MACMILLAN
CANCER SUPPORT

THE CANCER GUIDE FOR YOUNG PEOPLE

> My Macmillan nurse was amazing. She explained all my choices, what will happen next and came along to appointments.

Meriam, diagnosed with melanoma

About this booklet

Hello. Welcome to our information for young people living with cancer. We have written it for people aged 13 to 24.

This booklet explains what cancer is and how it can be treated. It also gives practical tips about coping with treatment, relationships and sorting out practical things like school, university, work and money.

We hope it 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.

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/teens**

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

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

We have some information in different languages and formats, including audio, eBooks, easy read, Braille, large print and translations. To order these visit **macmillan.org.uk/otherformats** or call **0808 808 00 00**.

How to use this booklet

The booklet is split into chapters to help you find what you need. You don’t have to read it from start to finish. You can use the contents list on page 3 to help you.

It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

Quotes

In this booklet we have included quotes from teenagers and young people. These quotes are from people who have had cancer, which you may find helpful. They have chosen to share their stories with us. Some names have been changed.

Contents

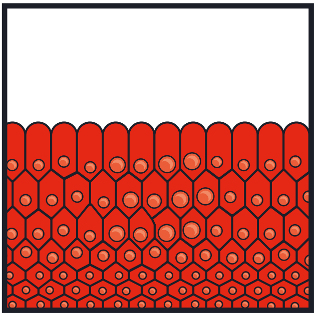
UNDERSTANDING CANCER

What is cancer?

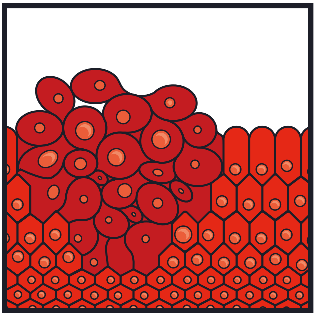
Our bodies are made up of billions of tiny parts that fit together like building blocks. These parts are called cells.

Healthy cells grow, divide and eventually get worn out and die. This cycle usually continues without any problems.

Cancer happens when something goes wrong with the cell and it grows and divides in an uncontrolled way. Cancer cells divide too much and don’t die in the way normal cells do. These cells can form a lump called a tumour.



Normal cells



Cells forming a tumour

A tumour can form inside:

- an organ (part of the body that does a specific job, such as the liver or kidney)
- a bone
- the lymphatic system (a network that helps defend your body from disease) – when a tumour forms here, it is called a lymphoma.

If the cancer affects your blood, the cancer cells do not form a tumour but affect the bone marrow (the spongy centre of your bones where your blood cells are made). This type of cancer is called leukaemia.

Cancer cells from a tumour can spread to other parts of the body. That is why having treatment as soon as possible is important.

There are more than 200 different types of cancer. Each type has its own name and treatments. People with cancer need to have tests to find out exactly what type of cancer they have, and to find out whether it has spread. This helps the doctors plan the right treatment for each person.

How did you get cancer?

Scientists are finding out more about cancer all the time. But we still don't always know why people get it. Particularly when you are a teenager or in your 20s, cancer is something that can just happen without a reason.

One thing we definitely know is that cancer is not a disease you can catch from someone else – it is not infectious.

You may worry that the cancer could be linked to things you have done – for example, smoking, drinking or taking drugs. But this is very unlikely when you are young.

Some cancers can be caused by inherited faulty genes. This means that the cancer is passed on from one generation to another (inherited). If this is the cause, it is likely that other members of your family will have had similar cancers in the past. But most cancers are not caused by inherited cancer genes. Doctors think that only 2 or 3 in every 100 cancers may be an inherited cancer. We have more information in our booklet **Cancer and genetics – how cancer can sometimes run in families**. To order a free copy, call **0808 808 00 00** or visit **be.macmillan.org.uk**

Different types of cancer

Cancer in teenagers and young adults is quite rare. Most cancers are diagnosed in people aged over 65. Although there are over 200 different types of cancer, certain cancers are more likely to affect teenagers and young people. Some of these are:

- ovarian cancer
- testicular cancer
- thyroid cancer
- bone cancer
- soft tissue sarcoma
- acute lymphoblastic leukaemia
- acute myeloid leukaemia
- lymphoma
- brain tumours (which are sometimes benign).

We have more information about these types of cancer on our website. Visit **macmillan.org.uk/teens**

Questions you might want to ask about cancer

Here are some questions you might want to ask your doctor or nurse.

- Where is the cancer?
- What caused the cancer?
- How serious is it?
- Can it be treated?
- Can it spread?
- Where could it spread to?
- What happens if it spreads?
- Could I have inherited the cancer from someone in my family?

Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you is collected in a national database. This is called the cancer registry. It helps the NHS and other organisations plan and improve health and care services. Your hospital will give information about you, your cancer diagnosis and treatment to the registry automatically, unless you ask them not to. As with all medical records, 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 about the registry. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out. You can find more information at **macmillan.org.uk/cancerregistry** To find details about the cancer registry in your area, see page 133.

‘I was in disbelief. I couldn’t quite come to terms with the fact that I was faced with six months of chemotherapy.’

Amrik, diagnosed with cancer aged 18

FINDING OUT YOU HAVE CANCER

Having tests and scans

When you are diagnosed with cancer, doctors will do some tests to find out as much as possible about the cancer.

This can mean spending a lot of time waiting for appointments and results. Sometimes you might feel that you are starting to lose touch with your normal life. If you are feeling well enough, try to carry on with things you enjoy, such as playing sport, going to the cinema or seeing friends.

Finding out why tests are being done and what they will involve can help you feel more prepared. Your healthcare team should explain any test you are having. But if you are unsure about anything, just ask.

If you are worried that a test may be uncomfortable, speak to your healthcare team. There might be things that can make it easier. They will usually offer this kind of help when they arrange the test. But sometimes they can be very busy, or may not realise how worried you are. Don't be afraid to speak up, even if it feels awkward. The doctors and nurses will understand what you are going through, and will do everything they can to help.

When the test results come back, you can ask to see your scans or x-rays. If you think it would help, you could ask your doctor to draw you a picture or diagram so that you can get a better idea of what is happening in your body.

Scans

There are different types of scans, including ultrasound, CT, MRI and PET/CT scans:

- Ultrasound scan – this is when a small device like a microphone is gently moved over the area being scanned. The device produces sound waves to build up a picture of the inside of your body. The scan does not hurt.
- CT, MRI and PET/CT scans – these usually involve lying still in a small space. There can often be a lot of humming and mechanical noise going on around you. These scans do not hurt.

Lots of people feel nervous about having a scan. Your healthcare team should tell you what the scan involves and what to expect. You may also find it helpful to look at the scanning machine before you have the scan. Just ask one of the nurses at the clinic or on the ward. If you think it would help, you could ask to meet someone who has had the scan recently. You may find that chatting about the experience helps reassure you.

Having a scan may not be relaxing, but it is an important part of finding out what is wrong so you can get the treatment you need.

If you find it hard to relax, the doctors or nurses may be able to give you a pill or an injection to calm you down before you have the scan. You will still be awake, but won't be as aware of what is happening. You are also unlikely to remember much about it afterwards.

We have more information for teenagers and young adults about tests and scans on our website. Visit **macmillan.org.uk/teens**

Finding information online

The internet can be a great source of information. However, online information is not always reliable. Sometimes you might read inaccurate information, which is not helpful.

You can find reliable health information websites by looking for the Information Standard logo (see below).

If an organisation has this logo, it means that their information is high-quality, accurate and regularly updated.

Health & care
information
you can trust

The Information Standard
Certified
Member

Here are some things to think about when you are looking at a website:

- Is the information regularly updated? You should be able to find the date when the information was last reviewed on each page.
- Is the website trying to sell you something? A good health information website won't do this.
- Is it clear who has written the information? You should be able to find out who has written the information.
- Are there references? A good website should list where the information has come from, or tell you who to contact to find out.
- Are there any phrases that you might not trust, such as 'miracle cure'? A good website will not use phrases like this.
- Are there contact details? You should be able to find these easily on the website.

You may also find information on the internet that is factually correct, but not relevant to you and your situation. Each person has a different cancer experience, even if they have the same type of cancer.

If you are unsure about a website or the information you have read, ask a member of your healthcare team.

> ‘I got some of my close friends to come around and then told them the news. They were amazing and supportive, and got me feeling and thinking positive.’

Matt, diagnosed with cancer aged 19

What to say to people

You may worry about what to say to people about your diagnosis. It can be difficult telling people what is happening, and you might be worried about how they will react.

It’s up to you how much you want to tell people and who you want to tell. You might decide to only tell your family and some close friends who you trust.

Think about how you let people know what is going on. You could talk face to face or on the phone. Or you may find it easier to send an email, letter or text. Social media can also be a great way of keeping in touch, but remember what you say will be seen by others, unless you send a private message.

Here are some tips:

- Think about how much you want to share. For example, you could say you are waiting for tests and results, but that you are trying to get on with life as normal.
- Introduce the subject gently. You could start with something like: ‘This is going to be difficult, but I need to tell you something’.
- Try to give small amounts of information. The person you are telling may not be able to take everything in at one time.

School or university

If you are at school or university, it is a good idea for you or someone close to you (like a parent or an adult family member) to talk to staff about your situation. If you are worried about your health or not feeling well, it can be hard to concentrate or do well in coursework or exams. If your teachers know what is happening, they may be able to help.

Work

If you are working, you may feel unsure about what to tell your employer. It can help to be honest at this stage, especially if you need to take time off for hospital appointments. We have more information about talking to your employer in our booklet **Work and cancer**. This information is written for all age groups. To order a free copy, visit **be.macmillan.org.uk** or call **0808 808 00 00.**

Whether you are in education or employment, you can always speak to your specialist nurse or social worker if you need help to explain your situation.

> ‘I thought it was a joke and didn’t want to believe that I had cancer. I didn’t know how to tell my parents, I didn’t know how to react.’
>
> **Meriam, diagnosed with cancer aged 19**

Your feelings

When your doctor tells you that you have cancer, you may find it hard to believe. It is common to feel shocked and numb. You may not be able to take in much information, and find that you keep asking the same questions again and again. The fear of what might happen next may sometimes be the only thing on your mind. You may feel very sad and upset.

You may know someone who has had cancer. If they did not get better, you might assume that getting cancer means you may die. But the number of people who are successfully treated and cured is increasing. Many cancers that affect young people respond well to treatment. This means that most young people with cancer will get better and have full and long lives.

You may find that your mood changes a lot. One minute you may be laughing with your friends, and the next you may burst into tears – this is completely normal. Or you may find your feelings hit you much later.

Finding out you have cancer is not easy, and it can be hard to fully understand what is happening. It can help to have someone you trust, such as a family member or close friend, with you when you go for your hospital appointments. They can provide support and be there to talk things through with you. They could also help by bringing a list of questions to ask and writing down the answers for you.

Talking about the cancer

After being diagnosed with cancer, you may find the idea of talking about it upsetting or uncomfortable. And putting your feelings into words may seem overwhelming. But talking about how you feel and what you need can help you feel supported. If talking feels too difficult, it may help to write down how you are feeling and then share this with someone you trust.

Sometimes it is hard to be open with the people closest to you. If it feels easier, you can talk to a doctor, nurse or any member of the team caring for you.

Counselling (support if you would like to talk about your feelings)

If you are struggling to cope or feeling low, then it might be a good idea to see a counsellor or psychologist. They are trained to help you understand your feelings so that you can cope better.

You can ask your GP or healthcare team to refer you to a counsellor. Some teenage and young adult (TYA) units will have a counsellor or psychologist as part of the team. Or there might be a counsellor at your school or university.

If you do see a counsellor, you can decide how much you would like to share with them. Anything you tell them will be confidential, so they won't tell anybody else.

You may feel embarrassed about needing to talk to someone, but psychologists and counsellors are there to help. You may also find it helps to talk to somebody who is not directly involved in your situation. If you are angry with someone or frustrated, you can talk to the counsellor about it without upsetting anyone.

If you decide that the counsellor you are given is not the right person to help you, tell someone. It is important that you trust your counsellor and feel comfortable with them. You shouldn't feel bad about asking to see someone else if it doesn't feel right. The person who referred you to the counsellor may be able to arrange for you to see a different counsellor.

> 'Surprisingly, I was quite relieved to know what was going on. I didn't think negatively, just thought what next, how can we deal with it.'
>
> **Ellis, diagnosed cancer aged 16**

Hopes and fears

It might help you cope if you talk about what is frightening you, and things that you hope will happen. If you are finding it difficult to talk about these things, the tool opposite might help. You could use it to write down your hopes and fears. Putting them down on paper might be easier than saying them out loud at first. Or it might just help you to work out how you feel.

Even if you don't want to share it with other people, you may still find it useful to write down your hopes and fears.

There is also space for you to think about what you could do next to help with your fears. This could be talking to someone in your healthcare team, talking to someone you trust, joining a support group, or just asking for some extra help with day-to-day things.

This thinking tool was written by people affected by cancer. You can find more tools, stories and help using the tool at **thinkaboutyourlife.org** If you have any comments about this thinking tool, please email **cancerinformationteam@macmillan.org.uk**

Hopes

Fears

Things I can do:

‘It didn’t really sink in for me until my first day of treatment when I actually walked into the hospital and realised what was going to happen to me.’

Megan, diagnosed with cancer aged 16

HAVING TREATMENT

Before you start treatment

Different treatments are used for different types of cancer. Your doctors will choose the treatment that is best for the type of cancer you have. You may have more than one type of treatment.

Planning your treatment

Your doctors will usually want to start your treatment as soon as possible. They will put together a plan to treat the cancer. You will meet different members of the healthcare team. This includes the consultant and other hospital doctors, nurses and other people who will be involved in your care. You may be given a keyworker – this is often a nurse who will keep in touch with you to make sure you have all the information and support you need. There is a list of different health professionals on pages 49 to 52.

Your doctors will talk to you (and maybe your parents or carers) about your illness and the treatment plan. There may be times when you prefer to talk to the medical staff on your own. You can ask for this if you would like.

Making decisions

When you are diagnosed with cancer, you may feel that you have lost control. You are seeing lots of doctors, nurses and specialists, and everyone seems to be telling you what to do.

Your cancer doctor or nurse may give you lots of information about cancer and treatments, and you may have decisions to make. It is important that you get all the facts and support you need to make these decisions.

It will help to know:

- what the treatment is
- how long it may last
- what the side effects might be
- what effect is it going to have on your life.

You should also have plenty of time to ask questions and to think about what you want to do. Treatment is different for everybody, and you won't know exactly what it is going to feel like until you start. But it will help to understand as much as you can. You may be able to chat to someone who has had similar treatment. Ask the hospital staff if you would like to do this.

If you want to look online for information about treatment, make sure you visit websites that you can trust (see pages 16 to 17).

If you aren't sure about having a particular type of treatment, you can ask for more time to think about it. Talk to your doctor or a nurse about anything you are worried about.

The doctors can't give you any treatment until you have agreed to have it. This is called giving consent. If you are aged under 16, you may need the written consent of your parent or guardian. If you are aged over 16, you can sign the consent form yourself.

Getting a second opinion

If you, or your parents or guardians, feel it would be helpful, you can ask for the opinion of another specialist. This is known as getting a second opinion. Either your GP or consultant should be willing to refer you to another specialist. However, getting a second opinion may delay the start of your treatment. So you, your doctor and your parents or guardians need to be sure that it will be helpful.

Surgery

This means having an operation to remove the cancer. This is usually done under a general anaesthetic, so you will be asleep. You usually need to stay in hospital to recover. How long you need to stay will depend on what type of operation you have. Your doctors will be able to tell you more.

You may find it helpful to talk to someone who has had the same operation. Your doctor or nurse may be able to arrange this for you.

You may be worried about how you will look and feel after surgery. We have more information about changes to your body on pages 79 to 89 that might be helpful.

We also have more detailed information about surgery on our website. Visit **macmillan.org.uk/teens**

Radiotherapy

Radiotherapy uses high-energy x-rays to destroy cancer cells. You usually have treatment every week day in the hospital radiotherapy department. It can often be done as an outpatient, which means you can go home after each treatment. Treatment is often given over a few weeks. Your doctors will tell you how long your course of treatment will be.

Having the treatment doesn’t hurt. You lie still on a narrow bed while a radiotherapy machine directs the rays at the cancer.

Radiotherapy can cause side effects. These will depend on the part of the body being treated. Your doctor and nurse can tell you what to expect and what will help.

We have more detailed information about radiotherapy on our website. Visit **macmillan.org.uk/teens**

Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. Different drugs are used to treat different types of cancer. Chemotherapy is often given as an injection or drip into a vein. But sometimes it is given as tablets.

If you have chemotherapy into a vein, your doctors may suggest that you have a central line put in. This is a long, thin, flexible tube which is put into one of the large veins in your chest. Having a central line means you won't need to have lots of injections and needles for each treatment. It can stay in for weeks, months or even years if necessary. The end of the line comes out of your chest. The nurses will show you how to look after it.

Sometimes other lines are used instead of a central line. Some people may have a portacath or a PICC line. You doctor or nurse will tell you about which line is best for you and how you will have it put in. We have more information about different lines on our website. Visit **macmillan.org.uk/teens**

Chemotherapy treatment usually takes a few months. You usually have the drugs over one or more days followed by a rest period. This is called a cycle of treatment. Some people may need to stay in hospital while they have treatment. Others can have it all as an outpatient, which means you can go home after each treatment.

Chemotherapy can have side effects. Your doctors and nurses can tell you what will help with these.

Side effects of chemotherapy

Risk of infection

This treatment can reduce the number of white blood cells in your blood. These cells fight infection. If the number of white blood cells is low, you are more likely to get an infection. A low white blood cell count is called neutropenia.

If you have an infection, it is important to treat it as soon as possible. Contact the hospital straight away on the 24-hour contact number you have if:

- your temperature goes over 37.5°C (99.5F)
- you suddenly feel unwell, even with a normal temperature
- you have symptoms of an infection.

Symptoms of an infection include:

- feeling shivery
- a sore throat
- a cough
- diarrhoea
- needing to pass urine often.

It is important to follow any specific advice your cancer treatment team gives you.

The number of white blood cells will usually return to normal before your next treatment. You will have a blood test before having more treatment. If your white blood cell count is low, your doctor may delay your treatment for a short time.

Tiredness

Most people find they get very tired when they have chemotherapy. This is sometimes called fatigue. There are things you can do to help you feel better. For example, you could:

- go for short walks
- get to know when you feel your best and try to do things you enjoy at those times
- make sure you tell people when you feel tired and need to rest.

We have videos about fatigue that you may find helpful. They feature three young people who have been affected by cancer – Ellis, Ruth and Faye. Visit **youtube.com/user/macmillancancer** to watch their stories.

Other side effects

Other side effects can include:

- hair loss (see pages 83 to 84) – this may be just the hair on your head, but could include your body hair, eyebrows and eyelashes
- feeling sick or being sick
- mouth infections and painful ulcers
- diarrhoea or constipation
- weight loss or weight gain.

There are lots of ways that the medical staff can help. Most side effects will get better or stop when treatment stops.

We have more information about side effects of chemotherapy on our website. Visit **macmillan.org.uk/teens**

Other treatments

If you have lymphoma or leukaemia, you may need different types of treatment.

To understand these treatments, you need to know what bone marrow and stem cells are:

- Bone marrow is a spongy material in the middle of your bones where blood cells are made.
- Stem cells are the cells in your bone marrow that develop into all the other types of blood cells.

High-dose treatment with stem cell support

High-dose treatment with stem cell support may be used to destroy any remaining cancer cells. It can increase the chances of curing certain types of cancer or leukaemia. It involves storing your stem cells and giving them back to you after treatment. This means you can have much higher doses of chemotherapy than usual.

Donor (allogeneic) stem cell transplant

Sometimes stem cells from another person (a donor) are used. Their bone marrow needs to be a good match for yours.

This type of stem cell transplant is sometimes used to treat some types of leukaemia or lymphoma that have come back after treatment.

We have more information about high-dose treatment with stem cell support and donor (allogeneic) stem cell transplants. This information is written for all age groups. To order information, visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

Clinical trials

What is a clinical trial?

Your doctors may suggest you take part in a clinical trial.

Clinical trials are done for lots of reasons. The most common type is a treatment trial. This may:

- test new treatments, such as new chemotherapy drugs
- look at new combinations of existing treatments
- change the way a treatment is given, to make it work better or to reduce side effects.

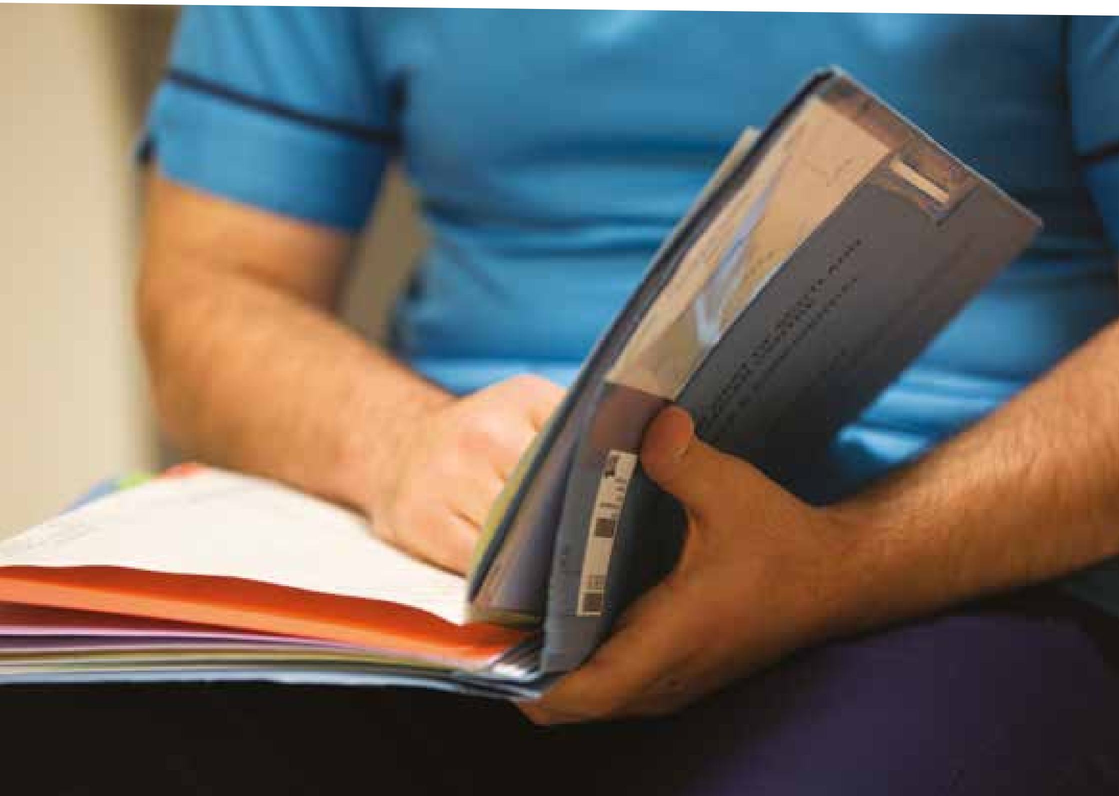
You will only take part in a trial if your doctors think that is the best treatment for you. Any clinical trial is strictly controlled, so you may need to visit the hospital more often.

Some trials are randomised. This means that the details of all the people taking part are fed into a computer, and the treatment is chosen at random by a computer programme. All the possible treatments are good, so you are not missing out if the computer does not choose a particular treatment for you. Trials are often randomised because if the researchers or doctors were to decide who should get which treatment, they might be influenced by what they know about their patients.

Your doctors won’t put any pressure on you to join a clinical trial, and they will talk to you about any concerns you have.

You can't be put into a trial without your written consent if you are aged over 16, or your parent or guardian's consent if you are under 16. If you decide to say no to a trial it is not a problem, and you will be given the best treatment available at the time.

We have more information about clinical trials in our booklet **Understanding cancer research trials (clinical trials)**. This information is written for all age groups. To order a copy, call **0808 808 00 00** or visit **be.macmillan.org.uk**



Getting through treatment

Being diagnosed with cancer can come as a big shock. Finding out about the treatment can be just as difficult to take in, especially when you learn about the possible side effects.

It is normal to feel anxious, stressed or low sometimes when you have cancer. You may go through lots of different emotions. There are things you can try (depending on your situation) to help you feel better:

- Talking to family, friends, a partner or your healthcare team can often help. Choose whoever is best for you. Your healthcare team will not be surprised by any of your feelings and can suggest things that might help.
- Listening to your favourite music, relaxation CDs, or podcasts, or playing computer games can all help you unwind.
- Writing and drawing are great ways to express your feelings. No one else has to see it, so you can write and draw whatever you like.
- Doing exercise can help reduce tiredness and improve your mood. You could try running, walking or riding a bike. Ask your doctor or specialist nurse for advice about this.
- If you have lost your hair, try out different hats, jewellery and make-up. Have fun and be as bold as you want. We have more information in our booklet **Coping with hair loss**. Call **0808 808 00 00** or visit **be.macmillan.org.uk** to order a free copy.

Complementary therapies

Some people use complementary therapies alongside other cancer treatments to help them feel better or to relieve symptoms or side effects. Complementary therapies don't claim to cure cancer. Some have been scientifically tested to check how effective and safe they are. Talk to your hospital staff if you want to try a complementary therapy.

We have more information in our booklet **Cancer and complementary therapies**. This information has been written for all age groups. Call **0808 808 00 00** or visit **be.macmillan.org.uk** to order a free copy.

Will you get better?

Cancer treatment is tough, but more and more people are being cured. This isn’t true for everyone though, and nobody can guarantee that treatment will be successful.

Coping with this uncertainty is one of the hardest parts of living with cancer. But even for people who aren’t cured, cancer can often be controlled for a long time with the right treatment. Doctors are learning more all the time about improving the treatments and helping people get the most out of their life.

Questions you could ask about treatment

Here are some questions you might want to ask your doctor or nurse.

- What are my treatment options?
- Can I have time to think about it before making a decision?
- What are the benefits and disadvantages of each treatment?
- What is the aim of this treatment?
- Will I need to be in hospital?
- How long will each treatment session take?
- How long will I need to have treatment for?
- Will it hurt?
- What are the side effects?
- If the treatment doesn’t work, what will happen?

GOING INTO HOSPITAL

Which doctors will you see?

When you first started to have symptoms, you probably saw your GP. Your GP is your family doctor, who deals with all types of general health worries and problems.

They may have referred you to a specialist for tests, which are usually done in hospital.

If the tests suggest you have cancer, you will be referred to a cancer specialist at the hospital. You may be referred to a teenage cancer unit if there is one in your area.

At the hospital, there will be one expert doctor who is in charge of the team that cares for you. This person is called your consultant. Every time you go to the hospital (for anything from a test to an overnight stay), the consultant will send reports back to your GP so they know what is happening.

We have put together a list of healthcare professionals you might meet while you are in hospital. The list also includes some different professionals who can help with things like money and work. It will help you to understand their jobs and ask them the right questions.

The A–Z of who does what

Benefits adviser

Benefits advisers are sometimes called welfare rights advisers. They can help people get payments 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.

Clinical nurse specialist (CNS) or keyworker

A nurse who specialises in a particular illness. They may also be your keyworker. Your keyworker is someone who will keep in touch with you and provide any extra support or information you need.

Community nurse

A nurse who can care for you at home. They can give you any medication you need, and provide other nursing care. They are also called district nurses.

Counsellor

Someone you can talk to about your feelings and worries.

Dietitian

Someone who can help you with eating and nutrition.

Doctors

You may meet some of the following doctors:

- **Consultant** – an expert doctor. They are in charge when you are given treatment in hospital. They have a team of doctors working with them.
- **GP** – a family doctor. You may know this person already. They can help when you are out of hospital.
- **Haematologist** – a doctor who specialises in blood problems.
- **Oncologist** – a doctor who is an expert in cancer.
- **Pathologist** – a doctor who studies cells and looks at biopsies.
- **Radiologist** – a doctor who is trained to look at x-rays and scans.
- **Surgeon** – a doctor who does operations.
- **Medical student** – someone who is training to become a doctor. They may visit you with the qualified doctors who are treating you, so they can learn about what happens.
- **Palliative care doctor** – a doctor who specialises in helping people cope with the symptoms of cancer.

Occupational therapist

Someone who can help you do everyday tasks if you are unwell or unable to do things yourself.

Oncology outreach nurse

A nurse who can visit you at home and arrange activities, like your return to school or university.

Pharmacist

Someone who gives out medicines that doctors have prescribed, and gives advice about medicines.

Phlebotomist

Someone who takes blood samples.

Physiotherapist

Someone who can help you with walking or moving around, if you have problems with this.

Psychologist

Someone who can help you manage your feelings, if you are finding it hard to cope.

Radiographer

Someone who takes x-rays and scans. They also give radiotherapy treatment, which is planned by an oncologist.

Social worker

Someone who can help you and your family with money or work issues or other problems.

Ward nurse

A nurse who makes sure you are looked after in hospital. They will give you any regular treatments you need.

Youth support co-ordinator

Someone who can arrange activities, and help you stay active and social during and after treatment. They are funded by the Teenage Cancer Trust (see page 130).

Youth worker

Someone who works with young people to help them stay active and social, and to reach any goals they would like to achieve.

Which hospital will you go to?

This will depend on:

- your age
- the nearest hospital with the best facilities for your illness
- where your consultant works.

If you are aged under 19, you should be treated in a centre that specialises in caring for young people (including children). This is called a **principal treatment centre**. There are principal treatment centres in every UK county. You can search for your nearest one on the CLIC Sargent website at **clicsargent.org.uk/in-my-area/principal-treatment-centres**

If you are aged 19 to 24, you should be offered the choice of being treated in a principal treatment centre, or an adult ward that has been approved to treat your age group.

Some hospitals have special units for teenagers and young adults. You can see where they are on the Teenage Cancer Trust website at **teenagecancertrust.org/get-help/how-we-can-help/our-units**

If there is not a unit for teenagers and young adults or a principal treatment centre close enough to where you live, you will be looked after on either a children's or an adult ward. Where possible, you should have some say in which part of the hospital you will be in, unless you are admitted as an emergency patient. Your doctor may have suggestions, but you can ask to see the other options and discuss it with your doctor before making a decision.

What is hospital like?

If you have never been in hospital before, you might be surprised by what it is like. You are there because you need care and treatment, but that doesn’t mean you will be in bed all the time.

There will be different facilities available depending on the hospital, and which part you are staying in.

There might be a day room, where you can watch TV and chat to friends and family. There may also be a kitchen where you can make yourself drinks and snacks.

Wards vary in size – there may be a lot of beds, or only a few. There may also be a few single rooms available. You might find a single room useful if you are feeling unwell and need some peace and quiet.

How long you will need to spend in hospital will depend on the type of treatment you need. You may go into hospital during the day and then go home again after the treatment. Or you might need to stay overnight. For some treatments, you may need to stay in hospital for longer.

Will there be facilities for young people?

This depends on which hospital you go to. If you go to a principal treatment centre or a hospital with a special unit for teenagers and young adults, you will be with other people of your own age.

You will also be cared for by nurses, doctors and maybe other workers (such as youth workers) who are used to working with teenagers and young adults.

As well as a day room, some young people's units have rooms with computers, internet access, games consoles, music and DVD players.

How to make hospital life easier

It may take a while to get used to being on a ward with other people. It often means having to fit in with everyone else's mealtimes and sleep patterns. It may also feel strange to suddenly lose your privacy if you are used to having your own room at home.

But there are lots of ways to make your stay in hospital easier and more comfortable.

Here are some tips from young people who have been in hospital:

Make yourself at home

Do everything you can to make your space in hospital your own. You may have your own room, or just a curtained cubicle on a ward. Take in pillows, cushions, photos – anything that will help you feel more at home. Sometimes you can take your own duvet in too.

You can close the curtains around your bed whenever you want to be on your own.

Bring entertainment

Take in a phone, tablet, or a hand-held games console – anything that will keep you entertained. You could download TV shows, films and books onto your phone or tablet, so that they are there if you need them. And take lots of books and magazines. You could ask your friends and family to bring in new ones when they visit.

Pack comfortable clothing

Unless you are having tests or need to stay in bed, you can wear your everyday clothes in hospital. Make sure you pack things that are comfortable and make you feel good. If you forget anything, ask your family or friends to bring it in.

Talk to other young people

You should have the chance to get to know other young people in hospital, especially if you are in a unit for teenagers and young adults. This can help you to feel more settled and comfortable in hospital. You may also be able to go out of the hospital with friends or family sometimes – just check with the staff on the ward first.

Stay connected

If you are in hospital a long way from home, try to stay in touch through phone calls, texts, social media, emails or letters. Let your family, friends or partner know that although you are in hospital, you are still the same person and you want to stay in touch.

> ‘I got left out of certain things because they thought I was too sick to come, or that I wouldn’t want to. I wanted to be treated like everyone else, so that was quite frustrating.’
>
> **Ellis, diagnosed with cancer aged 16**

Education

Making the effort to keep up with school or university work may help to pass the time. Your school or university should be able to arrange for you to do some work in hospital. If necessary, ask someone close to you (like a parent or an adult family member), your specialist nurse, or your CLIC Sargent social worker to talk to them about this.

Your friends and social life

You may sometimes feel quite isolated in hospital. Your friends are probably aware of this, but may not know what to say to you.

It's not always easy, but if you feel up to it you could ask a close friend to visit you in hospital. If you haven't seen them for a while, it might be a bit awkward at first. But you will soon relax with each other again, and they will see you are still the same person.

Seeing close friends in hospital can help to boost your confidence. As you start to feel more confident again, you could arrange to catch up with other friends. This could be face to face, or by texts, video, phone calls or social media. Reconnecting with your friends will probably help you feel better and more like yourself.

> 'My friends visited me in hospital and I think it shocked them as I was in bed. I don't think they thought of me as ill, as I carried on doing everything.'
>
> **Ruth, diagnosed with cancer aged 20**

The most important thing is not to rush things. You may worry about missing out on things your friends are doing, and this is understandable. You might find that you drift away from friends while you are having treatment, for example if you stop going to school or university for a while. But if you have friends you are close to, you will stay in touch and it won't take long to catch up.

If you use social media, we have listed the Facebook pages of some organisations for young people with cancer on pages 129 to 133. You could also visit **jtvcancersupport.com** – a website for young people with cancer, which lets you upload and watch video blogs.

Asking questions

When you are nervous or anxious, it can be hard to take in lots of information. Most doctors realise this, which is why your consultant should always check whether you have any questions. Even if you feel shy or embarrassed, they will recognise how important it is for you to find out and understand what is going on. One way to make sure you get the answers you want is by writing down your questions before an appointment. That way, you can take them with you as a prompt, or to show your doctor or nurse. Taking a family member or friend with you might also help – they can ask anything you forget.

If it helps, when you see your consultant you could ask them to write down the important points for you. They may recommend a booklet, website or video that answers your main questions. Remember that you can ask as many questions as you like. It is your body, and you have a right to know what is happening.

Making sure you are included

You may find that the doctors and nurses talk directly to the adults and not you. This may make you feel like your questions and thoughts don’t matter.

If you find this happening to you, don’t be afraid to speak up about it. You might be able to explain to an older family member that you are feeling left out. That way, they can make sure you are included next time you are with a health professional.

> ‘I really appreciated the fact that my consultant actually talked to me directly. This meant that I felt like I was more in control of my treatment.’
>
> **Shelbee, diagnosed with cancer aged 19**

Questions you could ask about going into hospital

Here are some questions you might want to ask your doctor or nurse.

- How long will I have to stay in hospital?
- What tests and scans will I have?
- What is the hospital like where I will be having my treatment?
- Do I have a choice of where I am treated?
- Will I have my own room?
- When can people come and visit me?
- What do I need to bring with me?

RELATIONSHIPS

Cancer and relationships

Going through cancer and its treatment can affect the relationships you have with people.

You might find that having cancer makes some of your relationships stronger. You might make new friends, or find new qualities in the relationships you already have.

But having cancer can sometimes have a negative effect on your relationships. This can be for lots of reasons, but things often improve over time. It can help to understand a bit about the issues that can affect relationships, and what can help you cope.

'My mum said she couldn't deal with my cancer diagnosis as one big scary thing. So we pinned a notice board up in the kitchen and put all the things we had to get through on it, along with things we would do as a family.'

Jenna, diagnosed with cancer aged 21

Your family

As a young person, you are probably going through the important, but difficult, stage of becoming more independent from your family. You might argue with your parents or other family members more than when you were younger, and this is normal. It is part of learning how to negotiate and compromise. But it can also make it difficult to talk to people.

When someone in the family has cancer, it can put a strain on everyone. It can cause lots of different emotions, and this can sometimes affect how your family talk and act towards you. They might get angry and upset more often, or argue more than usual.

You are also coping with a lot. Remember that this can affect your behaviour and relationships. Discovering you have cancer changes your life. Your treatment can take you away from home and put you in new and different surroundings. You have to meet lots of new people, like all the hospital staff. And you may be feeling unwell and anxious, which can make it difficult to cope.

It will take time for you and your family to come to terms with the cancer. Talking to each other and spending time together as a family can help.

> ‘When you’re 17, you feel ready to be more independent – move on with your life, go to university. But for me, it meant relying on my parents more.’

Megan, diagnosed with cancer aged 16

Parents or carers

Your parents or carers will be really worried about you. They want to protect you and make you well again, but they know that they can't do that. Feeling out of control can make them frightened.

These feelings might mean they are overprotective towards you. For example, they may tell you not to get too tired, say you shouldn't go out with your friends, or nag you to eat your dinner. You might find it reassuring that they are looking after you, but it can also be frustrating.

It helps if you and your parents or carers get clear information about what is safe for you to do, and what you should avoid doing. For example, there may be times during chemotherapy treatment (see pages 35 to 37) when you are at risk of infection. During this time, you should avoid spending time around anyone who is unwell. Your nurses and doctors can give you the information you need, and it is a good idea to talk it through together. Having this information may help your parents feel less anxious.

Your parents may sometimes disagree with each other about what is best for you. This could cause arguments. They may also argue about other things like money or work. Some of these things may have been problems before the cancer. But remember that you are not to blame.

If you or your parents need more support, you might find it helpful to talk to a social worker or counsellor. They are used to these kinds of problems and will be able to help.

Telling your parents or carers what you want

As you get older, it is natural to want to be independent. But when you are ill, you need your family's help and support. This is especially important when you are just diagnosed or when you feel low during treatment.

You may feel your parents or carers are putting on a brave face and trying to stay cheerful. Sometimes this may help, but it can also mean you worry about telling them how you feel in case you upset them. This is understandable, but the people closest to you would much rather know how you really feel.

Sometimes it can be hard to talk about serious and emotional things when you are sitting face to face, or when people are visiting you in hospital and you know they have to leave soon. It may be easier to talk about important things when you are doing something else as well. For example, when your parent or carer is driving you to a hospital appointment or you are in the kitchen together clearing up. When the focus of attention isn't just on you, it can be a lot easier to say what you feel.

If you feel overwhelmed by the attention and affection your parents or carers are giving you, explain clearly and calmly what you would like from them. If you want more time to yourself, just say so.

Remember, they aren't mind readers. And everyone gets things wrong sometimes. So it is important to talk to your parents or carers if you need more support, or if there are things they can do to help.

Brothers and sisters

It is natural for someone who is ill to become the centre of attention, at least for a while. If you have brothers or sisters, they may react in different ways.

They may be supportive and want to be there for you, and you might find that you become closer.

Or they may feel left out because your parents are spending a lot of time visiting you when they would normally be home.

They might feel scared about you being ill, or confused by changes to family life.

Because of this, they may not want to visit you in hospital, or they may behave badly at home or school. Try to understand that they aren't doing it to be unpleasant or mean.

However they react, they are probably worried about you and want you to get better.

If you want to help, let them know that there is support and advice available for them too. For example, they can call our cancer support specialists on **0808 808 00 00**.

If you have problems with your relationship with your brothers or sisters, you can talk to your parents, a social worker, youth support co-ordinator or specialist nurse.

Friends

Friendships often become very strong and important when you have cancer. But you might find that it's not the friends you expect who give the most support. Sometimes friends you were closest to can find it very difficult to deal with your illness.

Your friends might find it hard to support you if:

- you haven't been at school or university, or work – they may not know whether to get in touch or what to say
- they know you have missed out on what is happening and been left out of plans – they may not know what to say, or might worry about upsetting you
- they are frightened of the idea of cancer – if they don't know anyone else with cancer or have not have been in a hospital before, it can be hard to understand.

You might also find it hard to keep in touch with your friends. This can be for lots of different reasons, for example you aren't feeling up to it, or you are worried about what they will say.

But making an effort to keep in touch through texts, phone calls or emails can make a big difference (see pages 56 to 60). It can help you feel more confident and supported, and it can help your friends to know you are still the same person.

Making new friends in hospital

You may make new friends in hospital. Being in touch with other young people with cancer can be really comforting. There is so much they will understand without you having to explain it, and you don't have to worry about looking different or having off-days when you are with them. They know because it happens to them too.

You may also be able to join a young people's support group. Your nurse or the local Macmillan nurse will know about groups in your area.

> 'My close friends were fine with my illness, but others didn't understand how to treat me. Some people were scared by it.'
>
> **Ellis, diagnosed with cancer aged 16**

If someone you meet in hospital dies

Some of the friendships you have made in hospital will be very close and last for a long time. But sadly, some of the people you meet may die. This can be hard to cope with.

Grief affects everyone in different ways. You may feel sad, lonely or angry. You may also be scared about whether your own treatment will work. Or you may feel guilty because you are still here and your friend isn't.

Don't be afraid to talk about the person who has died, whether it's little stories about them, or talking about their cancer.

Remember there are people who can support you. It can help to talk with someone close to you about how you are feeling. You can also talk to your healthcare team. They can put you in touch with a counsellor if you would like to speak with one. A counsellor is someone who is specially trained to help you cope with difficult feelings (see page 24 to 25).

There are also organisations who can help people who are grieving. See pages 129 to 133.

Your partner

You may be single, or feel like you aren't ready for a relationship at the moment.

If you do have a partner, they may be someone you can talk to and a good source of support.

Some people find it difficult to start a new relationship after being diagnosed with cancer, especially with someone they didn't know before their diagnosis. You may feel unsure about what to tell a new partner about your cancer, if anything at all.

You may also worry about choosing the right time to tell a partner. Some people prefer to tell everyone straight away, while others prefer to wait. There is no right or wrong. It can help to talk it through with someone, such as a family member, friend or a professional.

We have more information about sex and relationships in our booklet **Sex and relationships – Support for young people affected by cancer** that you might find helpful. In it, we talk more about coping if you are in a relationship, if you are single and if you are starting a new relationship. Visit **be.macmillan.org.uk** or call **0808 808 00 00** to order a free copy.

Your sex life

Most people have questions about relationships and sex at some point during or after cancer treatment. This is whether you are in a relationship, are single, or if you have had sex or not.

Living with cancer doesn't have to stop your sex life. Continuing your sex life might help reassure you that, despite your cancer, the rest of your life goes on as normal. During your treatment and recovery, you may not always feel like having sex. But you can still enjoy being close with a partner.

If you have a partner, they may worry that they will hurt you by getting too close. It's a good idea to try to talk about your feelings and discuss any changes that may be needed in your relationship while you are ill.

You will need to use contraception during treatment, and for some time after treatment ends, to make sure you don't start a pregnancy.

It is also important to protect yourself and your partner by using contraception from small amounts of drugs that can get into your body fluids. Your doctor may advise that for a few days after treatment you:

- use a condom (or a latex barrier such as a dental dam) for oral sex
- use a condom for vaginal or anal sex.

You may not want to be in a sexual relationship while you are going through cancer. It's important to do what feels right for you.

It might be hard to talk about personal issues such as sex, and you may be embarrassed to talk about it with medical staff. But your doctors and nurses are used to talking about sex, and they should be able to answer your questions with sensitive advice. There should always be a private space available for this type of discussion, and you can ask to talk to a nurse or doctor of the same gender as you if you prefer. Your healthcare team can also give you information about sexual health and services that can help.

We have more information in our booklet **Sex and relationships – Support for young people affected by cancer**. It includes more about safe sex during treatment and how cancer could affect your relationships.

COPING WITH CHANGES TO YOUR BODY

Will you look different?

Cancer and its treatments can affect how you look. Some changes are temporary, such as losing your hair during chemotherapy. But even if you know some side effects won't last, it doesn't mean they will be easier to deal with.

Other changes may be more long-term, or even permanent. Accepting that you look different can be difficult. Changes to your body can have an impact on your body image (how you feel about your body).

It can help to find out more about some possible changes so you know what to expect. It is also important to remember that you are still the same person on the inside.

Possible body changes

These are some of the body changes that can sometimes be caused by cancer or its treatment. Remember, you probably won't have all these changes. And the effects are different for everyone. Your healthcare team can explain more about any of these changes, and tell you if any are more likely to affect you. They can also give you lots of support.

Weight loss or gain

When you are ill, or if you have chemotherapy, you may lose weight. This can make you look different.

Some people with cancer are given drugs called steroids as part of their treatment. These can make you put on weight.

You might be worried about how you will look if your weight changes. You may also be worried about what your family and friends will say or think. It might help to explain that any changes are temporary, and are caused by the drugs you are taking.

Tubes and drains

During chemotherapy (see page 35 to 37), you may have a central line or portacath put into your chest, or a PICC line in your arm. If you have surgery, you may need to have a tube or drain coming out of part of your body for a while afterwards.

Understandably, this may sound quite scary. Talking to your healthcare team and learning what the tubes are for can help you feel more confident. Your nurses will show you how to look after them. Most people get used to them very quickly.

Scarring of the skin

This often happens after surgery (see page 33). Whatever operation you have, the doctors will always try not to cause scarring, but sometimes it can't be avoided. Scars always look worse straight after surgery when they are red, but they do fade a lot with time. You may also have stretch marks after surgery – these are narrow lines where the skin has stretched. But these are not usually too noticeable and they fade over time.

There are things you can do to make scars and stretch marks less visible. For example, using oils, moisturisers and camouflage make-up, which you can buy from high-street shops. Speak to your healthcare team for more information.

If you are feeling anxious or low because of scarring, talk to your healthcare team. They will be able to give you lots of support and advice. They can also arrange for you to speak with a psychologist or counsellor (see pages 24 to 25), if you would like to.

Loss of a body part

Sometimes people need to have a part of their body (limb) removed. For example, someone with bone cancer might have an arm or leg removed (amputated).

Surgeons always try to save a limb if possible. For example, they might remove the part of the bone with cancer in it, and then replace it with a bone graft or metal part (prosthesis). But this is not always possible, and amputation of the whole limb or part of it may be the only way to treat the cancer.

It can be very difficult to come to terms with a major change such as an amputation. Losing a limb can feel very scary and it might help to talk to your specialist nurse, doctor or a counsellor about your feelings. It is important to get all the support you need.

Hair loss

Cancer treatment might not affect your hair at all. However, chemotherapy and other medicines can sometimes affect the condition and growth of your hair. It might become thinner, or sometimes fall out completely.

Wearing a cold cap (a hat filled with a cold gel) during chemotherapy can help reduce hair loss. But this is not recommended if you have a blood cancer.

Hair loss from chemotherapy is usually temporary, and your hair will start to grow back after treatment. If you have hair loss from surgery or radiotherapy, you might find there are areas where the hair doesn't grow back.

Coping with hair loss

If your hair starts to fall out, you may prefer to cut it short.

If you feel more comfortable covering up your hair loss, you can wear hats, scarves or wigs. Some people prefer not to wear anything on their head – do whatever feels right to you. Some people get a wig but then decide not to use it.

> 'Two of my friends came with me to pick a wig when my hair fell out. They always made me feel confident, even on the days I felt anxious about wearing it.'
>
> **Jenna, diagnosed with cancer aged 21**

Many hospitals offer a wig service. Your nurse or specialist should know about this, so feel free to ask. You may be entitled to a new wig every six months through the NHS in any style and colour you want. Real hair wigs may be available through charities such as the Teenage Cancer Trust and the Little Princess Trust (see page 130).

Here are some tips for wearing a wig:

- It is often better to get a wig as soon as possible. You can match the style and colour to your own hair or just get used to wearing it before you need it.
- You can take a wig to a hairdresser to be styled.
- If you do wear a wig, it is best not to keep it on at night as your scalp will benefit from being open to the air.
- Brush the wig regularly to prevent it becoming knotted.
- Wearing a wig in the summer can be hot and uncomfortable. A bandana or baseball cap can feel cooler and protect your head from the sun.

Your hair will usually grow back after treatment, but it can sometimes grow back a different colour or texture.

Getting support

Hair loss can be a big deal for some people – both male and female. Your healthcare team knows this and will try to give you all the support and advice you need. It may help to talk to other young people who have coped with hair loss.

We have more information in our booklet **Coping with hair loss** that you may find helpful. This information is written for all age groups. Call **0808 808 00 00** or visit **be.macmillan.org.uk** to order a free copy.

How can you cope with looking different?

Your family and the people around you may not understand how upset you are by changes to your body image. This is probably because their main concern is you getting better. But looking or feeling different from how you were before treatment is a big thing to cope with. You may feel unattractive or uncomfortable in your own body.

It may be okay while you are in hospital, but if you are hoping to go back to school, college, university or work you might be anxious about how people will react. You might worry about being laughed at, teased or even rejected because of your appearance. Or think it will be harder to get a boyfriend or girlfriend, or that your current partner might find you less attractive.

It might be tempting to keep quiet about what is on your mind. But most people will understand and want to help you.

Coping with feelings

Talking to people about your feelings can really help. But it's important to feel comfortable with who you talk to. If you don't want to open up to your family or friends, you can always talk to the professionals in hospital. Social workers, psychologists and counsellors are trained to listen and help you work through your feelings.

Expressing your feelings might not be easy for you, particularly if you always try to be brave. But crying can help to release any tension and stress you are under.

You may need to go through a grieving process, particularly if you have lost part of your body.

Another way of letting out your feelings is to express yourself through writing, blogging, playing music, drawing or painting. You may not have done any drawing or painting for years, but many people rediscover the fun and enjoyment of art while they are in hospital. It is also a good way to let out anger and other emotions. Many hospitals can refer you to music or art workshops, so ask if this is available.

If you use social media and want to share how you are feeling, you could try posting on, or sending private messages to, the Facebook pages of CLIC Sargent, the Teenage Cancer Trust and Teens Unite (see pages 129 to 131 for details). You can also read about other people's experiences on these pages.

Some people find that dealing with body changes makes them more determined to follow their ambitions or goals, or encourages them to think of new challenges.

Staying in touch with friends

Seeing and talking to your friends regularly can help you feel more confident about facing the world. They can support you, make you laugh and make things feel more normal.

But they might not always act how you would like or expect them to. Sometimes they might not give you the support you need. Remember, this is not your fault. If you can, talk to them about how you feel and what their friendship and support means to you.

Getting advice

It may be useful to get some practical advice about ways of coping with body changes, for example using cosmetics to cover scars. It can be difficult to have this kind of conversation, and you might feel embarrassed or self-conscious. But try to get the help you need, as it can really make a difference. The team at your hospital might organise support groups and sessions about body image and self-confidence, so ask them what is available. You can also get advice at your local Macmillan information centre.

If you would rather not discuss your worries face to face, you can call our cancer support specialists on **0808 808 00 00**. You will also find chat rooms and message boards online that are dedicated to helping young people with cancer connect with each other and share their experiences.

Can you still have children?

Cancer treatment can sometimes affect your fertility. Fertility means being able to get pregnant or make someone pregnant. Each treatment can affect fertility in men and women in different ways. If your fertility is affected, it is not always possible to say how long this might last. For example, you may still be able to start a pregnancy in the future.

Your cancer doctor or nurse will talk to you about your treatment options and possible side effects before you start any cancer treatment.

You may still be able to get pregnant or make someone pregnant during treatment. Some cancer treatments can be harmful to an unborn baby. If you are sexually active, it is important to use a condom or other form of contraception.

Your doctor and specialist nurse can discuss fertility with you and arrange for you to talk to a fertility specialist, if needed. You may also find it helpful to read our booklet **Fertility – Support for young people affected by cancer**. Call **0808 808 00 00** or visit **be.macmillan.org.uk** to order a free copy.

Questions you could ask about changes to your body

Here are some questions you might want to ask your doctor or nurse.

- How will my body change?
- Will I lose or put on weight?
- Is there anything I can do to manage my weight?
- Will I lose my hair and, if I do, will it grow back?
- What can I do if I lose my hair?
- Who can help if I am worried about body changes?
- Can I still have children?
- Will I need surgery to remove part of my body? Why? What will happen? What will I look like afterwards?

> ‘I really wanted to be like a ‘normal’ teenager, but it was difficult as not a lot of people could relate to what I had been through.’
>
> **Meriam, diagnosed with cancer aged 19**

GOING HOME

Getting ready to go home

When you are ill, the hospital can feel like a very safe place. You may look forward to going home, but the thought of being away from the hospital and your healthcare team can also be quite scary.

If everyone plans ahead and talks about any possible problems beforehand, going home should be a positive step.

Talking to people about any worries you have about going home can really help. You can often have this kind of discussion with a nurse or social worker while you are still in hospital. Start by discussing the medical things, and then go on to talk about your emotions, which are just as important. This is the time to talk about any concerns you have. For example, if you are worried the people close to you will fuss too much, or aren't sure how going home will affect your relationships with them.

If you are going home to your family, there may be things you could agree on before you go home. For example, having a space in the house where you can have some time to yourself.

It is also important to understand that sometimes going home can be an anti-climax. You may have been looking forward to it so much that you expected everything to be fantastic. But when you get there, you may realise that everyone has continued with their lives and you feel a bit left out. It may also be very quiet at home compared to being in hospital, and this can take a while to get used to.

Remember that you haven't fully recovered yet and you need to rest. It is also normal to feel down sometimes. Getting in touch with some close friends, including friends you made in hospital, may help. Spending time with your family, for example watching a film or playing a game, can also help you settle back into life at home.

If you live alone

It can be tough moving out of an environment where a team is there to care for you 24 hours a day. Even though you may value your independence, being ill can make you feel lonely and frightened.

Make sure the people close to you know you have returned home, so they can support you. You can also contact organisations who will understand what you are going through and offer support and guidance.

It's okay to ask for help. People who care about you will want to help in any way they can. Some people may find it difficult to talk, but may be happy to help in practical ways, like helping with your shopping or cooking you meals. Others may be able to talk and listen to you. This can help you to share any worries and fears.

Speak to your social worker about getting a home helper if you need one. Your GP, social worker, or community nurse will also be able to tell you what help and support is available from local health, social care and voluntary organisations (see pages 129 to 133).

If you are going home to your family

When you lived at home before, it might have seemed as though nothing ever happened. You would have been used to the good moods, bad moods, friendships and rows in your family. If you have been in hospital for a while, it might be hard being in the middle of it all again.

You might also find it difficult to get any privacy. In hospital, you could close your curtains or go back to your room when you were tired, and people would know not to disturb you. That is not always as easy at home.

If you have a small family, or there aren't many people living at home, things might seem very quiet compared to being in hospital.

It can take time to get used to being at home again. And having cancer might have affected your relationships with your parents or carers, brothers and sisters or other family members (see pages 65 to 71).

Your healthcare team will have helped lots of people in a similar situation, so ask them for help if you need it.

Managing at home

Leaving the security of the hospital can sometimes feel scary. In hospital, there is always somebody around if you feel ill or worried. When you get home, suddenly you can feel like you are on your own. You may worry that something could go wrong and no one will be there to help.

For example, you may go home with a central line, portacath or PICC line still in place. Your nurse will show you how to look after this, and you can always phone and check with hospital staff about any worries, day or night.

People with cancer can be particularly at risk from infection (see page 36). The coughs, colds and bugs that other people recover from quite easily can sometimes be very serious for you.

Your healthcare team will tell you when and how you need to take particular care of yourself. They will also tell you who to contact if you are worried.

Getting help when you are at home

- It is important that you know who to contact with any questions or concerns when you are at home. Your healthcare team should discuss this with you before you leave hospital. But it is also a good idea to go through it with the people close to you so they know what to do if there is a problem or emergency. Who you should contact in an emergency will vary depending on where you live and your situation. You will be told who to contact before you leave hospital.
- Write down any important phone numbers and contacts. Make sure everyone knows where to find them. Save important numbers in your mobile.
- You, or someone close to you, can ring the hospital ward for advice at any time, day or night. Some hospitals have patient helplines you can ring. Never be scared of worrying them unnecessarily as they are there to help you.
- Your GP and community team (if there is a local team available for your age group) should have been told that you are going home. They will be jointly responsible for your care when you are out of hospital.
- If problems happen and you were treated a long way from home, you may be able to see a consultant at a local hospital. If necessary, they can arrange an emergency admission or get you back to the hospital where you were treated.
- It is useful to have information about other support groups and advisers, such as local Macmillan nurses, specialist social workers or helplines. Your specialist nurse, key worker or community nurse will have details of local groups. Many areas now have acute oncology services, which can help people with cancer in an emergency. You will be given their contact details.

After treatment

Are you the same person?

Everyone changes throughout their life, whether or not they have been affected by cancer.

You have been through a major trauma and faced things many young people have never even considered. But even though you have been treated for cancer, you are still the same person you were before. It is just that the illness has probably made you reconsider what is important in your life, and your relationships with others.

Sometimes cancer and its treatment can affect your psychological and emotional development. These effects could be positive or negative. For example, you might become more anxious than you were before, but you may also be more mature than other people of your age – and even many adults.

These changes can make it hard for you to fit in with your own age group. You may see things differently from other young people because of what you have been through.

Although cancer treatment is over, it is not easy to put the illness behind you. The emotional shock of having cancer can stay with you for a long time.

Your feelings after treatment

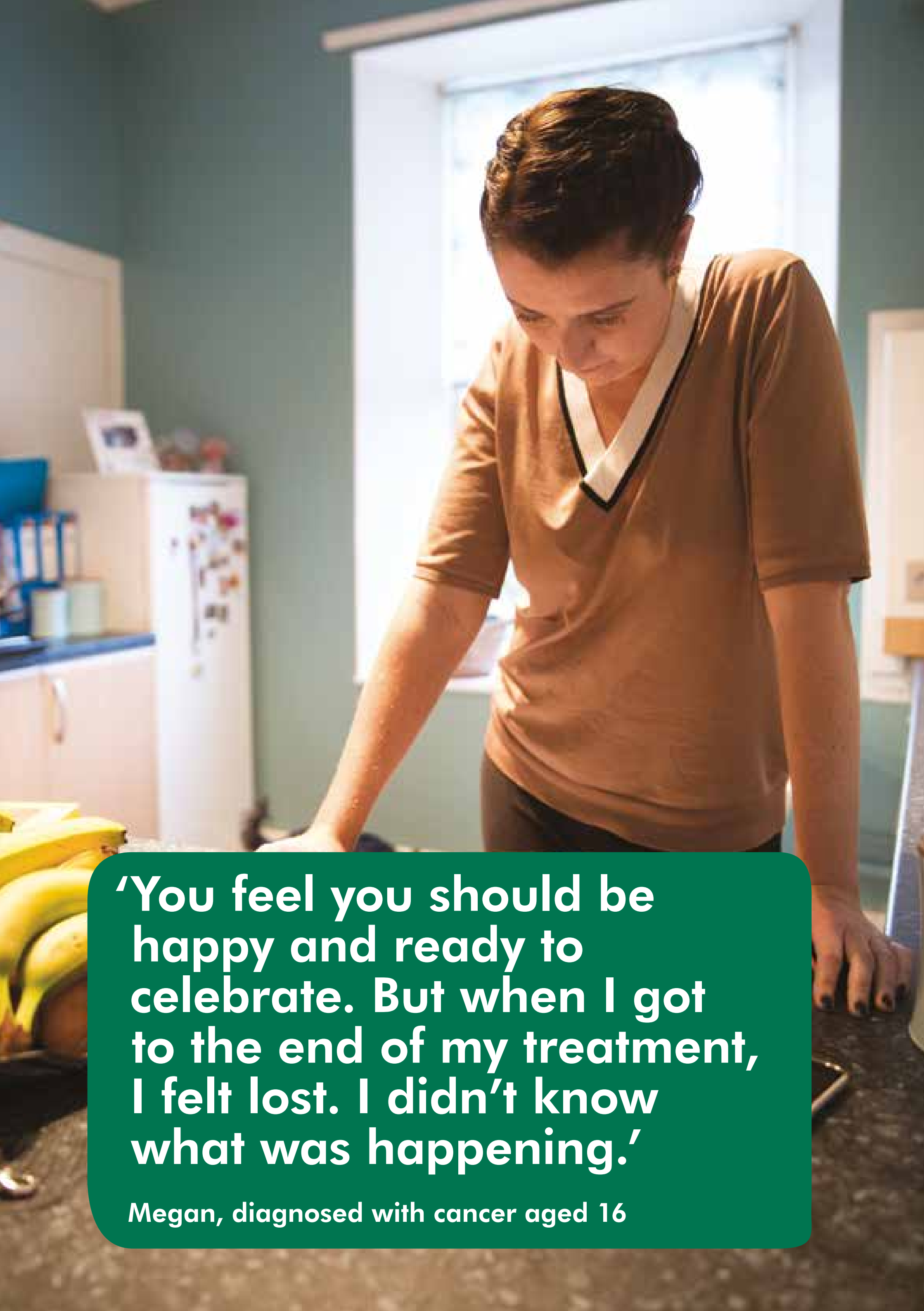
After treatment, it is common to feel a bit different. You might be relieved that treatment is over. Or surprised that your feelings are more complicated than you expected. You may feel sad, angry, lonely or uncertain. This might be because the cancer or its treatment has caused side effects or physical changes. Or it might be because your relationship with family, friends or colleagues has changed. There is no right or wrong way to feel.

Many young people talk about the anger they feel when the treatment is over. When they are dealing with the illness, they are too busy to be aware of it. But afterwards, they may feel angry about what has happened to them. Anger can stop you settling down and getting on with life. It is important to notice your mood – if you find yourself becoming frustrated, talk it through with someone you trust. Talking about your thoughts and feelings is the best way to make sense of them, and it will help you move on with your life.

Dealing with cancer and strong emotions can make you feel like you have grown up faster than your friends. But having experienced these things could help you in your relationships with people. For example you may have a different opinion on things or be able to deal with some situations better.

There may be times when you feel down. You may worry about the future and whether you will recover fully. Remember, most young people who have had cancer get better and go on to achieve the things in life they want – like having a career, getting married or having children.

You might find our booklet **How are you feeling? – The emotional effects of cancer helpful**. This information is written for all age groups. Visit **be.macmillan.org.uk or** call **0808 808 00 00** to order a free copy.



‘You feel you should be happy and ready to celebrate. But when I got to the end of my treatment, I felt lost. I didn’t know what was happening.’

Megan, diagnosed with cancer aged 16

Support groups

Joining a cancer support group is a good way of keeping in touch with other young people who have been through similar experiences. Even if you don't always go to meetings, it is useful to know there are people you can talk to. You might not feel ready to go along right now, but it is good to know you can go later if you want to.

Travelling after treatment

When your treatment is over, you might want to have a break and go on holiday. Even though you have had cancer, you can still travel abroad. You will just have to plan a bit more carefully.

It is a good idea to talk to your doctor or nurse before you book a holiday, because there might be things you need to think about. For example, if you have had radiotherapy or certain medicines, your skin might be more sensitive to the sun. This means it is even more important to protect your skin from the sun (we have more information in our booklet **Travel and cancer**).

Where to go

If you have had high-dose treatment with stem cell support, you will have to think carefully about which countries you go to. This is because you need vaccinations before visiting some countries, and there are certain live vaccines that you might not be able to have.

You should also think carefully about going to a country where there is malaria. Malaria can be very dangerous if you have had:

- your spleen removed
- high-dose treatment with stem cell support and total body irradiation.

Anyone visiting a country where there is malaria is advised to take full malaria precautions. Your doctor can give you advice about this. There are also specialist travel clinics that give health advice to travellers.

Before you travel

If you need to take medicines with you, for example strong painkillers, you might need to get a letter from your doctor so you can go through customs without any problems. You should also get a letter from your doctor if you need to take needles and syringes.

Sometimes people who have had cancer find it harder to get travel insurance, and they may have to pay more. But it is important to make sure you get travel insurance so if you are ill while you are away, you will be covered. We have more information in our booklet **Travel and cancer**. Call us on **0808 808 00 00** or visit **be.macmillan.org.uk** to order a free copy.

The Foreign and Commonwealth Office has information for people with disabilities and conditions like cancer about travelling abroad. There is also information on the website **gov.uk**

SCHOOL, WORK AND MONEY

Letting school, university or work know

It is important that your school, university or work knows about the cancer. They need to know the effect that the cancer and its treatment has had on you. It will also help if they know about any particular needs you may have. You, or an adult who is close to you (like a parent or carer) should get in touch with school, university or work to talk this through.

You may be able to get support from a CLIC Sargent care professional. They offer support with any issues that happen at your work or university. For example, they may talk to your employer about taking leave or reducing your working hours during treatment. Find out more at **clicsargent.org.uk/content/support-16-24-year-olds**

Going back to school, university or work

During treatment, you may need to have some time off from school, university or work. You may be able to return to school, university or work between treatments. If that isn't possible, once your treatment is over and you are feeling well again, you may want to get back to your normal life.

You may be anxious about mixing with people your own age again. You may worry about how friends who haven't seen you for a while will react, particularly if you look very different.

It is a good idea to try to meet up with your friends either at home or somewhere where you feel comfortable, before you go back to school, university or work. You could invite them round or go out together. It will give you confidence and make sure there are friendly faces around you when you go back to your normal routine.

Talking to teachers or employers

Teachers and employers may not know very much about your illness. Most of them will be supportive, but attitudes can vary, and sometimes people don't know enough about your situation. You will need to be clear about your needs. Don't assume that your teachers or employers understand or know anything about cancer, because this can lead to misunderstandings. For example, some teachers may get annoyed about pupils wearing hats, without realising this may be a way of dealing with hair loss. Explaining this beforehand can usually avoid any problems.

If you are going back to school, the school nurse should be able to support you and help you talk to staff about anything you need.

We have information for teachers and schools that might be helpful. You could show them our web page If a young person in your school has cancer. The information may help them to support you or other pupils with cancer at your school or university. Go to **macmillan.org.uk/information-and-support/resources-and-publications/information-for-teachers-and-schools/advice/young-person-has-cancer.html**

Bullying

Bullies pick on people who are different to them. If you are being bullied because you have cancer, or because of your cancer treatment or appearance, it is important not to blame yourself. Talk to someone about it. Tell your school. Perhaps they could arrange to teach a lesson about cancer. This may help your classmates and teachers understand more about your situation.

Your rights at work

If you are going back to work, tell your manager in advance. You can talk to them about any needs you may have and the best way to return.

If you are a member of a trade union, you could also contact your representative. If you work for a large company, there should also be an occupational health nurse who can help you deal with any issues you may have.

Sometimes it is hard to go back to work again. But if you have or have had cancer, you are protected by law from unfair treatment at work. It is illegal for an employer to treat you less favourably (discriminate against you) because of your cancer.

We have more information about your rights at work in our booklet **Your rights at work when you're affected by cancer**. This information is written for people of all age groups. Call us on **0808 808 00 00** or visit **be.macmillan.org.uk** to order a free copy.

Getting career advice

If you would like to get a job, change jobs or do a course, you could speak to a careers adviser. There are different career advisers depending on where you live in the UK:

- In England, if you are aged 13 or over, you can call the National Careers Service helpline for young people on **0800 100 900**. You can also chat with their advisers online at **nationalcareersservice.direct.gov.uk**
- In Scotland, contact Skills Development Scotland by calling **0800 917 8000** or visit **skillsdevelopmentscotland.co.uk**
- In Wales, contact Careers Wales by calling **0800 028 4844**, or chat with their advisers online at **careerswales.com**
- In Northern Ireland, contact the Careers Service NI on **0300 200 7820** or visit **nidirect.gov.uk/contacts/contacts-az/careers-service**
- Explain about the cancer, and tell them what kind of work or study you might be interested in. If they help you find a job placement, they will also advise you on the best way to tell employers about your medical needs. They can also give you information on courses, including less academic but more work-related qualifications like NVQs, Key Skills, AVCEs and BTECs. If you are aged 19 or over, you will be able to get help and guidance from your local Jobcentre. Visit **los.direct.gov.uk** for details of your nearest branch.

Financial help

Living with cancer can be expensive. There may be extra costs from things like travelling to hospital, and you may have to stop working for a while. Some people may have financial support from their family, but others may not.

If you are unable to find work or are struggling with money, you may be able to get benefits. Benefits are payments from the government to people in need. You can find out more about benefits by calling our cancer support specialists on **0808 808 00 00**. You can speak to one of our welfare rights advisers, who can tell you about benefits and help you apply for them. They can also provide details about organisations that can give financial help to young people with cancer.

We have information about benefits on our website.
Visit **macmillan.org.uk/benefits**

You can also call Citizens Advice or visit **gov.uk** (if you live in England, Scotland or Wales) or **nidirect.gov.uk** (if you live in Northern Ireland). Your social worker can help you make an appointment with a benefits adviser or Citizens Advice worker.

> ‘I’m an independent person, I like to earn money and fend for myself. So when I had to stop working, it was hard not knowing what money was coming in. It took a while to get back to normal.’
>
> **Jessica, diagnosed with cancer aged 16**

Student loans and tuition fees

If you were at university during your treatment, you may have had advice from the university's disability or financial advice team. They will be able to keep helping you, even if you haven't spoken to them for a while. If you needed time off because of treatment, they should be able to help you get funding for when you to come back.

As a student who has had cancer, you may be entitled to benefits. You can call the Disabled Students Helpline on **0800 328 5050** to talk to someone about the different options available.

Mortgages and insurance

Living with cancer might make it difficult to pay for housing costs. This may be because you have had to stop working for a while, or because you need to spend more money on heating and other bills.

There are things you can do and help that is available if you are struggling. For example:

- If you have a mortgage and are struggling to make the repayments after treatment, your mortgage lender may be able to give you a mortgage holiday or stop your repayments for a few months.
- If you are thinking about buying your first home, you might find it useful to get a broker to help. It can sometimes be harder to get a mortgage or insurance if you have had cancer.
- If you are finding it difficult to pay rent, you may be able to get Housing Benefit from your local council or housing executive to help with payments.
- You may also be able to get extra payments from the council to help with your council tax.

For more information about help with housing costs, call the Macmillan financial guides on **0808 808 00 00**.

Questions you could ask about school, work and money

Here are some questions you might want to ask your clinical nurse specialist, oncology outreach nurse, social worker or a benefits adviser.

- How can my school, or university support me?
- How much should I tell my school or university about the cancer?
- What will happen if I need to take time off from studying?
- What will happen if I need time off work?
- What are my rights at work?
- Can I get help with looking for a job?
- Can I get benefits or financial help if I am having money problems?

GLOSSARY

Medical terms

Anaesthetic

An anaesthetic helps make people more comfortable during a medical procedure. A general anaesthetic puts a person to sleep for a while. A local anaesthetic will numb a part of the body so the person cannot feel anything.

Benign

Benign means not cancerous. Benign tumours usually grow slowly. They do not spread to other parts of the body.

Biopsy

A biopsy is a small sample of cells taken from the body. Doctors look at the sample to see if there are cancer cells there.

Blood count

A blood count is a blood test which measures the levels of the different types of blood cells in the blood. The three main types of blood cell are:

- red blood cells, which carry oxygen
- platelets, which help the blood to clot
- white blood cells, which fight and prevent infection.

Central line

A central line is a long, thin, flexible tube. It is inserted into a vein in a person's chest to give chemotherapy and other drugs. A Hickman® line is a type of central line.

Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. It can be given alone or with other treatments.

Consent

When someone consents to treatment, it means they agree to having it.

Diagnosis

A diagnosis is a description of the illness a person has.

Fertility

Fertility (see page 88) is the ability to have children.

Intravenous (IV)

This means being given into a vein. A person may have fluids or drugs given into a vein.

Lymphatic system

The lymphatic system helps to protect us from infection and disease. It is made up of fine tubes called lymphatic vessels that connect to groups of lymph nodes throughout the body.

Malignant

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

Metastasis

A metastasis is a cancer that has spread from where it started to another part of the body. A metastasis is sometimes called a secondary cancer.

Oncology

Oncology is the medical specialty that deals with cancer.

Paediatrics

Paediatrics is the medical specialty that deals with children.

Palliative care

Palliative care is treatment to help manage symptoms (for example, pain) when the cancer cannot be cured.

PICC line

A PICC line is a long, thin, flexible tube. It is put into a vein to give chemotherapy or other treatments. It usually stays in until treatment finishes.

Portacath

This is a long, thin, tube that is put in under the skin to give chemotherapy and other drugs. The tube is connected to a small box under the skin.

Primary cancer

A primary cancer is where a cancer starts.

Prognosis

A prognosis is what is likely to happen with someone’s disease in the future.

Prosthesis

A prosthesis is an artificial body part, used if that part of the body has been removed.

Radiotherapy

Radiotherapy uses high-energy x-rays to destroy cancer cells.

Surgery

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

Terminal

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

Tumour

A tumour is a growth or lump. It may be benign (not cancer) or malignant (cancer).

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 leaflets or booklets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

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

Online information

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

Other formats

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

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

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

Help us improve our information

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

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

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

Other ways we can help you

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

Talk to us

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

Macmillan Support Line

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

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

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

Information centres

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

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

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

Talk to others

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

Support groups

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

Online Community

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

The Macmillan healthcare team

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

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

Help with money worries

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

Financial guidance

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

My Organiser app

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

Other useful organisations

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

Support for young people affected by cancer

Cancer Fund for Children (Northern Ireland)

Tel 028 9080 5599
Email support@cancerfundforchildren.com
www.cancerfundforchildren.com
Provides support for children, and young people diagnosed with cancer and their families.

Children's Cancer and Leukaemia Group (CCLG)

Tel 0116 252 5858
Email info@cclg.org
www.cclg.org.uk
www.facebook.com/ChildrensCLG
A charity concerned with all aspects of caring for children with cancer. It produces lots of publications for young people and their families, which you can download from the website.

CLIC Sargent

Tel 0300 330 0803
www.clicsargent.org.uk
www.facebook.com/clicsargentuk
Provides clinical, practical and emotional support to help children and young people cope with cancer and get the most out of life.

Ellen MacArthur Cancer Trust

Tel 01983 297750
Email info@emcancertrust.org
www.ellenmacarthurcancertrust.org
Takes young people aged 8 to 24 sailing to help them regain their confidence as they recover from cancer.

Great Ormond Street Hospital for Children

www.gosh.nhs.uk/teenagers
Information for teenagers about what to expect when they come into hospital. Also has information for parents and carers.

JTV Cancer Support

www.jtvcancersupport.com
A website where young people with cancer can watch and upload videos about their experiences.

Little Princess Trust

Tel 01432 760060
Email
info@littleprincesses.org.uk
www.littleprincesses.org.uk
Provides free real hair wigs for children who have lost their hair due to cancer treatment. Also funds some research into cancer.

Managed Service Network (MSN) for Children and Young People with Cancer in Scotland

www.youngcancer.scot.nhs.uk
If you live in Scotland, this website has useful information about treatment centres in Scotland. It also has links to information from other organisations.

NHS.UK – Cancer Care Choices for Young People

www.nhs.uk/young-cancer-care
Information for young people about treatment options and what it's like being in hospital.

Teenage Cancer Trust

Tel 020 7612 0370
(Mon to Fri, 8.30am to 5.30pm)
www.teenagecancertrust.org
www.facebook.com/teenagecancertrust
Builds cancer units for teenagers and young adults in hospitals, and organises support and information services for patients, their families, schools and health professionals.

Teenage Health Freak

www.teenagehealthfreak.com

Provides reliable health information for teenagers.

Teens Unite

Tel 01992 440091

Email info@teensunite.org

www.teensunitefightingcancer.org

www.facebook.com/teensunitefightingcancer

Teens Unite is for young people aged 13 to 24 who have cancer. Runs regular fun days out such as concerts, football matches, and art and beauty workshops. Teens Unite provides ongoing long-term support for teens, whether they are undergoing treatment or in remission.

The Brain Tumour Charity

Tel 0808 800 0004

www.thebraintumourcharity.org/TYA

Has a service for young people living with a brain tumour. They can put people in touch with someone going through a similar experience and offer emotional and practical support from a dedicated Young Adult Worker.

Youth Cancer Trust

Tel 01202 763 591

www.youthcancertrust.org

Provides free holidays to people aged 14 to 30 who are living with cancer.

Youth Health Talk

www.healthtalk.org/young-peoples-experiences/cancer/topics

A collection of interviews with young people about their experiences of health or illness. You can watch videos, listen to audio or read interviews.

General cancer support organisations

Cancer Research UK

Helpline 0808 800 40 40
(Mon to Fri, 8am to 6pm)

www.cancerresearchuk.org

The leading funder of cancer research in the UK. Provides information about cancer, cancer care and clinical trials for new treatments.

Cancer Support Scotland

Tel 0800 652 4531
www.cancersupportscotland.org
Offers information and support for cancer patients, families, friends, and healthcare professionals. Runs a network of monthly support groups and also provides counselling and complementary therapies.

Maggie's Centres

Tel 0300 123 1801
www.maggiescentres.org
Located throughout the country, Maggie's Centres provide information about cancer, benefits advice, and emotional or psychological support.

Tenovus

Helpline 0808 808 1010
(Daily 8am to 8pm)
www.tenovus.org.uk
Provides a range of services to people with cancer and their families in Wales, including counselling and a freephone cancer helpline.

Cancer Focus Northern Ireland

Helpline 0800 783 3339
Email nurseline@cancerfocusni.org
(Mon to Fri, 9am to 1pm)
www.cancerfocusni.org
Provides a range of services to people with cancer and their families, including a free telephone helpline, which is staffed by specially trained nurses with experience in cancer care.

Financial advice and information

Citizens Advice

Provide advice on a variety of issues including debt, benefits, legal, housing and employment issues. Use their online webchat or find details for your local office in the phone book or by contacting:

England

Helpline 03444 111 444
www.citizensadvice.org.uk

Wales

Helpline 03444 77 2020
www.citizensadvice.org.uk/wales

Scotland

Helpline 0808 800 9060
www.citizensadvice.org.uk/scotland

Northern Ireland

Helpline 0800 028 1881
www.citizensadvice.co.uk

Money Advice Service

Tel 0800 138 7777
(Mon to Fri, 8am to 8pm and Sat, 9am to 1pm)
Email enquiries@moneyadviceservice.org.uk
www.moneyadviceservice.org.uk

Offers online, printed and telephone information and advice about money matters.

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 020 7654 8000
Email enquiries@phe.gov.uk
www.ncras.nhs.uk
Tel (Ireland) 021 4318 014
www.ncri.ie (Ireland)

Scottish Cancer Registry

Tel 013 1275 7777
Email nss.csd@nhs.net
www.isdscotland.org/Health-Topics/Cancer/Scottish-Cancer-Registry

Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel 029 2037 3500
Email general.enquiries@wales.nhs.uk
www.wcisu.wales.nhs.uk

Northern Ireland Cancer Registry

Tel 028 9097 6028
Email nicr@qub.ac.uk
www.qub.ac.uk/nicr

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

Disclaimer

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

Thanks

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

With thanks to Wiebke Appel, Consultant Clinical Oncologist; Julie Cain, Clinical Nurse Specialist; Heather Jinks, Macmillan Palliative Care Specialist Social Worker; Gavin Maynard-Wyatt, Teenage and Young Adults Lead Cancer Nurse; Helen Sanderson and Lorraine Wright, Teenage Cancer Trust Youth Support Coordinator.

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

If you'd like further information about the sources we use, please contact **cancerinformationteam@macmillan.org.uk**

Can you do something to help?

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

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

5 WAYS YOU CAN HELP
SOMEONE WITH CANCER

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

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

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

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

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

Call us to find out more

0300 1000 200

macmillan.org.uk/getinvolved

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £

(Please delete as appropriate)
I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support

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

Card number

☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Valid from ☐☐ ☐☐

Expiry date ☐☐ ☐☐

Issue no ☐☐☐

Security number ☐☐☐

Signature

Date / /

Don't let the taxman keep your money

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

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

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

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

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

Registered with FUNDRAISING REGULATOR

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

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

27530

This booklet is for young people living with cancer. We have written it for people aged 13 to 24.

The booklet explains what cancer is and how it can be treated. It also gives practical tips about coping with treatment, relationships and sorting out practical things like school, work and money.

We're here to help everyone with cancer live life as fully as they can, providing physical, financial and emotional support. So whatever cancer throws your way, we're right there with you. For information, support or just someone to talk to, call **0808 808 00 00** (7 days a week, 8am to 8pm) 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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CANCER SUPPORT
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