance. A cancer diagnosis might also mean that you can get a payout from an insurance scheme that you already have.

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

We have more information in our booklet **Travel and cancer** (see page 108). Our Online Community forum on **Travel insurance** may also be helpful. Visit **macmillan.org.uk/travelinsurancegroup**

More information

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

You can also get information about benefits and other types of financial help from Citizens Advice (see page 117).

Our booklet **Help with the cost of cancer** has lots more information (see page 108).

Travel and holidays

Travelling can be fun and make you feel relaxed. But when you have cancer, you may have a few more things to think about if you are planning a trip.

It is important to check whether you are fit to travel. Your doctor or specialist nurse can tell you if there is anything that could make travelling unsafe.

They may advise you to avoid flying if you:

- have recently had surgery
- are breathless
- are anaemic (do not have enough red blood cells)
- are at risk of developing swelling in the brain.

Some cancer treatments, such as radiotherapy and chemotherapy, can cause short-term physical problems. These effects can:

- limit the amount of travelling you can do
- limit the type of activities you can do while you are away
- make your skin more sensitive to the sun.

If you are in the middle of treatment, it does not always mean you cannot travel. Talk to your cancer specialist about the best time to go away. They should also be able to give you advice about what you need to take, or any precautions. With good planning, you can often avoid travel problems.

If you want to travel abroad, it can be more difficult to get travel insurance when you have cancer. Depending on your circumstances, the price for insurance can be much higher than you might expect. Our Online Community travel insurance group is a good place to get recommendations for travel insurance providers (see page 111). You can also share your experiences with others.

We have more information in our booklet **Travel and cancer** (see page 108).

Planning ahead for your care

This is also called advance care planning. It is important to think about your future care in case there is a time when you cannot make or communicate decisions about your treatment.

There are lots of ways you can plan ahead. We have more information in the following booklets (see page 108)

- **Planning ahead for the end of life: Scotland**
- **Planning ahead for the end of life: England and Wales**
- **Your life and your choices: Northern Ireland**

Record your wishes for your care

Your wishes for your care include how and where you would like to be cared for if you become seriously ill or are reaching the end of your life.

Create a Power of Attorney

A Power of Attorney is when you give someone you trust the power to make decisions on your behalf. These decisions could be about your property and finances, or your welfare and healthcare, or both.

Create an Advance Decision to Refuse Treatment

An Advance Decision to Refuse Treatment (ADRT) is also called an Advance Directive or Living Will. You can make this decision now. It is a written statement of your wishes to refuse a certain type of treatment you do not want in the future. It lets your family, carers and health professionals know your wishes.

Other ways to plan ahead

Other ways you can plan ahead include:

- making a will – for more information, visit **macmillan.org.uk/writing-a-will**
- funeral planning.

COPING

Your feelings

It is common to have many different emotions when you are told you have cancer. These can be difficult to cope with. We talk about some common feelings here. Partners, family and friends may also have some of the same feelings. We have more information in our booklet **How are you feeling? The emotional effects of cancer** (see page 108).

There are lots of different reactions to cancer. You might not have any of the emotions we talk about here. There is no right or wrong way to feel. You will cope with things in your own way.

Talking to family, friends or other people affected by cancer, may help. Or you may get support from your healthcare team. We have more information in our booklet **Talking about cancer** (see page 108).

Shock and denial

You may find it hard to believe that you have cancer when you are first diagnosed. It is common to feel shocked and numb. You may not be able to understand all the information you are given. You may find that you keep asking the same questions. At first, it can be hard to talk about the cancer. Or you might find it hard to think or talk about anything else. Both reactions are normal. Your mind is trying to process what is happening. These feelings usually get easier over time.

> ‘There was a lot of waiting as I had biopsies and tests, but to be honest I was in complete denial. You never think it’s going to be you, but you think if it does come, I’ll be ready. The truth is you’re never ready for something like cancer.’
>
> **Louise**

Fear and anxiety

You may be anxious or frightened about whether treatments will work and what will happen in the future. This can be one of the hardest things to cope with. It can help to try to focus on things you can control. You may want to find out more about the cancer, your treatment options, and how to manage any side effects. It can also help to talk about your feelings. Try to keep doing the things that are important to you and that you enjoy.

Sadness and depression

You may feel sad if you have to change your plans because of the cancer, or if your future feels uncertain. Feeling sad is a natural reaction to changes or loss. This feeling may come and go during and after your treatment. For most people, these periods of sadness get better. But for some people, the sadness may continue or get worse. If you think the sadness may be turning into depression, there are things you can do to help.

Avoidance

You may cope by trying not to find out much about the cancer. Or by not talking about it. If you feel like this, tell people that you do not want to talk about it right now. You can also tell your cancer doctor if there are things you do not want to know or talk about yet.

Sometimes, it may be hard to accept that you have cancer. This can stop you making decisions about treatment. If this happens, it is very important to get help from your healthcare team.

You may feel that your family or friends are avoiding you or avoiding talking about the cancer. This is usually because they are also finding it difficult to cope. They may need support too. Try to tell them how this makes you feel. It may help you, and your family and friends, to talk openly about how you are feeling.

Anger

You may feel angry about your diagnosis. You may also resent other people for being well. These are normal reactions. They are more likely when you feel frightened, stressed or unwell. You may get angry with your family, friends or partner. Tell them you are angry at your illness and not at them. Finding ways to relax can help with anger. This can include talking about or writing down how you feel, doing gentle exercise, having relaxation therapy or meditating. We have more information in our booklet **Cancer and complementary therapies** (see page 108)

Guilt and blame

You may feel guilty or blame yourself for the cancer. You may want to find reasons for why it has happened to you. Most of the time, it is impossible to know exactly what causes a cancer. Over time, a combination of different risk factors may cause a cancer. Doctors do not fully understand all these factors yet. Try to focus on looking after yourself and getting the help and support you need.

Feeling alone

You may feel alone or isolated. This could be because you do not think you have support. Family and friends may live far away, be busy, or feel uncomfortable talking about the cancer. Try to tell your family and friends how you feel. This can help them find ways to support you.

You may have times when you want to be alone for a while. But if you find you are avoiding people a lot of the time, try to talk to your doctor or nurse.

If you need more support, you can call the Macmillan Support Line on **0808 808 00 00** and talk to one of our cancer support specialists. Our website can help you find local support groups. Visit **macmillan.org.uk/supportgroups** You can also talk to other people affected by cancer on our Online Community. Visit **macmillan.org.uk/community**

Coping with your emotions

You may feel that the cancer has taken over your life. This is a common reaction. The practical or emotional impacts of cancer can be very hard to cope with. But there are lots of things you can do to help you feel differently (see page 88).

If you feel you are not coping well, or need more support, it is important to get support. Talk to your cancer doctor, nurse or GP if:

- you feel anxious or worried a lot of the time
- you think you may be depressed.

> I have my cancer anniversary, or as I call it my ‘cancerversary’, soon and we’re going to have a proper girls’ night in. I just feel that I need to mark the date in a positive way. I want to keep trying to achieve my goals. It’s so important to have things to look forward to.

Melissa

Being positive

Being positive can mean different things to different people. It could mean:

- managing to deal with whatever situation you are in
- being optimistic
- finding ways of coping.

People find their own way to be positive. What works for one person may not work for another.

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

A lot of people have periods of feeling low in their lives. This is natural. Being told to be positive when you feel sad or angry can be frustrating. It can feel like someone is not accepting how you really feel, even if they are just trying to help. It might help to be honest and explain how that makes you feel.

No one can be positive all the time. You do not have to feel like you are always coping. It is also a positive step to acknowledge and talk about how you are feeling.

Talking to children about cancer

Deciding what to tell children about cancer is difficult. It can be hard to know what to tell them, and you may be worried about upsetting them. Children do not always show their feelings, but their behaviour may change at home or at school.

Talking to children about the cancer can:

- help them understand what is going on
- help them feel supported
- prepare them for any changes.

It may also help with some of your own anxiety too. For example, not telling them about hospital appointments may cause extra stress.

How much you tell children will depend on their age and how mature they are. It may be best to start by giving them small amounts of information, and then tell them more when they are ready. Teenagers usually understand what cancer is. Some will want to know more.

Whether they are teenagers or young children, talking about the cancer helps them cope. We have more information in our booklet **Talking to children and teenagers when an adult has cancer** (see page 108).


Fly Emirates

If you are a family member or friend

If you know someone with cancer, you might find it hard to talk about the cancer or your feelings. You might think it is best to pretend everything is fine. You might not want to worry them. Or you might feel you are letting them down if you admit you are worried or scared.

But not talking to the person with cancer about how you feel may make them feel alone.

You can support the person with cancer by listening and talking with them. Do not feel you have to talk about the cancer. Often it is enough just to listen and let the person with cancer talk when they are ready.

You may find some of the courses on our Learn Zone website helpful. There are courses to help with listening and talking. Visit **macmillan.org.uk/learnzone** to find out more.

We have more information in our booklet **Talking with someone with cancer** (see page 108).

If you are looking after a family member or friend with cancer, you may be a carer. We have more information and practical tips for carers in our booklet **Looking after someone with cancer** (see page 108).


HOW ARE
YOU FEELING?

Getting support

You do not need to cope with cancer on your own. For many people, family and friends are a main source of support. During your treatment, it is important to communicate with those around you.

But it is not always easy to talk to people you are close to. You may find it easier to talk to someone outside your family. There are many ways you can get the support you need. You can find more information in our booklet **Talking about cancer** (see page 108).

If you do not have a network of family and friends, you can still get support.

If you have a **Macmillan organiser**, you can write down what is important to you in the **My records** booklet. You can show this to your support network or healthcare team, to help them understand the areas in your life you need support with. You can order one, or a **My records** booklet for free (see page 108).

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

To find a support group in your area, visit **macmillan.org.uk/inyourarea** or call the Macmillan Support Line on **0808 808 00 00**.

> **‘I spoke to a Macmillan adviser and they encouraged me to join a cancer support group. It really helped to talk to other people who have been through it.’**
>
> **Myra**

Online support

Many people find support on the internet. You may want to join:

- online support groups such as the Macmillan Online Community (see page 111)
- social networking sites
- forums
- chat rooms
- blog sites.

You can use these to meet other people affected by cancer, share your experiences and get support. Many people find these communities a great way to get support from people who understand what you are going through. But it can help to remember that everyone has a different experience, even if they have a similar diagnosis to you.

Information centres

You can find Macmillan information and support centres in hospitals and libraries.

You can talk with someone face to face and get written information. If you would like to talk privately, most centres have a room where you can speak with someone alone and in confidence.

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

Cancer helplines

Some helplines are staffed by support specialists who can answer any questions you may have. The Macmillan Support Line is a good place to start. Call us on **0808 808 00 00** or visit **macmillan.org.uk/about-us/contact-us/ask-macmillan-form.html** You can also chat to us on our website.

Our free, confidential support line and webchat are open 7 days a week, 8am to 8pm. Our cancer support specialists can:

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

Counsellors

Some people find it very hard to cope with the impact of a cancer diagnosis. It can help to talk to a counsellor. A counsellor is a trained professional who can listen to you and help you explore your feelings in a place where you feel safe. Counselling is confidential. It can be a great support during a difficult time.

Many NHS services including GP practices and hospitals have a counsellor you can talk to. If they do not, they can put you in contact with one. Or you can refer yourself directly to a counselling service. You may need to wait a few weeks before your treatment starts. Visit **nhs.uk f**or more information.

Some support groups and charities also offer free counselling services, such as some local Mind locations (see page 116).

Macmillan health and social care professionals

Our nurses, doctors and other health and social care professionals give expert care and support to individuals and their families. Call us on **0808 808 00 00** or ask your healthcare team if there are any Macmillan professionals near you.

Looking after yourself

It can sometimes be difficult to take care of yourself if you are having treatment. It can also be hard to cope with the emotional effects of cancer. Try to take things one day at a time. Doing even the smallest tasks may help you feel better. If you are finding it hard to cope, there are things you can do to help:

- Rest when you need to. But try to keep to a regular sleeping pattern. If you can, get up, wash and dress every day.
- Try to do some regular physical activity, even if it is only gentle exercise like short walks (see page 42).
- Try to eat well every day (see page 41).
- If you feel unwell, talk to your doctor.
- Ask for and accept help when you need it.
- Try to share your feelings. This could be with friends, a support group, a counsellor, or in a journal or blog.
- Make plans to do things you enjoy. This can help you feel more in control. This could mean spending time with family, planning a nice activity, or starting a new hobby.
- Continuing your usual hobbies might be what works best for you. Or you might try new hobbies that suit your situation.
- Consider trying relaxation techniques or complementary therapies (see page 89).

Looking after yourself if you are a carer

It can be difficult to look after yourself if you are caring for someone living with cancer. If you are finding it difficult to cope, there are things you can do to help.

Try to share your feelings. It may help to talk to a member of your family, friends or your GP. Talking can help relieve stress. You may also find it helpful to join a support group or to speak to a counsellor. If you feel overwhelmed or stressed, your GP will be able to help. Relaxation techniques may also help.

Try to get plenty of rest and eat well. Sometimes this is not easy, especially if you are looking after someone who needs a lot of care at home (see pages 83 to 86). If you are struggling, there are organisations that can help (see pages 113 to 125).

We have more information in our booklets **Looking after someone with cancer** and **A guide for young people looking after someone with cancer** (see page 108).

Complementary therapies

Complementary therapies are generally used in addition to conventional medical treatments. Conventional medical treatments are those used by doctors to treat people with cancer. Sometimes complementary therapy is combined with conventional treatments. This is called integrated or integrative medicine.

There are many types of complementary therapy, such as acupuncture, meditation, and massage. They do not claim that they can treat or cure cancer. People use complementary therapies to help them relax or feel better. Sometimes they may be used to relieve symptoms or the side effects of conventional medical treatments.

Talk to your healthcare team before starting any complementary therapies. We have more information in our booklet **Cancer and complementary therapies** (see page 108).

GLOSSARY OF MEDICAL TERMS


Lisa McCauley
Macmillan Acute Oncology Nurse Specialist
HSC Health and Social Care
MACMILLAN CANCER SUPPORT

Medical terms

When you have cancer, you will hear or see lots of new words and may not know what they mean. We explain some of them here.

Remember, you can call the Macmillan Support Line free on **0808 808 00 00** if you need more information or support (see pages 110 to 112).

Abdomen is the part of your body with your stomach, bowel and other parts of the digestive system. It is often called the tummy.

Adjuvant therapy is treatment given after your main cancer treatment. For example, if your main treatment was an operation to remove the cancer, you may then have chemotherapy as an adjuvant therapy to reduce the risk of the cancer coming back.

Advance care planning is planning ahead for how you want to be cared for.

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

Anaemia is when you have a low number of red blood cells in your blood. This can make you feel tired and breathless.

Anaesthetic is a drug that makes you more comfortable during a medical procedure. A general anaesthetic puts you to sleep for a while. A local anaesthetic numbs a certain part of the body so you cannot feel anything in that area.

Benign tumour is a lump in the body that is not cancer. Benign tumours usually grow slowly and do not spread to other parts of the body.

Biopsy is when your doctor takes a small sample of tissue from your body. The cells are looked at under a microscope to see if they contain cancer cells or not.

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

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

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

Carcinoma in situ is a group of abnormal cells that have stayed in the place where they started. They have not spread. They may become a cancer and grow into nearby tissue.

Carer’s assessment is a chance to talk to your local council or social services department about what help you need if you are caring for someone. If you care for someone aged over 18, you have the right to a carer’s assessment and support. For more information, contact your local council in England, Wales and Scotland, or your Health and Social Care Board in Northern Ireland. You can also contact Carers UK (see page 123).

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

Chemotherapy is the use of anti-cancer (cytotoxic) drugs to destroy cancer cells. It can be given on its own or with other treatments.

Complementary therapies are not conventional medical treatments, but may be used in addition to them. They do not cure cancer but can sometimes help with side effects or symptoms. Examples include acupuncture and meditation.

Consent is agreeing to have treatment. The doctor will usually ask you to sign a form before you have treatment to say that you give your permission. No medical treatment can be given without your consent.

A central line

CT scan (computerised tomography scan) is a scan that uses x-rays to build a 3D picture of the inside of the body. This scan usually takes 10 to 30 minutes and is painless.

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

Diagnosis is a description of the illness a person has.

Diarrhoea is having frequent, loose or watery bowel movements (poo). It can be a symptom of cancer or a side effect of some cancer treatments.

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

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

Having a CT scan

Fertility is the ability to get pregnant or make someone pregnant.

Fine needle aspiration is a type of biopsy where a doctor passes a fine, hollow needle into a lump to take a small sample of cells to be examined.

Grade is a way for doctors to describe how quickly a cancer may grow.

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

Hormonal therapy is treatment that can change the amount or activity of certain hormones in the body. This can slow or stop cancer cells from growing.

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

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

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

Inoperable is when cancer cannot 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 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.

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

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

Lymph is a fluid that flows around your lymphatic system.

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

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

Lymphoma is a cancer of the lymphatic system.

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

Malignant tumour is a lump in the body that is cancer. Malignant tumours can grow into nearby tissue or spread to different parts of the body.

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

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

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

Nausea is feeling sick.

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

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

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

Oncology is the medical specialty that deals with cancer.

Orally is when you take something by mouth – for example, taking a tablet.

Outpatient is when you go into hospital for an appointment and leave on the same day. Outpatients do not stay in hospital overnight.

Paediatrics is the medical specialty that deals with children.

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

Pathology is the study and diagnosis of disease.

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

PICC line is a long, thin, flexible tube. It is put into a vein just above the bend in your elbow. It is used to give chemotherapy or other treatments. It usually stays in until treatment finishes.

Platelet is a type of cell found in your blood. Platelets help your blood to clot, which stops bleeding. Chemotherapy can reduce the number of platelets in your blood for a time, making you more likely to have bleeding and bruising.

Portacath is a long, thin tube that is put into a vein under the skin to give chemotherapy and other drugs. The tip of the tube sits just above the heart. The port lies under the skin on your upper chest.

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

A PICC line

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

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

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

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

Prosthesis is an artificial body part. A prosthesis is used if that part of the body has been removed. It helps with mobility and appearance.

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

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

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

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

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

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

Stage is a way for doctors to describe a cancer. It means the extent of the cancer. This usually means how big it is and whether it has spread from where it first started.

Subcutaneous injection (SC) is an injection given just under the skin.

Surgery is an operation, often to remove something (such as cancer) from the body.

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

Targeted therapies are treatments that interfere with the cell processes that cause the cancer to grow.

Therapy is another word for treatment.

Terminal is when no more treatment can be given to control the cancer. It may mean that someone should prepare for the end of life.

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

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

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

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

Ultrasound scan is a scan that uses sound waves to create a picture of the inside of the body.

X-ray scan is a way to take pictures of the inside of the body. It can show breaks or problems with bones and joints. It can also show changes to other body tissues and organs, such as the lungs or breasts.

Having an X-ray scan


THE BUILDING-UP DIET

FURTHER INFORMATION

About our information

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

Order what you need

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

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

Online information

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

Other formats

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

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

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

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

The language we use

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

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

We use gender-inclusive language and talk to our readers as ‘you’ so that everyone feels included. Where clinically necessary we use the terms ‘men’ and ‘women’ or ‘male’ and ‘female’. For example, we do so when talking about parts of the body or mentioning statistics or research about who is affected. Our aims are for our information to be as clear and relevant as possible for everyone.

You can read more about how we produce our information at **macmillan.org.uk/ourinfo**

Other ways we can help you

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

Talk to us

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

Macmillan Support Line

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

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

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

Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face. Visit one to get the information you need, or if you would like a private chat, most centres have a room where you can speak with someone alone and in confidence.

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

Talk to others

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

Support groups

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

Online Community

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

The Macmillan healthcare team

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

Help with money worries

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

Financial guidance

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

Help accessing benefits

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

Macmillan Grants

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing to a much-needed break. Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants.

We can also tell you about benefits advisers in your area. Visit **macmillan.org.uk/financialsupport** to find out more about how we can help you with your finances.

Help with work and cancer

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

Work support

Our dedicated team of work support advisers can help you understand your rights at work. Call us on **0808 808 00 00** to speak to a work support adviser (Monday to Friday, 8am to 6pm).

Other useful organisations

There are lots of other organisations that can give you information or support. Details correct at time of printing.

General cancer support organisations

Cancer Black Care

Tel **020 8961 4151**
www.cancerblackcare.org.uk
Offers UK-wide information and support for people from Black and ethnic minority communities who have cancer. Also supports their friends, carers and families.

Cancer Focus Northern Ireland

Helpline **0800 783 3339** (Mon to Fri, 9am to 1pm)
Email **nurseline@cancerfocusni.org**
www.cancerfocusni.org
Offers a variety of services to people affected by cancer in Northern Ireland.

Cancer Research UK

Helpline **0808 800 4040** (Mon to Fri, 9am to 5pm)
www.cancerresearchuk.org
A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

Cancer Support Scotland

Tel **0800 652 4531** (Mon to Fri, 9am to 5pm)
Email **info@cancersupportscotland.org**
www.cancersupportscotland.org
Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

Macmillan Cancer Voices

www.macmillan.org.uk/cancervoices
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 experience of cancer.

Maggie's

Tel **0300 123 1801**
Email **enquiries@maggies.org**
www.maggies.org
Has a network of centres in many locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

Penny Brohn UK

Helpline **0303 3000 118** (Mon to Fri, 10am to 2pm)
Email **helpline@pennybrohn.org.uk**
www.pennybrohn.org.uk
Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

Riprap

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

Tenovus

Helpline **0808 808 1010** (Mon to Fri, 9am to 5pm, and Sat and Sun 10am to 1pm)
Email **info@tenovuscancercare.org.uk**
www.tenovuscancercare.org.uk
Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online 'Ask the nurse' service.

General health information

Health and Social Care in Northern Ireland

online.hscni.net

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

NHS.UK

www.nhs.uk

The UK's biggest health information website. Has service information for England.

NHS Direct Wales

www.nhsdirect.wales.nhs.uk

NHS health information site for Wales.

NHS Inform

Helpline **0800 22 44 88** (7 days a week 8am to 8pm)

www.nhsinform.scot

NHS health information site for Scotland.

Patient UK

www.patient.info

Provides people in the UK with information about health and disease. Includes evidence-based information leaflets on a wide variety of medical and health topics. Also reviews and links to many health- and illness-related websites.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel **0145 588 3300** (Mon to Fri, 10am to 4pm)
Email **bacp@bacp.co.uk**
www.bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on their ‘How to find a therapist’ page.

UK Council for Psychotherapy (UKCP)

Tel **020 7014 9955**
www.psychotherapy.org.uk
Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

Emotional and mental health support

Mind

Helpline **0300 123 3393** (Mon to Fri, 9am to 6pm)
Email **info@mind.org.uk**
www.mind.org.uk
Provides information, advice and support to anyone with a mental health problem through its helpline and website.

Samaritans

Helpline **116 123**
Email **jo@samaritans.org**
www.samaritans.org
Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

Financial support or legal advice and information

Advice NI
Helpline **0800 915 4604**
Email **advice@advice.net**
www.adviceni.net
Provides advice on a variety of issues including financial, legal, housing and employment issues.

Benefit Enquiry Line Northern Ireland
Helpline **0800 232 1271** (Mon, Tue, Wed and Fri, 9am to 5pm, Thu, 10am to 5pm)
Textphone **028 9031 1092**
www.nidirect.gov.uk/money-tax-and-benefits
Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

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

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

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

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

Civil Legal Advice

Helpline **0345 345 4345** (Mon to Fri, 9am to 8pm, Sat, 9am to 12.30pm)
Textphone **0345 609 6677**
www.gov.uk/civil-legal-advice
Has a list of legal advice centres in England and Wales and solicitors that take legal aid cases. Offers a free translation service if English is not your first language.

GOV.UK

www.gov.uk
Has information about social security benefits and public services in England, Scotland and Wales.
Local councils (England, Scotland and Wales)
Your local council may have a welfare rights unit that can help you with benefits. You can also contact your local council to claim Housing Benefit and Council Tax Reduction, education benefits, and for help from social services (the Social Work department in Scotland).

You should be able to find your local council's contact details visit:

England

www.gov.uk/find-local-council

Scotland

www.cosla.gov.uk/councils

Wales

www.wlga.gov.uk/authorities

Macmillan Benefits Advice Service (Northern Ireland)

Tel **0300 1233 233**

Money Advice Scotland

Email **info@moneyadvicescotland.org.uk**
www.moneyadvicescotland.org.uk
Use the website to find qualified financial advisers in Scotland.

NiDirect

www.nidirect.gov.uk
Has information about benefits and public services in Northern Ireland.

StepChange Debt Charity

Tel **080 0138 1111** (Mon to Fri, 8am to 8pm and Sat, 8am to 4pm)
www.stepchange.org
Provides free debt advice through phone, email, the website and online through live chats with advisers.

Unbiased.co.uk

Helpline **0800 023 6868**
Email **contact@unbiased.co.uk**
www.unbiased.co.uk
You can search the website for qualified advisers in the UK who can give expert advice about finances, mortgages, accounting or legal issues.

Equipment and advice on living with a disability

British Red Cross

Tel **0344 871 11 11**
Email **contactus@redcross.org.uk**
www.redcross.org.uk
Offers a range of health and social care services across the UK, such as care in the home, a medical equipment loan service and a transport service.

Disability Rights UK

Tel **0330 995 0400** (not an advice line)
Email **enquiries@disabilityrightsuk.org**
www.disabilityrightsuk.org
Provides information on social security benefits and disability rights in the UK. Has a number of helplines for specific support, including information on going back to work, direct payments, human rights issues, and advice for disabled students.

Living Made Easy

Helpline **0300 999 0004** (Mon to Fri, 9am to 5pm)
Email **info@dlf.org.uk**
www.livingmadeeasy.org.uk
Provides free, impartial advice about all types of disability equipment and mobility products.

Scope

Helpline **0808 800 3333** (Mon to Fri, 9am to 6pm, and Sat and Sun, 10am to 6pm)
Textphone Use Type Talk by dialling **18001** from a textphone followed by **0808 800 3333**.
Email **helpline@scope.org.uk**
www.scope.org.uk
Offers advice and information on living with disability. Also supports an independent, UK-wide network of local Disability Information and Advice Line services (DIALs) run by and for disabled people.

Support for young people

Young Lives vs Cancer

Tel **0300 330 0803** (Mon to Fri, 9am to 5pm)
www.younglivesvscancer.org.uk
Provides clinical, practical, financial and emotional support to children with cancer and their families in the UK.

Teenage Cancer Trust

Tel **0207 612 0370** (Mon to Fri, 9am to 5.30pm)
Email **hello@teenagecancertrust.org**
www.teenagecancertrust.org
A UK-wide charity devoted to improving the lives of teenagers and young adults with cancer. Runs a support network for young people with cancer, their friends and families.

Youth Access

Tel **020 8772 9900** (Mon to Fri, 9.30am to 1pm, then 2pm to 5.30pm)
Email **admin@youthaccess.org.uk**
www.youthaccess.org.uk
A UK-wide organisation providing counselling and information for young people. Find your local service by visiting **youthaccess.org.uk/find-your-local-service**

Support for older people

Age UK

Helpline **0800 678 1602** (Daily, 8am to 7pm)
www.ageuk.org.uk
Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

LGBT-specific support

LGBT Foundation

Tel **0345 330 3030** (Mon to Fri, 9am to 9pm)
Email **helpline@lgbt.foundation**
www.lgbt.foundation
Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

Live Through This

www.livethroughthis.co.uk
A safe space for anybody who identifies as part of the queer spectrum and has had an experience with any kind of cancer at any stage. Also produces resources about LGBT cancer experiences. LTT runs a peer support group with Maggie's Barts.

Support for carers

Carers Trust

Tel **0300 772 9600** (Mon to Fri, 9am to 5pm)
Email **info@carers.org**
www.carers.org
Provides support, information, advice and services for people caring at home for a family member or friend. You can find details for UK offices and search for local support on the website.

Carers UK

Helpline (England, Scotland, Wales) **0808 808 7777**
(Mon to Fri, 9am to 6pm)
Helpline (Northern Ireland) **028 9043 9843**
www.carersuk.org
Offers information and support to carers across the UK. Has an online forum and can put people in contact with local support groups for carers.

Support with sight loss

Royal National Institute of Blind People (RNIB)

Helpline **0303 123 9999** (Mon to Fri, 8am to 8pm,
and Sat, 9am to 1pm)
Email **information@rnib.org.uk**
www.rnib.org.uk
Offers support and advice to blind and partially sighted people in the UK.

Support with hearing loss

RNID

Helpline **0808 808 0123** (Mon to Fri, 9am to 5pm)
Textphone **0808 808 9000**
SMS **07800 000 360**
Email **informationline@rnid.org.uk**
www.actiononhearingloss.org.uk
Offers support and practical advice to people in the UK with hearing loss and tinnitus.

Advanced cancer and end-of-life care

Hospice UK

Tel **020 7520 8200**
www.hospiceuk.org
Provides information about living with advanced illness. Also provides free booklets and a directory of hospice services in the UK.

Marie Curie

Helpline **0800 090 2309** (Mon to Fri, 8am to 6pm, and Sat 11am to 5pm)
www.mariecurie.org.uk
Marie Curie nurses provide free end-of-life care across the UK. They care for people in their own homes or in Marie Curie hospices, 24 hours a day, 365 days a year.

Cancer registries

The cancer registry

A national database that collects information on cancer diagnoses and treatment. This information helps the NHS and other organisations plan and improve health and care services. There is one in each country in the UK:

National Cancer Registration and Analysis Service

Tel **0207 654 8000**
Email **enquiries@phe.gov.uk**
www.ndrs.nhs.uk
Tel (Ireland) **0214 318 014**
www.ncri.ie (Ireland)

Scottish Cancer Registry

www.ndrs.nhs.uk/cancer-registration-your-rights-and-privacy

Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel **02920 104278**
phw.nhs.wales/services-and-teams/welsh-cancer-intelligence-and-surveillance-unit-wcisu

Northern Ireland Cancer Registry

Tel **0289 097 6028**
Email **nicr@qub.ac.uk**
www.qub.ac.uk/nicr

Your notes and questions

Your notes and questions

Disclaimer

We make every effort to ensure that the information we provide is accurate and up to date but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. Some photos are of models.

Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by Prof Tim Iveson, Macmillan Consultant Medical Oncologist.

With thanks to: Dr Anthony Cunliffe, National Lead GP Adviser Macmillan Cancer Support; Amy Dugdale, Macmillan Gynaecology Nurse Specialist; Liz Egan, former Macmillan Working Through Cancer Programme Lead; Teresa Gonzales, Macmillan Cancer Information Development Nurse; Polly Guest, Macmillan Work Support Adviser; Maria Lavery, Macmillan Senior Information Development Nurse; Dr Ashling Lillis, Consultant in Acute Medicine; Sian Robinson, Macmillan Service Knowledge Specialist; Azmina Rose, Macmillan Cancer Support and Information Specialist; Dr Richard Simcock, Consultant Clinical Oncologist; Andrea Ward, Macmillan Breast Care Nurse Specialist Team Leader; and Hilary Weaver, Macmillan Cancer Information Development Nurse.

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

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

Sources

Below is a sample of the sources used in our practical support information. If you would like more information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

Cancer Research UK. (2020, October 30). Signs and symptoms of cancer. Retrieved March 22, 2021, from https://www.cancerresearchuk.org/about-cancer/cancer-symptoms

Citizens Advice. (n.d.). NHS Patients' Rights. Retrieved April 8, 2021, from https://www.citizensadvice.org.uk/health/nhs-healthcare/nhs-patients-rights/#h-consent

General Medical Council. (2021). Managing and protecting personal information. Retrieved July 2021, from GMC: https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/confidentiality/managing-and-protecting-personal-information

National Institute for Health and Care Excellence. (2021, 06 17). Shared decision making underpins good healthcare. Retrieved July 2021, from NICE: https://www.nice.org.uk/news/article/shared-decision-making-underpins-good-healthcare

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Can you do something to help?

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

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

5 ways you can help someone with cancer

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

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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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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.

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

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

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

If you would rather donate online go to **macmillan.org.uk/donate**

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REGULATOR

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

MACMILLAN
CANCER SUPPORT

This booklet is for anyone who has been diagnosed with cancer. There is also information for carers, family members and friends.

This booklet explains what cancer is and what to expect when you have been diagnosed. It has information to help with emotional, practical and financial issues. It also explains where you can get more information and support.

At Macmillan, we give people with cancer everything we've got. If you are diagnosed, your worries are our worries. We will help you live life as fully as you can.

For information, support or just someone to talk to, call **0808 808 00 00** or visit **macmillan.org.uk**

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use.

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

Need information in different languages or formats? We produce information in audio, eBooks, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call our support line.

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