

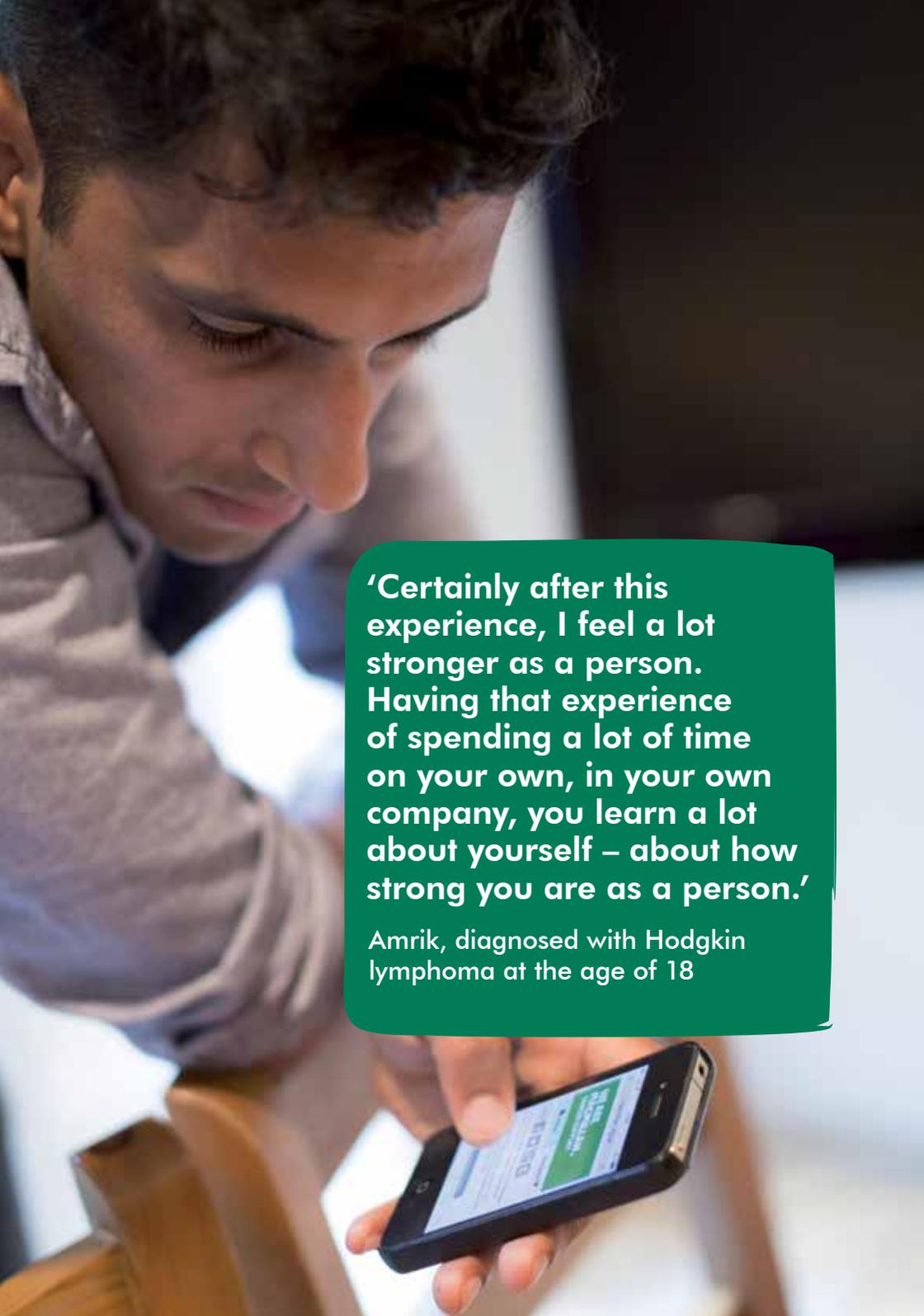
WE ARE
MACMILLAN.
CANCER SUPPORT

A practical guide to living with and after cancer

THE CANCER GUIDE FOR YOUNG PEOPLE

What to expect when you're affected by cancer





'Certainly after this experience, I feel a lot stronger as a person. Having that experience of spending a lot of time on your own, in your own company, you learn a lot about yourself – about how strong you are as a person.'

Amrik, diagnosed with Hodgkin lymphoma at the age of 18

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About this booklet

This booklet is about living with cancer. We've written it with people aged 12–25 in mind.

Finding out you have cancer is a huge shock for anyone, but it can be especially tough when you're young. You might be experiencing lots of different emotions.

Just remember that however you're feeling right now is fine. You may be scared, confused or going through other strong emotions. These are all perfectly natural responses.

But no matter what's going through your mind, you don't have to deal with everything alone. From medical staff to your family and friends, you're probably about to be offered more support, care and understanding than you've ever experienced before.

It's important to remember that cancer treatments are improving all the time. Most young people with cancer are treated successfully and get better.

'Cancer has changed my life dramatically but I don't think I would ever say I wish it wasn't me. I could name five positive things for every negative thing someone says as a result of having cancer.'

Amy

How to use this booklet

This booklet is split into different chapters:

- **Chapters 2–5** look at what cancer is and how it can be treated.
- **Chapters 6–9** give tips about dealing with your feelings and sorting out practical things.

You may not feel like reading this booklet from cover to cover. You can use the contents list to find the chapters that are relevant to you. Different chapters might be useful to you at different times.

Throughout the booklet, we've included some questions you might have when you have cancer. You could ask these to a member of your healthcare team, such as your doctor or nurse.

Being told you have cancer can feel overwhelming, but people often feel more confident and in control of their situation as they learn more about cancer. We hope this booklet helps you feel this way.

'I think the information from Macmillan allows you to take control of your life a little bit more. Just because you know what's going to come, you know what to expect. You can prepare for every eventuality.'

Amrik

Thanks

On some pages, you'll see quotes from other young people who have had cancer. Some of them are from young people who've chosen to share their story with us. Others are from the website **healthtalk.org** Some names have been changed.





WHAT IS CANCER?

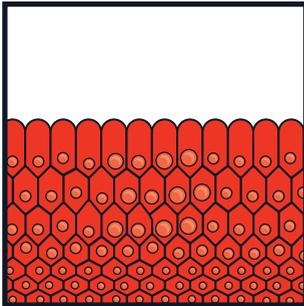
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What is cancer?

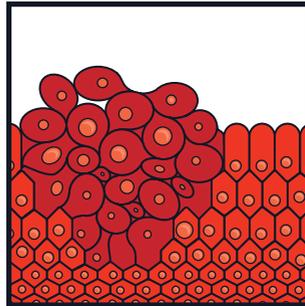
Our bodies are made up of billions of tiny parts that fit together like building blocks. These parts are called cells.

Healthy cells grow, divide and eventually get worn out and die. This usually happens all the time without any problems.

Cancer happens when this process gets out of control. Cancer cells divide too much and don't die when they are supposed to. They form a lump called a tumour. The tumour can damage the healthy cells surrounding it and this makes you ill.



Normal cells



Cells forming a tumour

A tumour can form inside:

- an organ (part of the body that has a special job, such as the liver or kidney)
- a bone
- the blood (when a tumour forms here, it is a type of cancer called **leukaemia**)
- a network that helps defend your body from disease called the lymphatic system (when a tumour forms here, it is a type of cancer called **lymphoma**).

Cancer cells from the tumour may spread to other parts of the body after a while. That's why having treatment as soon as possible is important.

There are more than 200 different kinds 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 in the body. 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 it happens to people. In your teens and 20s especially, it's something that can just happen without a reason.

One thing we know for sure is that cancer isn't a disease you can catch from another person – it isn't infectious.

Some young people worry that the cancer could be linked to things they've done – for example, smoking, drinking or taking drugs. But this is extremely unlikely when you're young.

Some cancers can be caused by inherited faulty genes. If this is the case, it's likely that other members of your family will also have had similar cancers in the past.

'First I was thinking, "Is it my fault? Did I do something wrong?". I kept on blaming myself. Then the doctors kept on saying, "It's just one of those things that happen. It's not your fault. You shouldn't be blaming yourself.'"

Raj

Questions you might want to ask about cancer

- Where is the cancer?
- How serious is it?
- What happens if it spreads?
- How does it spread?
- What caused the cancer?
- Is it inherited?





DISCOVERING YOU HAVE CANCER

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Some people are scared by it, while others don't even like saying the word. So being told that you have cancer is bound to be a shock.

Doctors will carry out a variety of tests to find out as much as possible about what's wrong with you. They'll want to find out the exact type of cancer and how far it has developed or spread.

This can involve lots of waiting for appointments and results. Sometimes it can seem as though it's going on for so long that you begin to lose touch with your normal life. If you're feeling well enough, try to carry on with things you enjoy, such as playing sport, going to the cinema or just chatting to your friends.

'It's something you just don't think would happen at such a young age. Naively I thought cancer was something that only older people get.'

Amrik

Wondering what to say to people

You may wonder what to say to people. It might be tough to tell them what's happening, but you have nothing to hide. You could just say that you're waiting for tests and results, but that you're trying to get on with life as normal.

If you're at school or university, it's a good idea for you or your parent(s) to talk to staff about your situation. If you're concerned about your health, it can be hard to perform well in coursework or exams, so your teachers need to know what's happening.

If you're working, you may feel unsure about what to tell your employer. Again, it can help to be honest at this stage, especially if you need to take time off for hospital appointments.

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

See the A–Z of who does what on pages 110–114.



We can send you more information about work and cancer. Just call our cancer support specialists on 0808 808 00 00 or go to macmillan.org.uk/work

Finding out more

Finding out why tests are being done and what they will involve can help you feel more prepared. Hospital staff should explain any test you're having. But if you're unsure about anything at all, just ask. If you're worried that a test may be uncomfortable, don't be afraid to ask whether anything can be done to make it easier. The staff 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 hesitate to speak up, even if it feels awkward. They'll understand what you're going through, and will do everything they can to help.

When the test results come back, you can ask to see the scans or x-rays, which will show you where any problems are. If you think it would help, you could even ask your doctor to draw you a picture or diagram so that you can get a better idea of what's happening in your body.

'A lot of the time they spoke to my parents rather than speaking to me first. But then when they gave me the diagnosis the doctor spoke to me personally and that really helped. I didn't want people to be sparing me.'

Olivia

Your feelings

Finding out you've got cancer is never easy, and it can be hard to take in everything you're told. It can help to have someone you trust with you, such as a family member or close friend. They can provide support and be there to talk things through with you.

Some people wrongly assume that getting cancer means they're going to die. But the number of people who are successfully treated and cured is increasing. Many of the cancers that affect young people react the most positively to treatment, so most young people with cancer are cured.

Doctors are discovering more about cancer and how it can be overcome all the time. They know a lot about stopping the effects of cancer on your body, which makes it easier for you to carry on with your normal life. Cancer doesn't always cause pain, but when it does, doctors and nurses can control the pain and help you feel more comfortable.

Sometimes it's hard to be open with the people closest to you. You may be scared of upsetting or frightening them with your feelings. If it feels easier, you can talk to a doctor, a nurse, or any member of the team caring for you. Talking about your feelings with an experienced listener can be helpful. You can also call our cancer support specialists on **0808 808 00 00**.



Having scans

Lots of people feel nervous about having a scan. There are a number of different types of scan, including ultrasound, CT, MRI and PET scans.

An ultrasound scan is usually very simple and completely painless. It involves having a kind of microphone gently rubbed over the skin of the part of your body that's being examined. CT, MRI and PET scans usually involve lying very still in a small space. There can often be a lot of humming and mechanical noise going on around you.

Having a scan may not be very relaxing, but it's a vital part of getting your diagnosis right so that you can receive the treatment you need. It definitely doesn't hurt.

If you're nervous, which is understandable, you may find it helps if you can have a look at the scanning machine beforehand. Just ask one of the nurses at the clinic or on the ward about it. They may also be able to introduce you to someone who's had a scan recently. You might find that just chatting about the experience helps reassure you.

If you find it hard to stay calm, it's sometimes possible to have a pill or an injection to calm you down before having the scan. You'll still be awake but very woozy and unlikely to remember much about it afterwards.

'You would just lie there in the PET scanner and go to sleep if you want to and it's totally painless.'

Andrew



GOING INTO HOSPITAL

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Which doctors will you see?

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

As soon as your GP thought something was wrong, they would have referred you to a specialist at the hospital, or at a teenage cancer unit if there's one in your area.

There will be one very experienced 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's happening.

For a full list of the healthcare staff you might meet in hospital, see the glossary at the back of this booklet.

Which hospital will you go to?

This will depend on:

- your age
- the nearest hospital with the best facilities for your illness
- the consultant you were referred to by your GP.

Each consultant works in a particular hospital, or sometimes a group of hospitals. To be under their care, you'll need to become a patient at one of these hospitals.

If you're under 19, you should be treated in a specialist centre called a **principal treatment centre**. There are principal treatment centres in every UK country. You can search for your nearest one on the CLIC Sargent website at clicsargent.org.uk/in-my-area/principal-treatment-centres

If you're aged 19–24, you should be offered the choice of being treated in a principal treatment centre that specialises in the care of young adults, or an adult ward that has been approved to treat your age group. You can read more about your choices at nhs.uk/young-cancer-care

If you are over 25, you will usually be treated on an adult ward.

What facilities are there for young people?

This depends on where you live. There are now special units for teenagers and young adults in some places. Eventually, there should be one in every area of the UK, but they aren't everywhere yet.

You can see how many there are so far and where they are on the Teenage Cancer Trust website at teenagecancertrust.org/get-help/how-we-can-help/our-units

If there is a special unit near you, it means you'll be with other people of your own age. You'll 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.

If there isn't a local special unit for young people, then you'll be well looked after on either a children's or an adults' ward. Your consultant or specialist will involve you in this decision as much as possible.

Where possible, you should have some say in which part of the hospital you'll be in, unless you're admitted as an emergency patient. Your doctor or specialist may have their own suggestions, but you can still ask to see the other options and make your own decision.



What's hospital like?

If you've never been in hospital before, you might be surprised by what it's like. Of course you're there because you need care and treatment, but that doesn't mean you'll just be lying in bed all the time.

There will be different facilities available, depending on which part of the hospital you're in.

There might be a day room, where you can watch TV and chat to friends, and maybe a kitchen where you can make yourself drinks and snacks. Some young people's units have rooms with computers, internet access, games consoles, music and DVD players.

Wards vary in size – there may be a lot of beds, or only a few. There may also be a few individual rooms available for you to stay in during a particular part of your treatment. You might also find these rooms useful if you're feeling unwell and need some peace and quiet.

'It was quite enjoyable – it didn't feel like a hospital. It was like walking in to a teenager's bedroom because you're surrounded by people your age. So you start losing your hair and everyone looks the same, but they're all bubbly, they're all your age, you're always around people you can talk to.'

Alistair

How to make hospital life easier

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

Being on a ward with other people can take a bit of getting used to. It often means having to fit in with everyone else's mealtimes and sleep patterns. It can also feel a bit weird to suddenly lose your privacy if you're used to having your own room at home. At the same time, you'll understandably be worried about your illness and wondering what's going to happen.

However you find your time in hospital, there's plenty you can do to make your stay better. Here are some tips from young people who've been through the experience:

- You may have your own room, or just a curtained cubicle on a ward. But do everything you can to make the space your own. Take in cuddly toys, posters of your favourite band, photos of your dog, or anything special to you. Sometimes you can take your own duvet in too.
- You can close the curtains around your bed whenever you like. There are bound to be times when you want to be on your own, and you have a right to do that.
- Take in a smartphone, tablet, or a hand-held games console – anything that will keep you entertained. Maybe you could borrow things from friends and family, such as a portable DVD player and films you haven't seen before. And take lots of books and magazines. Again, ask your friends and family to bring in new ones to swap.

- Unless you're having tests or need to stay in bed, you'll be able to wear your everyday clothes in hospital. Make sure you pack things that are comfortable and make you feel good. A hat or bandana could also come in useful (see pages 65–66). And if there's anything you've forgotten, ask your family to bring it in.
- Read the A–Z of who does what in hospital on pages 110–114. The more you understand about what's going on, the more relaxed you'll feel.
- You should have chances to get to know the other young people in the hospital. You may even be able to go out of the hospital with friends or family sometimes – just check with the staff on the ward first.
- Hospital meals never quite seem to match home cooking. If you feel like a change, ask your family and friends to bring in food and drink. As long as you ask a member of the ward team, you could even go out to get a takeaway.
- If you're far from home, try to stay in touch through texting, social media, emails or writing letters. When it comes to what to say, make it clear that although you're in hospital you're still the same person as ever and that you want to stay in touch.
- 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 carry on with some work in hospital. If necessary, ask your parent(s) to talk to them about this.



Keeping in touch with friends

You may be feeling isolated in hospital. Your friends are likely to be aware of this, but may not know how to break the ice with you. Maybe you could take the lead. It's not always easy, but if you feel up to it, you could contact a close friend and invite them to visit. It might be a bit awkward to begin with, but they'll soon see that you're the same person you've always been.

As your confidence returns, you can arrange to catch up with other friends. Reconnecting with your social life should help you feel stronger.

The key is not to rush things. You may worry about missing out on things friends are doing, and this is understandable. Sometimes young people do drift from friends while they're having treatment, for example if they stop going to school for a while. But often if you have friends you're close to, you'll stay in touch and it won't take long to catch up.

'Young people can't understand what it is like to go through having cancer until it happens to you. Some of my friends just lost interest. I had a couple of friends who stayed with me through everything and I am very grateful for that.'

Lillie

After you've had treatment, it's common to feel a bit different. Dealing with cancer means you often have to face some strong emotions. This can leave you feeling like you've grown up faster than your friends. As long as you see this as a positive thing, you could find it helps you in terms of dealing with friends, both new and old.

So for now, take one step at a time. You'll need to focus on your recovery first. You can still keep your social life going by inviting people to visit and staying in touch by text, email or social media sites like Facebook or Twitter.

If you use social media, we've listed the Facebook pages of some organisations for young people with cancer on pages 129–131. You could also visit **itvcancersupport.com** – a website for young people with cancer, which lets you upload and watch video blogs.

'At first I think my friends found it quite difficult to talk to me because they weren't sure what sort of reaction I'd give – if I'd want to talk about it or if I'd want to change the subject.'

Jack

Asking questions

When you're nervous or anxious, it can be hard to take in lots of information. Most doctors realise this, which is why your consultant will always check whether you have further questions. Even if you feel shy or embarrassed, they'll recognise how important it is for you to find out what's going on in words you understand. One way to make sure you get the answers you want is by writing down your questions in advance.

If it helps, when you see your consultant you could ask them to write down the important points for you. They may even recommend a leaflet or DVD about cancer treatment that answers your main concerns. Remember that you can ask as many questions as you like. This is your body and you have a right to know what's happening.

'It is important to feel that you can ask questions. And I think if I went through it again I would ask a lot more questions.'

Matt

Questions you could ask about going into hospital

- How long will I have to stay in hospital?
- How long will my treatment take?
- What scans will I have?
- What are the hospitals like where I'll be having my treatment?
- Do I have a choice of where I'm treated?





TREATMENT

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Who's in charge?

Treatment will begin as soon as possible. Your medical team will put together a plan of action to treat the illness as best as they can.

The experience of having treatment is different for everyone, but it helps to know what you can expect.

Your consultant is in charge of your treatment. You may not see them every day, but you or your family can always ask for an appointment to talk to them.

You should also have a keyworker. This is a particular nurse who will keep in touch with you and provide any extra support or information you need. They may be a clinical nurse specialist – a nurse who specialises in a specific health condition.

You'll also be introduced to the nurses who will care for you on the ward. You should be able to talk to them about any worries you have about your cancer treatment. Whatever's on your mind, they'll be happy to listen and help.

You have a right to a full discussion and explanation of your illness and treatment. There may be times when you prefer to talk to the medical staff without your parent(s) being there. You can always ask for this if you'd like.

If you or your parent(s) feel it would be helpful, you may want to get another medical opinion. Either your GP or consultant should be willing to refer you to another specialist for a second opinion.

However, getting a second opinion may delay the start of your treatment. So you, your doctor and your parent(s) need to be confident that it will give you useful information.



The main types of cancer treatment

There are various types of cancer treatments available.

Your doctors will choose the treatment or combination of treatments that's most appropriate for you. They'll also explain why they have chosen that treatment.

Surgery

This means having an operation to remove a cancerous lump or tumour. This is usually done under a general anaesthetic. It usually means staying in hospital for at least one night and possibly longer, for example until the wound has healed. When the cancer is all in one place and surgery is possible, surgery is a very effective way of getting rid of it.

You may be worried about how you'll look and feel after surgery. See pages 60–71 for more information about coping with body changes.

It can be helpful to talk to someone who's had the same operation. Your doctor or nurse can usually arrange for you to do this.

Radiotherapy

Radiotherapy treats the cancer with high-energy x-rays. You lie still on a table while a machine directs the x-rays precisely at the site of the cancer. The treatment doesn't hurt. A while after the radiotherapy has finished, your skin may feel as though you have sunburn and it could be red and sore. But many people only have mild skin reactions.

Radiotherapy is often done as an outpatient treatment. This means you can go home after the session. A normal course of treatment would mean one radiotherapy session every weekday for up to about six weeks. You'll be told how to look after your skin to stop it getting too sore. Any discomfort will go away within six weeks of the treatment stopping.



Chemotherapy

This is a way of treating the cancer with a special mix of anti-cancer drugs. Different cancers respond to different drugs, and your doctor will prescribe the most effective combination for you. Chemotherapy is given in different ways, depending on which type of cancer you have.

It can be given as tablets or medicine, but it's often given into a vein (intravenously) in one of the following ways:

- A **central line** (also known as a skin-tunnelled catheter) is a long, fine tube inserted into one of the large veins in the chest. It saves you the hassle of injections and needles. It can stay in for weeks, months or even years if necessary. The line is visible. Central lines aren't suitable for everyone, but if it's not right for you, your healthcare team should tell you why.
- A **portacath** works in a similar way to a central line, but it looks very different. It's a dome-shaped device, about the size of a 10p coin, which is surgically fitted under the skin over the chest. Inside is a silicone bubble. You can have injections into this bubble. It leads to a tube underneath, which is inserted into a vein above the heart. Having a portacath isn't painful, and it isn't as visible as a central line.
- A **PICC line** is a flexible tube inserted into a vein, usually in your upper arm. The PICC line is then threaded along the vein into your chest.
- A **cannula** is a short, thin tube that your nurse or doctor will put into a vein in your arm or the back of your hand.

When any of these are put in, the area of skin will be numbed. If you are worried, talk to your healthcare team and you may be given a medicine to help you feel more relaxed and minimise any pain (a sedative).

Occasionally lines and ports become infected and need to be replaced. If this happens, you'll be given antibiotics straight away to treat the infection.

It usually takes several months to complete a course of chemotherapy treatment, with breaks between each session. Chemotherapy is sometimes given as an outpatient procedure. This means you may be able to live at home and travel to the hospital for treatment.

Other treatments

Different cancers respond to different kinds of treatment. Sometimes the same type of cancer can be treated in more than one way. You may even find there's someone else on your ward with the same type of cancer as you who's having a different treatment. Don't let this worry you. Just discuss it with your nurse or doctor and they'll help ease any concerns.

Sometimes people with either lymphoma or leukaemia need different types of treatment. These treatments still use chemotherapy and radiotherapy, but also involve the use of stem cells or bone marrow.

High-dose therapy with stem cell support

This treatment may be used if you need to have very high doses of chemotherapy (or sometimes radiotherapy).

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

The bone marrow is important because it's where all your blood cells are made. It contains blood cells called stem cells, which make all the blood cells your body needs.

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

Before you have high-dose treatment, some of your stem cells will be collected from your blood. You can have this done as an outpatient. The stem cells are then stored until they're needed.

Once you've had high-dose treatment, you're given your stem cells back as a drip (called an intravenous infusion). Then your body can make the blood cells it needs again.

Donor (allogeneic) stem cell transplant

Sometimes stem cells can be used from another person whose bone marrow is a good match for yours. The person most likely to be a good match is a brother or sister, but some people can be given stem cells from a person not related to them.

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

Bone marrow transplant

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



Side effects of treatment

The cancer treatments used today are the result of years of research, and they work better than they ever have before.

But because they're so strong, they can have side effects.

These may include:

- having less resistance to infections – this means you have to be careful not to catch other people's bugs (see pages 48–49)
- feeling extremely tired (fatigue)
- hair loss – this may be just the hair on your head, but could include your body hair, eyebrows and eyelashes (see pages 65–66)
- feeling sick or being sick
- achy, flu-like symptoms
- mouth infections and painful ulcers
- diarrhoea
- constipation
- weight loss – this can be quite sudden and dramatic
- irritated or sore skin on areas where you've had radiotherapy
- weight gain – this is often linked to a type of drug called steroids.

Most people who are treated for cancer have some side effects. But there are lots of ways that the medical staff can help.

For example, some types of chemotherapy can make you feel very sick. But you'll be given drugs before and during your chemotherapy that will greatly reduce the chance of any sickness and will help you feel better. It's important that you tell your medical team exactly how you feel, so they can find the combination of drugs that will work best for you.

Some side effects only happen with a particular chemotherapy drug or group of drugs. As there are lots of different chemotherapy drugs, your doctor should explain what to expect with the particular ones you're taking. If you have any questions, make sure you ask your doctor.



We can send you more information about the side effects of cancer treatment.

Most side effects clear up when treatment stops.



Managing infection

Chemotherapy and radiotherapy increase your risk of getting an infection. This is because they temporarily weaken your immune system (your body's defence system against illness).

In some cases an infection can quickly become serious, so it's important to act fast. As a rule, if you develop a high temperature when you've had chemotherapy, you'll need some antibiotics.

Call your hospital as soon as you've realised you have a high temperature. This may be over 37.5°C (99.5°F) or over 38°C (100.4°F) depending on the hospital's policy – follow the advice your chemotherapy team has given you.

You should also report any other symptoms, including:

- feeling unwell
- a fever
- an upset stomach
- a sore throat
- a rash
- earache

You should also let the hospital know if you've been in contact with someone who has chicken pox.

At the hospital, they will take a blood test, monitor your temperature, blood pressure and other vital signs, and possibly give you antibiotics. You may need to stay in hospital and be put in your own room (in isolation) so you don't catch anything else, and be monitored closely until you're better. For infections, you may be treated in your local hospital rather than a specialist cancer centre.

To reduce the risk of infection, you should:

- try to avoid people with colds or who are ill
- avoid crowded places, for example shopping centres, pubs, nightclubs and sporting venues
- wash regularly and properly using soap – especially your hands.

Complementary therapies

It's 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 do to help feel better, and for some people this includes complementary therapies.

Complementary therapies are treatments people can use alongside conventional cancer treatments, to help them relax and feel less stressed. There are many different types of complementary therapy – see pages 120–121 for more information.

Your kind of therapy

Here are some other suggestions for tackling the kind of anxiety often associated with cancer treatment:

- Listening to your favourite music, relaxation CDs, or podcasts can help you unwind.
- Writing and drawing are great ways to relieve anxiety and other bottled-up emotions.
- Trying out different hats, jewellery and make-up can help you feel more confident if you look different during your treatment.

You may have other ideas yourself. You can make a note of them on the page at the back of this booklet.

'I could put my thoughts down on paper in a visual form so I could offload some of the pressure that was on my head, which was very helpful.'

Brian

Do I have any choice in my treatment?

One of the big problems with suddenly becoming very ill is the feeling of being out of control. You're seeing all these doctors, nurses and specialists and everyone seems to be telling you what to do. They have your best interests at heart, but it's only human to feel like saying 'Hang on, don't I have any say in this?'

You should always be told of any decisions or changes made to your treatment plan. However, even the best doctor or nurse can forget to tell you, or they may assume you already know what's happening. If you're in any doubt, or if you don't understand what's happening, just ask.

Your doctors should involve you in discussing your treatment options. The final decision should always be made by you or your parent(s). This means your doctor should make time to explain what the treatment involves and any possible side effects, as well as answer any questions you may have.

Also be aware that treatment can't be carried out without your consent. Up until you're 16, you may need the written consent of your parent or guardian. If you're over 16, you can sign the consent form yourself.

If you aren't sure about agreeing to a particular type of treatment, you can always ask for more time to think about it. Talk to your doctor or one of your nurses about the issue. There may even be other young people on your ward who have experience of the same treatment, and they can give you an idea of what to expect. But remember that no two experiences of treatment are the same.

Even if it's an emergency situation and there isn't a lot of time to make up your mind, you can usually ask for a few minutes to think or talk to a nurse. Remember the hospital staff will always recommend what they think is best, but you still have a right to keep control over what's done to you.

Making choices

Whenever it's possible to choose between two methods of treatment, you should be given the options available.

The doctors should give you all the information they can to help you make your decision. Just be aware that often they can't offer you much choice, because they have to recommend the best treatment for your particular condition.

You might find it helpful to look online for information about treatment. But make sure you visit sites that you can trust, as there's a lot of incorrect and misleading information online. We've included examples of some good websites on pages 129–132.



Clinical trials

Huge advances have been made over recent years in cancer treatment, particularly for the kinds that affect young people. Today, many more people are cured than ever before.

Often there may be a new treatment available. Or sometimes a tried and tested treatment could be used in a new way with more effective results, such as giving a different dose of a drug over a longer or shorter period of time than usual. But to improve cancer treatment, clinical trials need to be carried out.

What is a clinical trial?

A clinical trial is a medical research study that compares an older treatment with a newer one. The aim is to find out whether the newer treatment works better. One group of people has the established treatment and the other has the newer one. The results are studied in terms of their benefits and drawbacks, such as side effects.

It's good to remember that any clinical trial is strictly controlled, and that what's best for you remains the top priority throughout. All trials will have been tested fully in the laboratory, and often on other people too.

In a clinical trial, certain rules have to be followed to avoid ending up with misleading results. For example, everyone in the trial must have a similar condition and situation. One of the most important rules is that the trial should not be biased in favour of one treatment over the other.

Some trials are 'randomised'. This means that the details of all the people taking part are fed into a computer, and their treatment is chosen at random from those included in the trial. This means there's an element of chance in it, but the trial will have been planned following strict guidelines. There must be very good reasons for believing that a new or different treatment may give better results than the usual one, although there can be no guarantee of this.

Clinical trials are reviewed every few months. It may become clear during a trial that one treatment is definitely better than the other. In this case, the trial will be stopped and the more effective treatment will be given to everyone.

How can I be sure it's the right choice to make?

You're bound to have questions if your consultant suggests that you take part in a clinical trial. They won't want you to feel under any pressure to join in, and they'll be happy to talk about any concerns you have. You might feel like it's basically an experiment, but if there's a chance that it could lead to improved results then it's worth considering.

You can't be entered into a trial without your written consent if you're over 16, or your parent or guardian's if you're under 16. No one is going to put you under pressure to enter a trial. If you decide to say no, it's not a problem, and you'll be given the best treatment available at the time.

Is it all worth it?

Finding out you have cancer can come as an enormous shock. Facing treatment might be just as difficult to take in, especially when you learn about the possible side effects. It's not surprising that some people wonder if it's worth the trouble and pain.

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

Amrik

Often, people start their treatment thinking that they'll take whatever happens in their stride. But the treatments themselves can make you feel ill, and most people find that there are times when they feel very down. When this happens, it's easy to lose confidence and hope. Sometimes it's tempting to shut yourself off and not talk to anyone. However, it's really important to talk about how you're feeling with the doctors and nurses, or with someone else you can trust. You could also call our cancer support specialists on **0808 808 00 00**.

Cancer treatment is tough, but with all the great advances that are happening, more and more people are being cured. This can't be true for absolutely everyone though, and nobody can give you a guarantee that treatment will be 100% successful. Learning to live with this uncertainty is one of the hardest parts of living with cancer. Even for those people who aren't cured, cancer can often be controlled for long periods with the right treatment. Today, advances in medicine mean doctors are learning more about improving the effects of the illness and helping people get the most out of their life.

Questions you could ask about treatment

- Can I have some time to think about my choices?
- If this treatment doesn't work, what will happen?
- What are the side effects of the treatment?
- What are the effects of steroid treatment?
- Will I feel sick?
- Is there anything I can take to stop me feeling sick?





COPING WITH CHANGES TO YOUR BODY

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Both cancer and its treatments can affect how you look. Sometimes this is temporary, such as losing your hair during chemotherapy. But even if you know some side effects won't last long, it doesn't necessarily make them any easier to deal with at the time.

Other changes may be more long-term, or even permanent, and coming to terms with looking different can be difficult. It can have an impact on your body image, which is the way you feel about your body.

That's why the most constructive thing you can do at this time is to find out what you can expect, and remind yourself that you're still the same person on the inside.

'I coped with the hair loss because I have never been a particularly girly-girl. So I cut my hair short beforehand and then I wore a lot of hats. If anything, it made life easier.'

Shelbee

How might my looks change?

Weight loss or gain

This is an issue for many young people with cancer. When you become ill, particularly if you start having chemotherapy, you may suddenly lose a lot of weight. Apart from leaving you feeling weak, it will also make you look different.

Some people with cancer are prescribed drugs called steroids and these can make you put on lots of weight very suddenly. This can be particularly hard to deal with if you've had weight problems in the past. You may be worried about what your friends will say or think. You can tell them that the change is temporary and is caused by all the drugs you're taking.

Tubes and drains

During chemotherapy, you may have a central line or portacath inserted into your chest or a PICC line in your arm. After surgery, you may need to have a tube or drain coming out of part of your body for a while.

Understandably, some people are scared by the thought of this. It should help you feel more confident if you ask questions, talk to your nurse and learn what the tubes are for and how to look after them. Most people get used to them very quickly.

Scarring of the skin

This often happens after surgery. 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're red and very obvious, but they do fade a lot with time. Sometimes after surgery you may also have stretch marks – narrow streaks where the skin has stretched. But these are usually not too noticeable and they fade over time.

There are often things you can do to make scars and stretch marks less visible, such as using camouflage make-up, which you can buy from high-street shops. Speak with your GP, or another health and social care specialist, if you'd like more information.

If you're feeling anxious or low because of scarring, speak to your healthcare team. If you want to, they can arrange for you to speak with a counsellor.

'I have struggled with my scar and it was only recently I felt confident to put myself out there in a bikini. That was a scary moment because I didn't want people to stare, but I felt better for it. It wasn't easy but I knew that young kids with cancer might look up to me and I was not going to let them down.'

Monique

Loss of a body part

Sometimes people might lose a part of their body. For example, people with bone cancer might have an arm or leg amputated. This is something that anyone would dread, but sometimes it's the only way to stop the cancer.

Surgeons always try to spare a limb if possible, for example by removing the part of the bone with cancer and replacing it with a prosthetic (artificial) part instead. But this is not always possible, and amputation of the limb or part of it may be necessary. The doctors will consider the best way to get rid of the cancer and tell you what options there are.

Even if the surgeons recommend amputation, your healthcare team will do everything they can to make sure you stay mobile after you've recovered from surgery by fitting you with a prosthetic replacement (a false arm or leg).



Hair loss

Some people having cancer treatment find that it doesn't affect their hair at all. However, chemotherapy and other medicines can affect the condition and growth of your hair. Some people find that their hair becomes thinner, and in some people it falls out completely. Some people wear a cold cap (a hat filled with a cool gel) for a while during chemotherapy to reduce hair loss.

Any hair loss from chemotherapy is almost always temporary. People who have surgery or radiotherapy may find they have areas where their hair doesn't grow back.

If your hair starts to fall out, you may prefer to have it cut short. It will grow back after treatment, but it can sometimes grow back a different colour or texture.

If you feel more comfortable covering up your hair loss, you can wear hats, scarves or wigs. Or you may prefer not to wear anything on your head. Do whatever feels right to you.

We can send you more information about coping with hair loss.

'I had bandanas I would wear, or a wig. However, I didn't wear anything in hospital because there were so many people with the same problem so I felt quite normal.'

Kirsty

Many hospitals offer a wig service. Your nurse or specialist should know where the service is, so feel free to ask.

You may be entitled to have 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 Princesses Trust (see page 130 for contact details).

You can even take a wig to a hairdresser to be styled. It's often better to get the wig as soon as possible, so you can match the style and colour to your own hair or just get used to wearing it before you need it.

Many people get a wig but then decide not to use it. If you do choose to wear a wig, it's best not to keep it on at night, as your scalp will benefit from being aired. Brush the wig regularly to prevent it becoming knotted. Wearing a wig in the summer can sometimes be hot and uncomfortable. A bandana or baseball cap can feel cooler and protect your head from the sun.

Hair loss can be a big deal to some people, and not to others. Healthcare professionals are aware of this and aim to provide all the support and advice you need. Sometimes, it helps to talk to other young people who have coped with hair loss.

'I decided to get a real hair wig, which was made exactly to fit me. It was great – I could just treat it like normal hair just like I had wished for.'

Kirsty

How can I cope with looking different?

Sometimes your family and the people around you may not understand how upset you are by worries about your body image. Their main concern is you getting better. This can mean that unless you tell them what's worrying you, they may not realise. But feeling unattractive and different from other people are big issues.

It may be okay in hospital, but if you're hoping to go back to school, university or work then you could be anxious about being laughed at, teased or even rejected because of your appearance. You might even think it would be harder to get a boyfriend or girlfriend, or that your existing partner might find you less attractive.

For many people in this situation, the temptation is to withdraw and keep quiet about what's on their mind. But in reality, most people will understand and want to help. Try to be open and honest. Give people a chance to remind you that your appearance can't change your personality – which is what makes a lasting impact on the people around you.

One way to restore confidence in yourself is by making an effort to stay in touch with friends. If you can arrange to see them on a regular basis, you'll have less time to let body image insecurities grow. Even just calling, texting or emailing can help you feel more confident about facing the world again.

It's also very important to express your feelings. This might not come naturally to you, particularly if you've always been told to be brave. Crying is one way of dealing with it, as it helps to release any tension and stress you're under. Another way is to simply talk things through with someone you trust.

You may also need to go through a kind of grieving process, particularly if you've lost part of your body. Some people find this makes them even more determined to follow their ambitions or goals, or encourages them to think of new challenges.

But if your treatment has forced you to review what you're able to achieve, it can come as a blow. Whatever the situation, if it's left you feeling low then it's vital to open up about it.

Talking to people about your feelings can really help. The key is to feel comfortable in the way you choose to do it. If you don't want to open up to your family or friends, you can always turn to the professionals in hospital. Social workers and counsellors are trained to listen and help you work through your feelings.

If there's no one around, or if you prefer not to discuss your worries face to face, you can always call our cancer support specialists on **0808 808 00 00**. You'll 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. See page 127 for details of Macmillan's online community.

Another way of letting out your feelings is to express yourself through writing, blogging, playing music, drawing or painting. You may not have tried to draw or paint in years, but many people rediscover the fun and enjoyment of art while they're in hospital. It's also a good way to let out anger and depression.

If you use social media and want to share how you're feeling, try the Facebook pages for CLIC Sargent, the Teenage Cancer Trust and Teens Unite (see pages 129–131).



Can I still have children?

During cancer treatment, it's common for both men and women to be infertile (unable to have children) for a while. This isn't always predictable though. For example, some girls' periods stop as a result of cancer treatment, but it's not necessarily a sign that they won't be able to get pregnant now or in the future. However, if you're sexually active, it's important to use a condom or other form of contraception, and to not assume that you or your partner can't get pregnant.

If you would like to have a child, it's not recommended that you or your partner try to get pregnant during or for a time after cancer treatment. If this is an issue, you should discuss it with your consultant.

Your doctor and specialist nurse can discuss fertility with you and arrange for you to talk to a fertility specialist, if needed.



We can send you a free copy of our booklet
Fertility – support for young people affected by cancer.

You can also contact the Teenage Cancer Trust for more information on fertility. See page 130 for contact details.

There is more information about sex and relationships on pages 94–95.

Questions you could ask about changes to your body

- How will my body change?
- Will I lose or put on weight?
- Will I lose my hair and, if so, when will it grow back?
- Can I still have children?





SCHOOL, WORK AND MONEY

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You may be able to return to school, university or work between treatments. Even if that isn't possible, once your treatment is over and you're feeling well again, you might want to get back to your normal life.

You may be anxious about mixing with people of your own age, particularly if you look very different. You may worry about how friends who haven't seen you for a while will react to your hair loss or change in weight.

It's 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 or work. Invite them round or go to the cinema together. It will give you confidence and ensure there are friendly faces around you when you go back to your normal routine.

'It was a very strange feeling going back to school. It was a bit of a shock to the system at first but I got used to it, particularly as my hair started growing back. It got better slowly.'

Jack

Letting people know

It's also important that teachers and employers, as well as your friends and colleagues, know something about the effect that the treatment has had on you, as well as any needs you may have. You or your parent(s) should get in touch with school, university or work before you go back and ask to talk this through.

Different reactions

Teachers and employers may not know very much about your illness. While most of them will be supportive, attitudes can vary, and sometimes people aren't well-informed. You need to be clear about your needs and shouldn't assume that they understand or know anything about cancer, because this can lead to misunderstandings. For example, some teachers get annoyed about pupils wearing hats, without realising this may be a way of dealing with hair loss. Explaining this beforehand can usually avoid unnecessary trouble.

If you're going back into education, the school or college nurse should be able to support you and help you talk to staff about anything you need.

You may find it helpful to read a booklet by the charity CCLG called *I have finished my treatment... what happens next?* This is for older children and teenagers. Contact CCLG for details (see page 129).



Work

If you're returning to work, tell your manager in advance. If you're a member of a trade union, then your representative could also be a helpful contact. If you work for a large company, there should also be an occupational health nurse who can address any issues you may have.

Sometimes it's hard to go back to work again. Some people can't return to their jobs and, sadly, sometimes employers make it difficult for people to continue working and attend hospital check-ups.

Careers advice

You can speak to different career advisers depending on where you live in the UK.

- In England, if you're 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/careers-service**

Explain about your illness and tell them what kind of work or study you might be interested in. If they help you find a job placement, they'll 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're 19 or over, you'll be able to receive help and guidance from your local Jobcentre. Visit **los.direct.gov.uk** or call **08456 060 234** for details of your nearest branch.

Financial help

Living with cancer can be expensive. It can mean paying for extra things, such as trips to hospital, and can reduce your earnings by making it difficult (or sometimes impossible) to work. You may have financial support from your family, or you may not.

If you're unable to find work or are struggling with money, you may be entitled to benefits (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**. They can put you through to 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.

You can also call Citizens Advice (see page 132) 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 also help you make an appointment with a benefits adviser or Citizens Advice worker. Some of them do hospital visits as well.

Questions you could ask about school, work and money

- How can my school/college/university support me?
- What will happen if I need to take time off from studying?
- What will happen at work if I need time off for treatment?
- Can I get help with looking for a job?
- Can I get benefits or financial help if I'm having money problems?





RELATIONSHIPS

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Any two people who communicate on a regular basis have a relationship, whether they are family, friends or partners.

Even if your little sister irritates you and all you ever do is shout at her, it's still a relationship. Communication isn't just about talking face to face. It's everything from a hug to a grunt, and from an email to a love letter.

It's natural to feel short-tempered and snappy when you're unwell, and it doesn't help if you're having steroid treatment, as that can also affect your mood. In the same way, parents, siblings, friends and partners can find it hard to handle the stress of the situation. They might also become irritable or short-tempered, and if you haven't been getting along well anyway then it can be a source of conflict.

Your relationship with your family

When someone in the family has cancer, it puts a big strain on everyone – especially in the way you relate to each another.

As a young person, you're probably going through the important but difficult stage of breaking away from your family and becoming an individual in your own right. This can lead to a communication breakdown. All teenagers have rows with their parents – it's part of learning how to negotiate and compromise. But this can also make it difficult to talk to people.

Sometimes you can't say what you want to the people closest to you. In the same way, if someone seems intimidating, like a head teacher or senior doctor, it can be hard to know how to relate to them.

Discovering you have cancer changes your life. All of a sudden, your focus shifts. At the same time, your treatment can take you away from home and put you in unfamiliar surroundings. You have to deal with lots of new people, like all the different hospital staff you meet. And because you may be feeling unwell and anxious, it can be difficult to cope.

Many young people with cancer, even if they're really self-confident before they go into hospital, find themselves feeling nervous. It can seem like they don't have any control over what's going on.

That's why understanding what treatments you're having – and why – can help you regain some of the control you need to feel confident in yourself.

Just be aware that you're not the only one affected by what's happening. Your family and friends are also under pressure, and this can put pressure on how they talk and act towards you. They may also have issues of their own, which can all combine to place a strain on your relationship.

'I think my diagnosis bought my family closer together and that way we coped so much better. Not just with the cancer, but also with everything else that was putting strain on us. It certainly made my dad give up smoking.'

Amy



How will my parent(s) cope with my illness?

Your parents will probably be really worried about you. They want to protect you and make you well, but they realise that they can't do that. So they feel out of control, which can make them frightened.

As a result, they may be overprotective. For example, they may tell you not to get too tired, or say you shouldn't go out with your friends, or nag you to eat your dinner. This can be really frustrating.

It helps if you and your parent(s) can get clear information and advice about what's safe for you to do, and about anything that you should avoid. For example, there may be times during chemotherapy treatment when you're particularly at risk of infection. During this period, it wouldn't make sense to be around anyone who's unwell.

Your nurses and doctors can give you the information you need, and it's a good idea if you can all talk it through together.

Sometimes parents were already having problems before the cancer. Without you being aware of it, they may have been disagreeing about money, work or other major things.

If this happens, you must remember that you're not to blame. Social workers and counsellors are familiar with these sorts of problems and can help your parents, as well as helping you.

How do I tell my parent(s) what I want?

As you get older, it's natural to want to feel independent. When you're ill, however, you do need your family's help and support – particularly at worrying times like receiving a diagnosis or when you feel really low during treatment.

You may find it hard to ask for or even accept that help, but try to remember that everyone needs to be looked after sometimes.

If you're scared of being smothered by affection, then explain clearly and calmly what it is you'd like from them. If you feel you need more time to yourself, just say so.

Parents aren't mind readers and although on the whole they're always trying to get it right, everyone gets things wrong sometimes. So give them some help.

Some young people with cancer are scared to talk to a parent about their real feelings because they're worried about upsetting them. They feel like their parents are putting on a brave face and trying hard to remain cheerful, and worry about raising the issue for fear of upsetting anyone. This is an understandable fear, but the people closest to you would generally much rather know the truth about how you feel.

Sometimes it can be hard to talk about serious and emotional things when you're sitting face to face, or when people are visiting you in hospital and you know they have to go very soon.

If you have the chance, it can be easier to talk about really important things when you're doing something else. Perhaps your mum is driving you to a hospital appointment or you're in the kitchen together clearing up. When the focus of attention isn't directly on you, it can be a lot easier to say what you really feel.

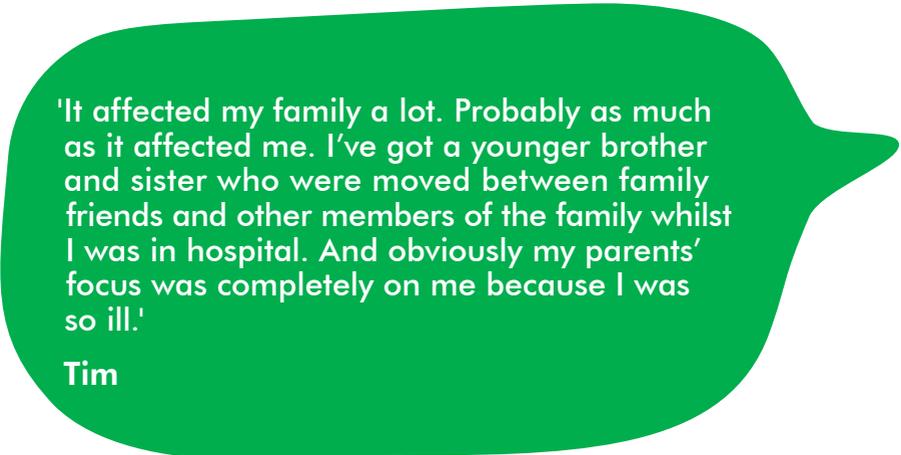
How does my illness affect my siblings?

It's natural for the person in a family who's ill to become the centre of attention – for a while at least. So it's no surprise that if you have brothers and sisters, they may be unhappy about this. They may be fed up that everyone always asks how you are before they say anything to them, and that your parents are spending a lot of time visiting you when normally they'd be home and available for the rest of the family.

These feelings can show themselves in many different ways. Your brother or sister may not want to visit you in hospital, or they may behave badly at home or school, or say spiteful things. This can be hard to take, but it can be a natural reaction. If your brother or sister behaves this way, it's important that you understand that they aren't doing it to be unpleasant or hateful, but just to show that they need attention too. If you want to help, make sure they know that there's support and advice available for them. For example, they can call our cancer support specialists on **0808 808 00 00**.

Or, you may find that your brother or sister is supportive and openly wants to be there for you. It just depends on your relationship with each other, your personalities and the situation. However they are acting, your sibling is probably worried about you and wanting you to get better.

If you have any problems with your relationship with your siblings, you may want to discuss them with your parents, together with a social worker, youth support coordinator or specialist nurse.



'It affected my family a lot. Probably as much as it affected me. I've got a younger brother and sister who were moved between family friends and other members of the family whilst I was in hospital. And obviously my parents' focus was completely on me because I was so ill.'

Tim

How will it affect my friends?

People often find that friendships become very strong and important while they have cancer. But it isn't always the friends you expect who give the most support. Sometimes even friends you've been close to can find it very difficult to deal with your illness.

It's partly to do with you not being at school, university or work, which means you miss out on what's happening and can be gradually left out of plans. But it's also because many people are so frightened of the idea of cancer. They may really want to come and visit you, but make excuses because they find the prospect hard to handle. Sometimes you can break the ice by making an effort to keep in touch with them, such as by texting or emailing them. The upside is that those friends who do stay in touch will probably always be really close friends.

'You can't share experiences at that age. I think that's the hardest thing – even though you're not consciously left out of things, you're forced to sit out on the sidelines. You can only look at photos on Facebook or hear bits and pieces of gossip here and there.'

Amrik



Making new friends in hospital

Depending on where and how you're treated, you may make new friends in hospital.

You may also be able to join special young people's support groups. Your nurse or the local Macmillan nurse will know about groups in your area, and you can see more suggestions on pages 126–132.

Talking to and emailing other young people with cancer can be really comforting. There's so much they'll understand without you having to explain it, and of course you don't have to worry about losing your hair or having off-days when you're with them. They know because it happens to them too.

Some of the friendships you build up in this way will be very close and last for a long time. But the sad reality is that some of the people you meet may die. This can be really hard to deal with if it happens. Remember there are people who can support you. It can help to talk with someone close to you about how you're feeling. You can also talk to health and social care workers, who could put you in touch with a counsellor if you'd like to speak with one. A counsellor is someone who's specially trained to help you cope with difficult feelings.

'During my treatment I made six really good friends. Unfortunately we lost two of them on our journey. I will always remember them for their courage and spirit, and it is them I always remember when times get tough.'

Amy

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 get started with new relationships 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. If your fertility might be affected (see page 70), you may worry that they won't be interested in you if you can't have children.

You may also worry about choosing the right time to tell them. Some people prefer to tell everyone straight away, while others prefer to wait. There's no right or wrong, but it can be difficult to decide how to handle it. It can help to talk it through with someone, such as a family member, friend or a professional.

Your sex life

For a number of reasons, you may feel that the time isn't right for a sexual relationship. If this is the case, it's completely fine.

You may have been in a sexual relationship before you became ill and be wondering how to cope now. Or you may even meet someone while you're ill or after your treatment.

Living with cancer doesn't have to stop your sex life. Sometimes continuing your sex life can help reassure you that, despite your cancer, the rest of your life goes on as normal. On some occasions during your treatment and recovery you may not feel like having sex, but a cuddle or comforting hug can still be very welcome.

Your partner may be worried that they'll hurt you or do you harm by getting too close. It's a good idea to try to talk about your feelings and discuss what changes may be necessary in your relationship while you're ill.

Most people find it hard to talk about personal issues such as sex, and many are embarrassed to raise the subject with medical staff. But doctors and nurses appreciate that sexuality is an important part of your personality and well-being, 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.

If you're using the contraceptive pill, your doctor may ask you to stop taking it before you have surgery or start chemotherapy or radiotherapy.

It's a good idea to use condoms during sex if you're having chemotherapy, and for a few days after the treatment is complete. This is because there's a possibility that chemotherapy drugs could be passed on. It's important to make sure your partner is safe.

It's also not a good idea to get pregnant, or to get your partner pregnant, while having chemotherapy. This is because the treatment may temporarily damage the sperm or eggs.

If you have any other questions, be sure to ask. Your doctor will understand and try to reassure you. For more information about sexual health and services that can help, speak to your GP, consultant or specialist nurse (CNS).



You may find it helpful to read our booklet *Sex and relationships for young people affected by cancer*.



GOING HOME

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All through your treatment, one of the things you'll have been longing for is the day you get to go home. But as this time approaches, a lot of people feel anxious or even scared.

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. In this situation, make sure your friends and family know you've returned home, so they can keep an eye on you. Speak to your social worker about getting a home helper if you need one.

You can connect with organisations both online and offline who'll understand what you're going through and offer support, guidance and further advice (see pages 126–132 for details).

'You have to go out into the real world and the real world is a scary place. I didn't want to be there. I had become used to living in that bubble and being surrounded by people who knew what to do. There was a structure there and that goes away, which is pretty scary.'

Olivia

Sorting out problems before they happen

Talking to your family 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're still in hospital. Start off by discussing the medical things and then go on to the emotional aspects, which are just as important. This is the time to bring up any concerns you have about people fussing too much or brothers and sisters having a go at you.

No one can protect you from this fully, but maybe you could agree that there'll be some space in the house where you can take time out when you've had enough of everyone. If you explain beforehand that this is a normal part of recovering from an illness, then people are less likely to get upset or sulk when you say you'd rather be alone for a while.

It's also important for you to understand that sometimes going home can be a bit of an anticlimax. You may have been looking forward to it so much that you expected everything to be fantastic, but in fact you quickly realise that everyone is going about their own business and you feel a bit left out.

Remember that you aren't fully recovered yet and you do need to rest – and that it's normal to feel down sometimes. Make an effort to get in touch with some close friends and don't be scared to keep in touch with friends you made in hospital too.



If you're going back home to your family

When you're ill, hospital can feel like a very safe place, and it's amazing how quickly you get used to it. Going back home can feel like having a lifeline cut away, and you're also suddenly surrounded by everyone else's problems and worries.

However, as long as everyone plans ahead for it and talks about any problems beforehand, going home should be a positive step towards getting on with your life.

When you lived at home before, it might have seemed as though nothing ever happened. But in most families, there's a natural flow of good moods, bad moods, friendship and rows. You'll have been protected from this in hospital, but now you're going to be in the middle of it all again.

Your parents will be anxious about you and may have their own fears about how well they can look after and protect you once you're home. You may find them fussing and nagging, and if you're feeling tired and a bit anxious, it's easy to fall out with them.

If you have brothers or sisters, they're going to have to get used to having you around again. If they haven't been happy about the attention you've been getting so far, it could be even harder for them once you're back home.

On top of this, you might also find it difficult to get any privacy. In hospital, at least you could close your curtains or go back into your room when you were tired, and people would know not to disturb you. That's not always as easy at home.

Managing on your own

Leaving the security of the hospital can sometimes feel scary. In hospital, there's always somebody around if you feel ill or worried. When you get home, suddenly you can feel like you're 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. You'll have been shown how to look after this in hospital 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. The coughs, colds and bugs that other people manage to shake off can sometimes be very serious for you.

The ward staff will warn you when you need to take particular care of yourself. They can also talk through with you how you're going to do it. Even so, there'll be occasions when you need to learn how to recognise signs of infection as well as who to contact if you're at all worried. The information about managing infections on pages 48–49 may help.



How to get help when you're at home

- It's important that once you get home, you have clear information about who to contact with any questions or concerns. Your medical team should discuss this with you before you leave hospital, but it's also a good idea to go through it with your parents and family so they know what to do if there's a crisis.
- Note down any important phone numbers and contacts. Be sure everyone knows where to find them. Save important numbers in your mobile.
- You or your family 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. They're there to help you.
- Your GP and community team (if one is available for your age group locally) should have been told that you're going home. They'll be jointly responsible for your care when you're out of hospital. But who you should contact in emergency will vary depending on where you live and your situation. You'll be told who to contact before you leave hospital.
- If problems arise, and you were treated a long way from home, it may be possible for you to see a consultant at a local hospital. If necessary, they can arrange emergency admission or arrange to get you back to the hospital where you were treated.

- It's also very useful to have information about other support groups and advisers, such as the local Macmillan nurse, specialist social workers or helplines. You'll find details of some of these on pages 126–132. Your specialist nurse, key worker or community nurse will also have details of other local groups. Many areas now have acute oncology services, which can help people with cancer in an emergency – you'll be given their contact details.



But am I still the same person?

Everyone changes through life, whether or not they've been affected by illness. Even though you've been treated for cancer, you're still the same person you were before. It's just that the illness has probably made you reconsider what's important in your life, and your relationships with others.

You've been through a major trauma and faced things many young people have never even considered. Sometimes cancer and its treatment can interfere with a young person's psychological and emotional development. On the one hand, they can become more anxious than they might have been before, but on the other hand they're often more mature than other people of their age – and even many adults.

This can make it hard to fit in with your own age group. It may mean you don't have patience with the day-to-day things that other young people get worked up and anxious about.

It would be nice to say that the cancer is over and you can put it behind you, but the emotional shock of such a severe illness can stay with people for a long time.

Many young people talk about the anger they feel when the treatment is over. At the time when they're dealing with the disease they're too busy to be aware of this, but afterwards they may feel furious about what's happened to them.

But anger can be a destructive force. It can stop people settling down and getting on with life. That's why it's so important to notice your mood and talk it through with someone you trust if you find yourself becoming worked up. Voicing your thoughts and feelings is the best way to make sense of them and it will let you move on with your life.

Moving on

Many people find that joining a cancer support group is a good way of keeping in touch with other people who share your experiences. Even if you don't go to meetings, it's useful to know there are people you can contact. Keep a list of their numbers. Even if you don't feel you'll go along right now, it's good to know you can go later if your feelings change.

There are bound to be times when you feel down, so don't forget that most young people who've had cancer go on to return to good health and achieve the things in life they want – including having a career, getting married and having children.

See pages 73–79 for more information about moving on with education and work.



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The A–Z of who does what

Benefits adviser

Can help people get money from the government if they need it. These payments are called benefits. Benefits advisers are sometimes called welfare rights advisers.

Clinical nurse specialist (CNS)/keyworker

A nurse who specialises in a particular illness. They may also be your keyworker. Your keyworker is a particular nurse 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 give people any medication they need. They are also called district nurses.

Counsellor

Someone you can talk to about your feelings and worries.

Dietitian

Someone who can help you with your nutrition.



20/10

Health and Social Care
Name Tag

HSC Health and Social Care



Doctors

You may meet the following kinds of doctors:

- A **consultant** is an expert doctor. They are in charge when you are given treatment in hospital.
- A **GP** is a local doctor. You may know this person already. They can help when you are out of hospital.
- A **haematologist** is a doctor who specialises in problems with the blood.
- An **oncologist** is a doctor who is an expert in cancer. They are trained to treat people with cancer.
- A **pathologist** is a doctor who tests the blood. They do this to find out what is wrong. They can also look at samples of cells under a microscope.
- A **radiologist** is a doctor who is specially trained to look at x-rays and scans. This helps them find out what is happening.
- A **surgeon** is a doctor who carries out operations.
- **University medical students** are people who are training to become doctors. They may come round with the qualified doctors who are treating you, so that they can learn about what happens.

Occupational therapist

Someone who can help you carry out everyday tasks or find new things for you to do while you're feeling unwell.

Oncology outreach nurse

A nurse who can see you at home and arrange activities, such as your return to school or university.

Pharmacist

Someone who gives out medicines that doctors have prescribed. They can also give advice about medicines.

Phlebotomist

Someone who takes blood samples.

Physiotherapist

Someone who can help you to walk or move around, if you have been having 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 (see photo on page 114). They also give radiotherapy treatment, which is planned by the radiologist.

Social worker

Someone who can help you and your family with money, work 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 coordinator

Someone who can arrange activities, and help you stay active and sociable after treatment. They are funded by the Teenage Cancer Trust.

Youth worker

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



Medical terms

Anaesthetic

An anaesthetic helps make people more comfortable. It can be a general anaesthetic, which puts you to sleep for a while. Or it can be a local anaesthetic, where you stay awake but part of your body becomes numb for a while.

Benign

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

Biopsy

A biopsy is where a doctor takes a small sample from the body. The sample is then checked under a microscope. This is done to see whether the cells are cancerous.

Blood count

A blood count is a type of blood test. It measures different types of cells in the blood. There are platelets, which help the blood clot if you have a cut or become bruised. Then there are red blood cells, which carry oxygen around the body. And white blood cells help defend your body against illness.

Cell division

Cell division is where cells divide in two – doubling their number each time. This is how living things develop and grow.

Central line

A central line is a thin, flexible tube. It is inserted through the vein near the heart for chemotherapy. One end stays outside the body.

Chemotherapy

Chemotherapy is a type of cancer treatment. It is where drugs are used to destroy cancer cells.

Consent

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

Cytology

Cytology is where individual body cells are examined in very close detail. This is very important in making a diagnosis.

Diagnosis

A diagnosis is a description of what disease someone has. When someone is diagnosed, it means the doctors tell them what is wrong.

Infertility

When someone is infertile, it means they can't get pregnant or make someone pregnant.

Intravenous (IV)

When a drug or fluid is given intravenously, it means it is given into a vein.

Hickman® line/Groshong® line

A Hickman line is a thin tube. It is inserted through the skin of the chest and into a vein, so that chemotherapy can be given. One end stays outside the body. A Groshong line is very similar to a Hickman line.

Lesion

A lesion is where body tissue has been damaged or changed, and it may or may not be cancer.

Lymphatic system

The lymphatic system is part of the body that defends against infection and disease.

Lymphoma

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

Malignant

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

Metastasis

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

Oncology

Oncology is the study and practice of treating cancer.

Paediatrics

Paediatrics is the medical care of children.

Palliative care

Palliative care is treatment that helps to reduce pain. It aims to meet the physical, spiritual, psychological and social needs of a person with cancer.

PICC line

A PICC line is a thin, flexible tube. It is put into a vein to give chemotherapy or other treatments.

Primary cancer

A primary cancer is one that starts in a single area of the body. Most cancers, other than leukaemias and lymphomas, are primary cancers. See also secondary cancer.

Prognosis

A prognosis is a prediction of how someone's disease is likely to affect them in the future.

Prosthesis

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

Radiotherapy

Radiotherapy is a type of cancer treatment. It uses high-energy x-rays to destroy cancer cells.

Scan

A scan is a computer-generated image of the inside of the body.

Secondary cancer

A secondary cancer is one that has spread to another part of the body.

Steroids

Steroids are a type of drug that can help treat cancer.

Surgery

Surgery means an operation to remove a cancerous lump or tumour.

Terminal

When a cancer is terminal, it means no more treatment can be given to control the cancer. This means the end of life is near.

Tumour

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



Complementary therapies

Complementary therapies are treatments people can use alongside conventional cancer treatments, to help them relax and feel less stressed. There are many different types of complementary therapy.

If you're thinking about trying one, it's important to talk it through with your consultant, doctor or nurse first. You need to be sure it won't interfere with your medical treatment.

Here is a list of popular complementary therapies that are unlikely to affect your treatment, but that can help you relax and feel more able to cope:

Acupuncture

Acupuncture is careful insertion of needle tips under the skin. Some people believe this affects the flow of energy in the body.

Aromatherapy

Aromatherapy uses natural oils from flowers, plants or trees. The oils are thought to have therapeutic properties.

Art and music therapy

Art and music therapy lets you express yourself through art and music to help you relax.

Massage

Massage relaxes the body and the mind.

Meditation

Meditation is a way of relaxing your mind and feeling calmer.

Reflexology

Reflexology uses pressure on the feet to stimulate pressure points around the body and improve well-being.

Reiki

Reiki is a hands-on, spiritual approach to restoring inner balance.

Relaxation

Simple breathing and relaxation exercises can help reduce anxiety and stress.

Sea bands

Sea bands apply gentle pressure to points on the wrists. Some people find this helps relieve nausea and sickness. They're available from your pharmacist.

Tai chi

Tai chi focuses on building strength, balance and flexibility through slow, fluid movements.

Visualisation

Visualisation uses the calming power of your imagination.

Yoga

Yoga is a combination of physical exercise and breathing control.

Some people benefit from complementary therapies like these, but they don't work for everyone. We all relax in different ways. What matters is that you know how to relax and recognise that it can help you deal with your illness.



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About our information

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

Order what you need

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

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

You can find lots of information written specifically for young people on our website at **macmillan.org.uk/cancerinformation/teensandyoungadults**

Other formats

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

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

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

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

Help us improve our information

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

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

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



Other ways we can help you

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

Talk to us

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

Macmillan Support Line

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

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

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

Information centres

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

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

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

Talk to others

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

Support groups

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

Online community

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

The Macmillan healthcare team

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

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

Mal

Help with money worries

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

Financial advice

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

Help accessing benefits

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

Macmillan Grants

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

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants. We can also tell you about benefits advisers in your area.

Visit [macmillan.org.uk/financialsupport](https://www.macmillan.org.uk/financialsupport) to find out more about how we can help you with your finances.

Help with work and cancer

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



Macmillan's My Organiser app

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

Other useful organisations

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

For young people affected by cancer

Children's Cancer and Leukaemia Group (CCLG)

University of Leicester,
3rd Floor, Bosworth House,
9 Princess Road West,
Leicester LE1 6TH

Tel 0116 249 4460

Email cclg@le.ac.uk

www.cclg.org.uk

facebook.com/ChildrensCLG

A network of hospitals that specialise in caring for children with cancer. You can download lots of publications for young people and their families from the website.

CLIC Sargent

Horatio House,
77–85 Fulham Palace Road,
London W6 8JA

Tel 0300 330 0803

www.clicsargent.org.uk

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

Units 53–57,
East Cowes Marina,
Off Britannia Way,
East Cowes,
Isle of Wight PO32 6DG

Email info@emcancertrust.org

Tel 01983 297750

Takes young people aged 8–24 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.

Headstrong – The Brain and Spine Foundation
www.headstrongkids.org.uk

Interactive website with information for children with brain tumours.

Little Princess Trust

28 Castle Street,
Hereford HR1 2NW
Tel 0845 094 4509

Email

info@littleprincesses.org.uk
www.littleprincesses.org.uk

Provides free, real hair wigs to children affected by hair loss due to cancer treatment. Also provides a personal fitting and styling service.

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

www.youngcancer.scot.nhs.uk/support-information

If you live in Scotland, this website has useful information about treatment centres in Scotland.

NHS Choices – 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

3rd Floor,
93 Newman Street,
London W1T 3EZ
Tel 020 7612 0370
(Mon–Fri, 8.30am–5.30pm)
www.teenagecancertrust.org
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
Reliable health information for teenagers.

Teens Unite

99 High Road,
Broxbourne,
Hertfordshire EN10 7BN
Tel 01992 440091
Email info@teensunitefightingcancer.org

**www.teensunite
fightingcancer.org
facebook.com/
teensunitefightingcancer**

Runs regular fun days out for young people aged 13–24 who have cancer and other illnesses. Provides ongoing long-term support for teens, whether they are undergoing treatment or in remission.

Youth Cancer Trust

Tracy Ann House,
5 Studland Road,
Alum Chine,
Bournemouth BH4 8HZ
Tel 01202 763591

Email admin@yct.org.uk

www.youthcancertrust.org

Provides free holidays to people aged 14–30 who are living with or beyond cancer and other illnesses.

Youth Health Talk

www.youthhealthtalk.org

A collection of interviews with young people about their experiences of health or illness.

**General cancer
support organisations**

Cancer Research UK

Angel Building,
407 St John Street,
London EC1V 4AD

Tel 020 7242 0200

www.cancerresearchuk.org

Has patient information on all types of cancer and has a clinical trials database.

Cancer Support Scotland

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

Tel 0800 652 4531

Email info@

cancersupportscotland.org

**www.cancersupport
scotland.org**

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

Maggie's Centres

2nd Floor Palace Wharf,
Rainville Road,
London W6 9HN

Tel 0300 123 1801

Email enquiries@
maggiescentres.org
www.maggiescentres.org

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

Tenovus

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

Tel 0808 808 1010

(Mon–Sun, 8am–8pm)

www.tenovus.org.uk

Provides a range of services to people with cancer and their families, including counselling and a freephone cancer helpline.

Ulster Cancer Foundation

40–44 Eglantine Avenue,
Belfast BT9 6DX

Helpline 0800 783 3339

(Mon–Fri, 9am–5pm)

www.ulstercancer.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 and work advice

Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues.

England and Wales

www.citizensadvice.org.uk

Scotland

www.cas.org.uk

Northern Ireland

www.citizensadvice.co.uk

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

Money Advice Service

Holborn Centre,
120 Holborn,
London EC1N 2TD

Tel 0300 500 5000

Email enquiries@
moneyadvice.service.org.uk

www.moneyadvice.service.org.uk

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

Disclaimer

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

Thanks

This 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, Tim Iveson, Macmillan Consultant Medical Oncologist.

With thanks to: Wendy King, Teenage and Young Adult Consultant Nurse; Heather Nicklin, Macmillan Palliative Care Specialist Social Worker; and Lorraine Wright, Teenage Cancer Trust Youth Support Coordinator. Thanks also to the people affected by cancer who reviewed this booklet, and those who shared their stories.

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Can you do something to help?

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

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



Share your cancer experience

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

Campaign for change

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

Help someone in your community

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

Raise money

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

Give money

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

Call us to find out more

0300 1000 200

macmillan.org.uk/getinvolved

Please fill in your personal details

Mr/Mrs/Miss/Other _____

Name _____

Surname _____

Address _____

Postcode _____

Phone _____

Email _____

Please accept my gift of £ _____

(Please delete as appropriate)

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

OR debit my:

Visa / MasterCard / CAF Charity
Card / Switch / Maestro

Card number

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Issue no

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Signature _____

Date / / _____

Don't let the taxman keep your money

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

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

I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax in each tax year, that is at least equal to the tax that Charities & CASCs I donate to will reclaim on my gifts. I understand that other taxes such as VAT and Council Tax do not qualify and that Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

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

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



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

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



This information has been endorsed by the Teenage Cancer Trust.

More than one in three of us will get cancer. For most of us it will be the toughest fight we ever face. And the feelings of isolation and loneliness that so many people experience make it even harder. But you don't have to go through it alone. The Macmillan team is with you every step of the way.

We are the nurses and therapists helping you through treatment. The experts on the end of the phone. The advisers telling you which benefits you're entitled to. The volunteers giving you a hand with the everyday things. The campaigners improving cancer care. The community there for you online, any time. The supporters who make it all possible.

Together, we are all Macmillan Cancer Support.

For cancer support every step of the way,
call Macmillan on 0808 808 00 00
(Mon–Fri, 9am–8pm) or visit macmillan.org.uk

Hard of hearing? Use textphone
0808 808 0121, or Text Relay.
Non-English speaker? Interpreters available.
Braille and large print versions on request.

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CANCER SUPPORT**