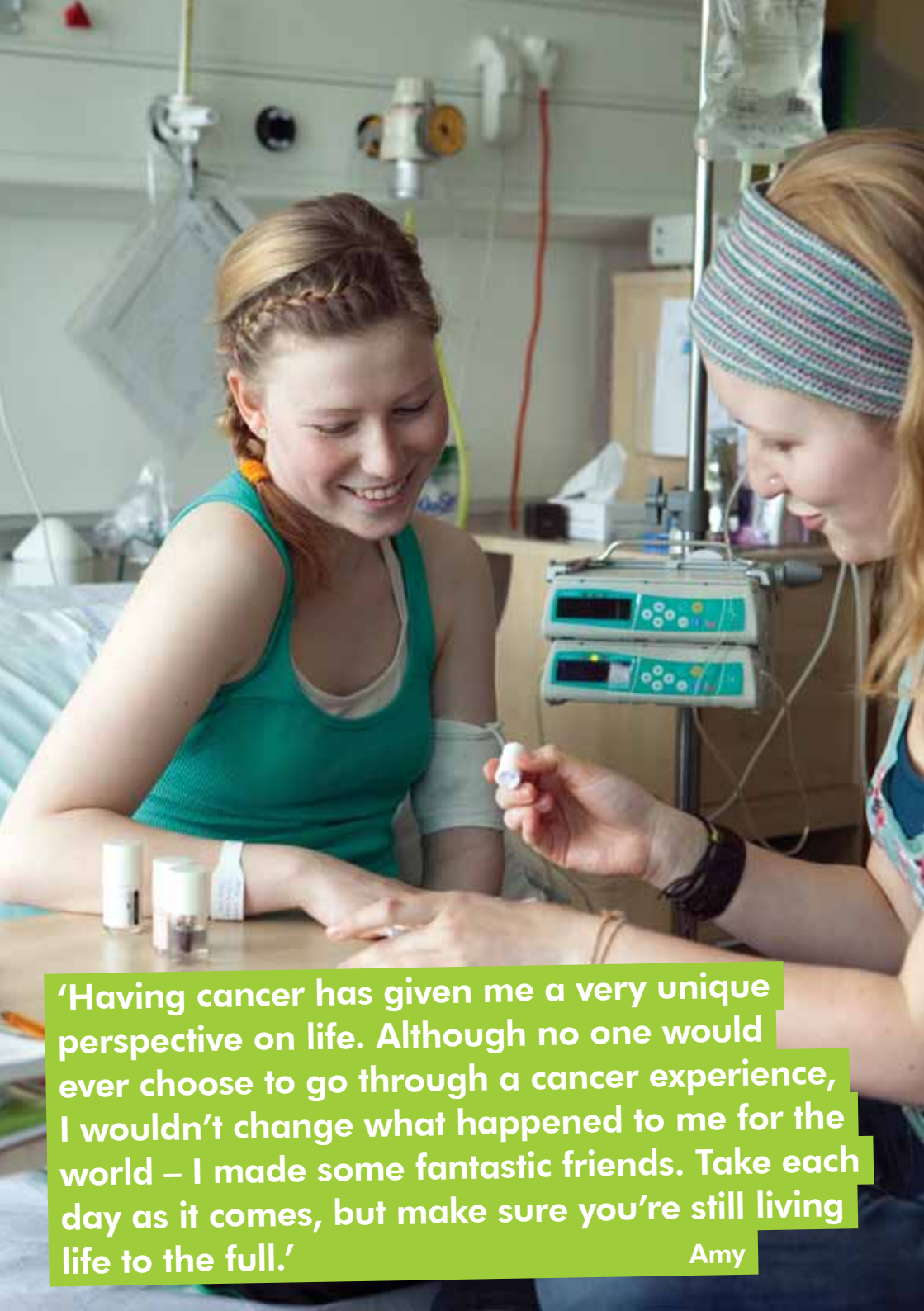


A guide for young people
living with cancer

I'M STILL ME



**WE ARE
MACMILLAN.
CANCER SUPPORT**



'Having cancer has given me a very unique perspective on life. Although no one would ever choose to go through a cancer experience, I wouldn't change what happened to me for the world – I made some fantastic friends. Take each day as it comes, but make sure you're still living life to the full.'

Amy

I'm still me – here for you

However you're feeling right now is fine. From shock and disbelief to confusion, fear or just a sense of unreality, these are perfectly natural responses to being diagnosed with cancer.

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

Being told you have cancer can be overwhelming. There's a lot to take in, which is why having access to the facts is important. The more you understand about your kind of cancer, the more confident you're likely to feel about facing it head-on. By getting to grips with what's happening, you can play an active role in tackling this illness and even take some control.

Making *I'm still me* work for you

This booklet is for 12–25 year olds living with cancer. It aims to answer some of the questions you may have and offer you tips.

You may not feel like reading it from cover to cover, which is why it's been designed so you can pick out the issues that are relevant to you. At different times throughout your illness you can refer to it to find all the information you need.

The first five chapters take you through the different stages of your illness, from the discovery that you have cancer to going into hospital, having tests and receiving treatment. You'll find facts, advice and coping strategies, as well as some personal experiences from young people who've been affected by cancer.

Chapters 6–8 of this booklet explore the impact cancer can have on the way you feel about yourself, and on your relationships with other people. The aim is to encourage you to be open and honest about your feelings, with yourself as well as with those who care for you.

Chapter 9 includes some blank pages, which you may want to use to write about your experiences, make notes or jot down questions. Fill them in however you like. Putting things into words may help you understand what's on your mind.

Chapter 10 is a glossary, which explains the medical terms you're likely to come across. The final chapters have information about how we can help you, as well as a list of useful organisations that can give you more advice or help in practical ways. This list could also be useful for your family, friends or carers. A carer is someone (of any age) who provides unpaid support to a family member or friend who wouldn't be able to manage without this help.

Throughout the booklet we've included some comments from young people affected by cancer, which you may find helpful. We'd like to thank Laura, Dan, Gemma, Rian, Shelley, Cameron, Jonathon, Rochelle, Natalie, Jenny, Terrence, Elizabeth and Adam for letting us use their quotes.

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What is cancer?

How did I get cancer?

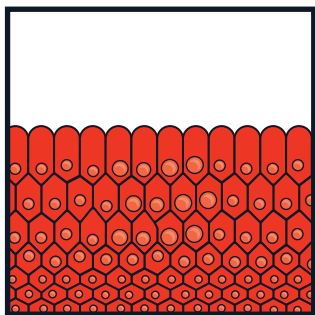
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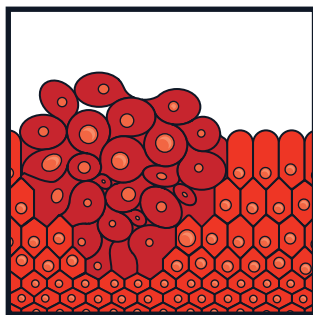
Every part of our body is made up of cells that fit together like building blocks. Cells of the same type group together to make different kinds of tissue, for example fat, muscle, bone, nerves and blood (a liquid tissue). Cancer is a disease of these cells.

Cells get worn out and die, but new cells are being made all the time in your body. A normal, healthy cell will split to create two new cells, and then carry on dividing in a controlled way. If this process gets out of control, the cells develop into a lump called a **tumour**. This can be in:

- an organ, such as the liver or kidney
- a bone
- the blood (which causes a type of cancer called **leukaemia**)
- the lymphatic system (which causes a type of cancer called **lymphoma**).



Normal cells



Cells forming a tumour

Cancer can also spread to other parts of the body, which is why it's important to have treatment as soon as possible.

There are more than 200 different kinds of cancer, each with their own names and treatments. People with cancer have to

have tests, scans and investigations 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 I get cancer?

About one in three people will have cancer at some point in their life. Even so, it's still a rare disease in young people. In the UK 2,022 people aged 15–24 and 1,578 people aged 0–14 are diagnosed with cancer each year.

Cancer isn't a disease that you can catch from another person – it isn't infectious. Many young people worry that their cancer is somehow linked to their lifestyle, such as smoking, drinking or taking drugs. But this usually isn't the case. We all know smoking is linked to cancer, but it's very unlikely to be a cause in your teens or 20s.

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.

In your teens and 20s, developing cancer is just something that can happen without explanation. It's natural to search for reasons or find ways to blame yourself. But the important thing is to look ahead. Expressing your feelings may help you focus on this. People who understand about cancer will recognise that you may be feeling confused, angry or scared. You can always talk to a health professional about how you're feeling, for example your nurse, doctor or social worker. If you would prefer to talk to someone over the phone, you can call our cancer support specialists on **0808 808 00 00**. They can answer any questions you have, offer support, or simply listen if you need a chat.



'When I was diagnosed with cancer, it seemed so unfair. I wanted to know why it had happened to me. Of course, there was nothing the doctors could say to this. I just had to accept it.'



Discovering you have cancer

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We understand more about cancer now than ever before. All sorts of new and successful treatments are available. But even though many forms of cancer can be cured, it's still something many people don't talk about openly.

Waiting and worrying

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 carry out a variety of tests to make their diagnosis. Their aim is to find out as much as possible about what's wrong with you. They'll want to pinpoint the exact type of disease 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 feel well enough, try to carry on with things you enjoy, whether that's sport, going to the cinema or just talking to friends on the phone.

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 still in education, it's a good idea for you or your parent(s) to talk to staff at your school or university 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 hesitant about telling your employer. Again, it can help to be honest at this stage,



especially if you need to take time off for hospital appointments. We can send you more information about work and cancer. Just call our cancer support specialists on **0808 808 00 00** or see it on our website at **macmillan.org.uk/work**

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

See the A–Z of who does what on pages 24–27.

Tests and diagnosis

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 in doubt 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. This kind of help is usually offered when the test is arranged. But sometimes hospital staff 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.

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.

‘My GP sent me for a scan when a lump on my leg grew to the size of a golf ball. I was a bit scared – it never even crossed my mind that it could be cancer. The specialist said the lump was malignant, but I didn’t know what that meant. It wasn’t until I heard the word tumour that I twigged what he meant. My mum and dad were with me throughout and were really supportive. The doctors and nurses also turned out to be really helpful.’

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. So, if it feels easier for you, 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 contact our cancer support specialists on **0808 808 00 00**.





Going into hospital

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When you first became ill, or started to have worrying symptoms, you probably saw your family doctor. He or she is a **general practitioner (GP)** and deals with all types of general health worries and problems.

As soon as your GP suspected something was seriously 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 senior doctor, called a **consultant**, who is in charge of your overall care. 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 pages 24–27.

Which hospital will you go to?

This will depend on:

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

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. This could be a local hospital, but in some cases you may need to be treated at a specialist unit.

If this is a long way from home and you're unable to visit in advance, you can always call the ward staff and ask any questions you have. You might have questions about visiting



arrangements or what to take with you. Whatever's on your mind, they'll be happy to help.

3
'There was always a member of staff on the unit who made time to explain everything properly. If they didn't know the answer they'd go and find it out for you. It made me feel in charge of what was going on.'

What facilities are there for young people?

This depends on where you live. In recent years, special units for young people have been introduced. Eventually the plan is that there will 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're located by visiting nhs.uk/young-cancer-care/pages/teenage-young-adult-cancer-units.aspx

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 and doctors who are used to working with young people.

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. The NHS promises in its Patients' Charter that: 'Young people can expect to be asked if they want to go to a children's or an adults' ward, or any accommodation specially for young people. They can expect to see any of the facilities the hospital has for young people.'

This means that unless you're admitted as an emergency patient, where possible you should have some say in which part of the hospital you'll be in. Your doctor or specialist may have his or her own suggestions, but you can still ask to see the other options and make your own decision. See the NHS webpage [nhs.uk/young-cancer-care](https://www.nhs.uk/young-cancer-care) to find out more about having your say on which hospital you go to.

What's hospital like?

If you've never been in hospital before, you might be pleasantly 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.

Depending on whether you're in a special teenage unit, on an adults' ward or on a children's ward, there will be different facilities available. Wherever you are, you'll spend quite a lot of time out of bed, so you can wear normal, casual clothes.

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. There should also be somewhere quiet for you to catch up on school or university work, play games or take up some new hobbies. Some young people's units have rooms with computers, 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.





How to make hospital life easier

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

Being on a ward with other people can take some 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 be understandably anxious about your illness and wondering what's going to happen.

4 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:

- Whether you have your own room or just a curtained cubicle on a ward, 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.

'My mum pretty much brought my entire bedroom to me in hospital to make me feel more at home. I had all my teddy bears and posters with me. She never left my side and slept in a bed at the end of my room in the hospital every night. Whenever I needed anything or just wanted to talk, my mum was there for me.'

- Take in an MP3 player or a hand-held games console – anything that's guaranteed to keep you entertained.
- Borrow things from friends and family, such as portable DVD players and films you haven't seen before.
- 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 56–57). 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 24–27. 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 tell 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 by texting, writing letters or emailing. 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.

The A–Z of who does what

Anaesthetist A doctor who's trained to look after you when you're having an operation. They'll give you the right anaesthetic for your surgery. If you need to be asleep during the operation, they'll use a general anaesthetic. If you need an area to be numbed, they'll use a local anaesthetic.

Consultant The senior doctor who's in charge of your treatment. They'll check your progress and plan your treatment. They'll look closely at all the results from the tests you have and decide on the best treatment. They'll also be in charge of your overall care (see also multidisciplinary team).

Doctors This includes Foundation Year 1 and 2 doctors (FY1s and FY2s) and specialist registrars (SpRs) on the ward. These doctors work with your consultant to care for you during your hospital stay.

Domestic In some hospitals domestics give out drinks and meals on the ward. In other hospitals they clean the wards.

GP The doctor who will care for you when you're back at home. You may have seen them with symptoms before you were told you had cancer. Your consultant will keep the GP informed about your treatment.

Macmillan nurse or specialist nurse A nurse who will closely monitor your progress and provide any extra support or information you need.

Oncologist A doctor who looks after people who have cancer. Most are either medical or clinical oncologists. A medical oncologist is trained in the use of drugs to treat cancer, and a clinical oncologist is trained to give both drugs and radiotherapy.

University medical students These are people who are training to become doctors. They may come round with the doctors who are treating you so that they can learn some of the skills they need to be qualified doctors.

Ward nurse A nurse who carries out day-to-day care and provides ongoing treatment, from giving injections to taking blood samples and blood counts, to giving medication or chemotherapy.

Depending on what type of cancer or treatment you have, you may also come into contact with the following people:

Benefits or welfare rights adviser Someone who can provide expert advice on any financial benefits that you may be entitled to.

Community or district nurse A nurse who provides care at home and gives any medication you may need.

Counsellor Someone you can talk to about your feelings and any worries you have.

Dietitian Someone who can help you with your nutrition.

Haematologist A doctor who specialises in blood disorders.

Multidisciplinary team (MDT) The name given to the team of specialist healthcare professionals who will be looking after you. Your own consultant will be a member of an MDT and will discuss your care with them to get their expert advice.

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 sees you at home and coordinates activities such as your return to school or university.

Pathologist Someone who tests the blood that's taken from you to check that your blood count is okay. They can also examine any biopsy samples under a microscope to look at the different cells.

Pharmacist An expert in medicines and what they're used for. They provide you with information on how to manage your medicines. They also give out medicines that the doctors prescribe for you.

Phlebotomist Someone who takes blood samples.

Physiotherapist Someone who can help you with your physical mobility.

Psychologist If you're worried about treatment, or finding it hard to cope with being ill, this is someone who can help you come to terms with the situation and help you work out coping strategies.

Radiographer Someone who takes x-rays and does scans. They also give radiotherapy treatment, which the radiologist works out for you.

Radiologist A doctor who's specially trained to look at x-rays and scans.

Social worker Someone who can discuss financial, work or social issues with you and your family.

Surgeon A doctor who carries out operations, such as taking a sample of a tumour (called a biopsy), or removing a tumour.

Teacher Often a teacher from your school or university can give you extra help to keep up with your studies. You may also have education from hospital teachers while you're in hospital.

Youth support coordinator Someone who's funded by the Teenage Cancer Trust to encourage young people to stay sociable and active during and after treatment. They also arrange activities.

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.

'Unless you've got a close friend or relative who's had cancer, it can be hard to find people to speak to who understand what you're going through. I sometimes felt isolated and needed support and reassurance. It doesn't have to be such a lonely experience, though. There are professionals and organisations that understand and are able to offer support. You shouldn't be embarrassed to tell anyone how you feel.'

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. You could even start by ringing the ward or clinic where you're going to have your treatment. (Just ask them to call back if they're busy.) You could ask your parent to call on your behalf, but by doing it yourself you can make sure you ask about everything that's on your mind.

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.

'I wanted to know what was happening at every stage. The doctors were really helpful and willing to tell me all the details.'

Having scans

Plenty 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 special microphone gently rubbed over the skin of the part of your body that's being examined. CT, MRI and PET scans often involve lying very still in a small space, and 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. On the upside, 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.

'I had MRI scans – they're noisy and not particularly nice, but they're not scary. It's a bit daunting the first time because you don't know what's going to happen, but after a while you just get used to it.'

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. So why not take the lead? 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.

'I've been in hospital for some time now. All I can think about is getting back my normal life, but it's so frustrating not knowing when that will happen. What worries me is that everyone will have moved on without me, and I'll be left out.'

'I knew it was hard for my friends to know what to say to me, and I thought my appearance made it even worse for them. I stayed close to three friends who were always really supportive though.'

You may want to focus on getting back on your feet again. The key is not to rush things or create anxiety for yourself by feeling like you're missing out. You only have to think about what it's like when you get home after a holiday to realise it won't take long to catch up with everyone.

After a period of 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.

'My outlook on life has changed a lot throughout my illness. I've become a much stronger and more positive person. I enjoy helping others a lot more.'

So for now, take one step at a time. Restoring your health is central to rejoining life outside the hospital. You can still keep your social life going by inviting people to visit and staying in touch via text, email or social networking sites like Facebook.





Treatment for cancer

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If you're diagnosed with cancer, treatment will begin at the earliest opportunity.

Your medical team will put together a plan of action to combat 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.

Who's in charge?

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.

'I don't know how I'd have coped without my consultant. He explained everything really well and it was easy to have a good joke with him, too. He's a really nice man.'

You'll also be introduced to the nurses who will care for you on the ward. They have specialist experience of working with young people with cancer. 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 and 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.

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

What sorts of treatment are used for cancer?

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 for your cancer.

'My brain tumour was of high-grade malignancy, so the doctors knew they had to act fast. They decided I should have radiotherapy. However, three days before starting radiotherapy they decided it was best to operate. 90% of the tumour was removed during surgery, and after that I also received radiotherapy. What was left of the tumour has shrunk and is now dormant – so long as it doesn't grow any more, I'm happy and just getting on with my life.'

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, surgery is a very effective way of getting rid of it.

You may be worried about how you'll look and feel after surgery. 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 usually only lasts about a minute and it doesn't hurt. Afterwards, however, your skin may feel as though you have sunburn and it could be red and sore.

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 when the treatment stops.

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. Having a central line doesn't hurt, but the line is visible.
- 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 10 pence coin, which is surgically fitted over the chest. Inside is a silicone bubble, which injections can be made into. The silicone bubble 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 thin, plastic tube inserted into a vein in the hand, wrist or arm using a needle with a plastic tube. When the needle is taken out the plastic tube remains, but it can only stay in place for a day or two. A cannula can be useful if you only need intravenous treatment for a short time.

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.

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 other treatments may be used as well as (or instead of) surgery, chemotherapy or radiotherapy. These include:

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 very special 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 from another person whose bone marrow is a good match for yours can be used. 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 42–43)
- feeling extremely tired
- hair loss – this may be just the hair on your head, but could include your body hair, eyebrows and eyelashes (see pages 56–57)
- feeling or actually 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.

S Most people who are treated for cancer experience 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 them.

Most side effects clear up when treatment stops. We can send you more information about the side effects of cancer treatment. Call our cancer support specialists on 0808 808 00 00 to find out more.



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 a course of antibiotics.

You should also report any of the following to the hospital:

- feeling unwell
- a fever
- an upset stomach
- a sore throat
- a rash
- earache
- being in contact with someone who has chicken pox.

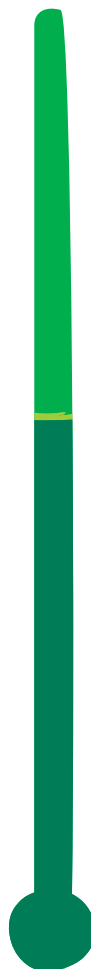
A nurse will take a blood test, monitor your temperature, blood pressure and any other vital signs, and possibly put you on antibiotics. You may need to stay in hospital and be put in your own room (in isolation) so you don't catch anything else, and be monitored closely until you're better. For infections,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

38°C

temperature
needs to be
reviewed

37.5°C

temperature
requires close
monitoring



To reduce the risk of infection, you should:

- try to avoid people with colds or who are ill
- wash regularly and properly using soap – especially your hands
- wash and peel all fruit and vegetables thoroughly.

'It's important to be strict with yourself and constantly keep an eye on your health. There was one night when I was at home in between chemotherapy treatments when I was feeling hot and feverish. I should've taken my temperature but I was so tired I couldn't be bothered. My dad eventually persuaded me to do it, and because it was high he took me to hospital. By the time they'd done any tests it was about 2am and it turned out I had an infection in my lungs. So it really was worth making the effort to get checked out, even if all I wanted to do at the time was go to bed.'

5

Fertility

Some cancer treatment can affect fertility (the ability to have children) in both men and women. Your doctor should tell you if any of the treatments you're having could affect your ability to have children in the future. They can also tell you if there are things that can be done to help protect your fertility. You'll probably be in hospital for at least the start of your

treatment, so be sure to talk to any of the staff about your worries. You can ask for further help or information at any time. Even if you're at home, you can always ring the ward for advice. For more information on fertility, see page 63.

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 vital that you talk it through with your consultant, doctor or nurse first. You need to be sure it won't interfere with your medical treatment.

Below 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 Careful insertion of needle tips under the skin. Some people believe this affects the flow of energy in the body.

'I've found acupuncture to be really helpful in building my strength and energy up.'

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

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

Counselling A way of dealing with worries and anxieties through talking.

Massage This destresses the body and the mind.

Meditation A way of relaxing your mind and feeling calmer.

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

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

Relaxation therapies These aim to help you unwind and promote a sense of well-being.

Sea bands These apply gentle pressure to points on the wrists to help relieve nausea and sickness. They're available from your pharmacist.

Tai chi A gentle martial art that promotes good health.

Visualisation This taps into the calming power of your imagination.

Yoga A combination of physical exercise and breathing control.

Some people really 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 tackle your illness.



Your kind of therapy

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

- Listening to your favourite music, relaxation CDs or podcasts on an MP3 player 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 accept it if you're going to look different for a while.

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

'I listened to a lot of music to help me get through my worst moments. I also planned to go to lots of gigs in between chemo treatments, so it gave me something to look forward to.'

Do I have any say 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.

'It was scary waiting around and not knowing how I was going to be treated – I was worried that the tumour could grow bigger in the meantime. Eventually, I insisted on having a consultation – this made me feel a bit more in control.'

S Your doctor(s) 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, the written consent of your parent or guardian may also be required. 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.

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. This should be backed up with all the information the doctors can provide 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.

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. In order to push the boundaries of cancer treatment forward, however, 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 is given the established treatment and the other is given 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 a number one 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 being included in the trial 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. If you agree to take part in one, and it becomes clear before it's over that one treatment is definitely better than the other, it 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 taking 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 has to be worth considering.

'I was under 16 when I took part in a clinical trial, so my mum and dad had to give permission for me to do it. I was happy to let the doctors get on with it because I trusted them.'

You can't be entered into a trial without your written consent if you're over 16, or that of a parent or guardian 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 in use 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 whether it's worth the trouble and pain. Often people set out on their treatment thinking that whatever happens, they'll take it 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, and 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.

Multi Games

The logo for 'Multi Games' is positioned at the top of the image. It features the words 'Multi' and 'Games' in a bold, blue, sans-serif font with a white outline. The text is set against a vibrant background of red and yellow starburst patterns. A small, stylized figure of a person is visible within the starburst design.



Am I still me?

How might my looks change?	54
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Will cancer affect my sex life?	60
Can I still have children?	63

Both cancer and its treatments can affect how you look and feel. Sometimes this is temporary, such as losing your hair during chemotherapy. But even if you know some 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 (the way you think about your body and how it makes you feel).

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

6

How might my looks change?

Weight loss/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.

'I felt really weak and lost a lot of weight. I'm 6ft 1in and went down to nine stone, so I looked a bit like a Twiglet. I didn't feel self-conscious of the way I looked in front of my friends and family, although I wouldn't have wanted to go into town when I was at my worst because I was aware of how ill I looked.'

Some people with cancer are prescribed drugs called steroids and these can make you put on a great deal 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, so you should 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 (under anaesthetic or sedation – see page 37). In the same way, after surgery you may need to have a tube or drain coming out of part of your body.

Understandably, some people are worried or frightened by the thought of this. Asking questions, talking to your nurse and learning what the tubes are for and how to look after them will help you feel more confident. Reassuringly, 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 to make sure you end up looking as normal as possible, but some scarring may be inevitable. Scars always look worse straight after surgery when they're red and very obvious, but they do fade a lot with time.

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 (cut off). This is obviously 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) one instead. But this is not always possible, and amputation of the limb or part of it may be necessary. The doctors will make their decision by considering the best way to get rid of the cancer. Even if the surgeons recommend amputating the limb, or a section of it, they'll do everything they can to make sure you stay mobile afterwards 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 it falls out completely.

6

'I had hair loss to the area of my head treated with radiotherapy. Losing my hair didn't really affect my confidence though – I suppose I was more concerned about my brain tumour at the time. Besides, I had really big, thick, bushy hair before and I just thought it would save me a fortune in shampoo and hours of straightening.'

Any hair loss from chemotherapy is almost always temporary. People who have surgery or radiotherapy to their head 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. Just call our cancer support specialists on 0808 808 00 00 for more information.

Many hospitals offer a wig service. Your nurse or specialist should know where the service is, so feel free to ask. You may well be entitled to have a new wig every six months through the NHS – in any style, colour and shape you want. 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 avoid 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.

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



'Before getting ill, I was a well-built lad – I'd been working as a builder's labourer for years. During chemo I lost every hair on my body and became quite thin. My self-confidence has grown since then, and I haven't had any problem getting girlfriends.'

mean that unless you tell them what's worrying you, it may not register with them. But feeling unattractive and feeling 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 build. Even just calling, texting or emailing can help you feel more confident about facing the world again.

It's also very important that you 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 set their sights on 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 that you open up about it. The key is to feel comfortable in the way you choose to express yourself.

Talking to people about your feelings really does help. 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 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 the contacts section on pages 107–108 for details).

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 since you were a child, 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.

Will cancer affect my sex life?

You may be single, or you may feel that you aren't ready 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 are wondering how to cope now. Or you may even meet someone while you're ill or in remission.



For a number of reasons, you may feel that the time isn't right for a sexual relationship.

But 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.

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Most people find it hard to talk about deeply 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 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 any sexual activity if you're receiving chemotherapy, and for a few days after the treatment is complete. This is because there's a slim possibility that chemotherapy drugs could be passed through seminal

and vaginal fluids. It's important to take responsibility for your partner's welfare by using this barrier method.

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.

Can I still have children?

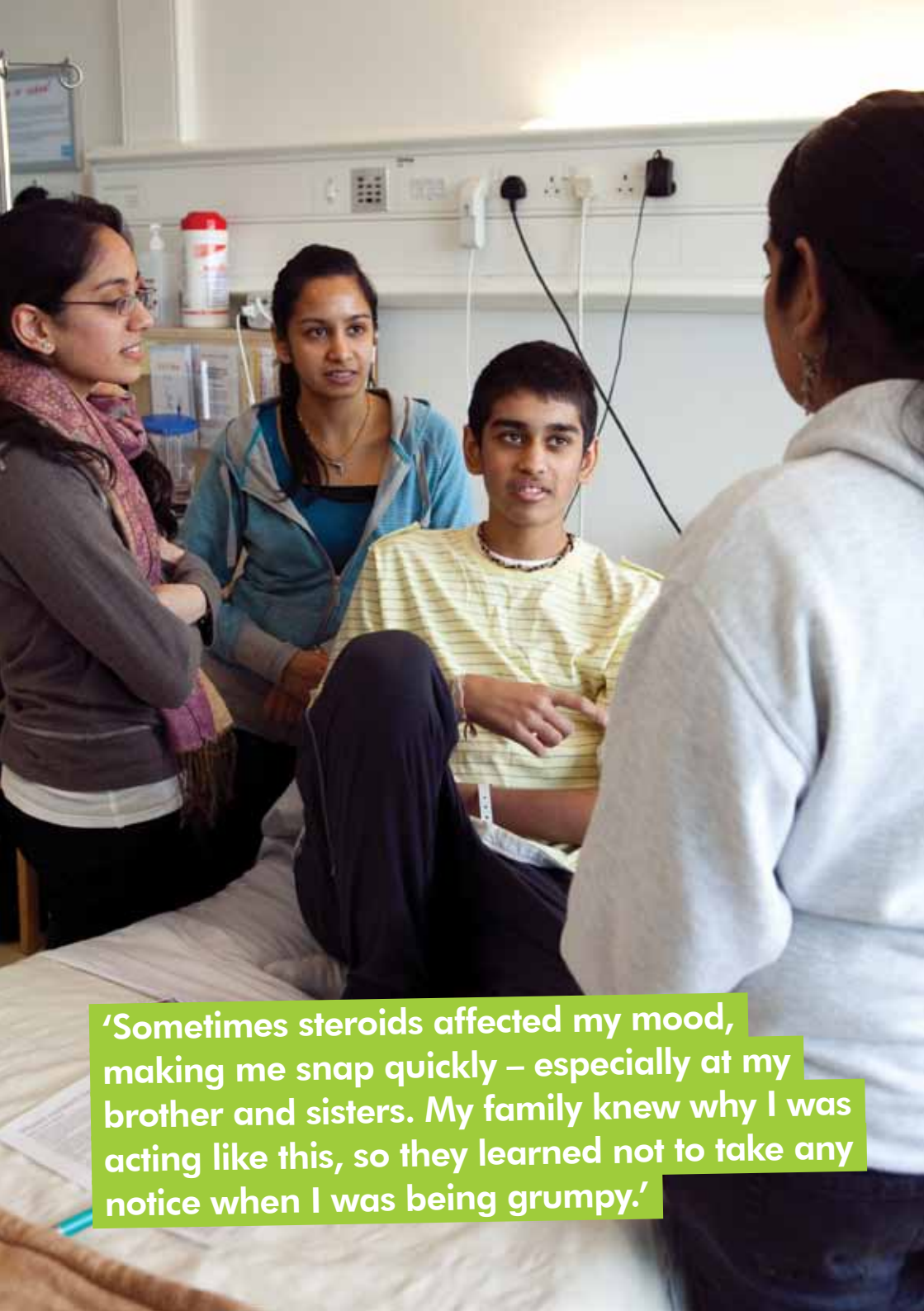
During cancer treatment it's common for both men and women to be infertile (unable to have children) for a while. This isn't always predictable though. For example, some girls' periods stop as a result of cancer treatment, but it's not necessarily a sign that they won't be able to get pregnant now or 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.

Even 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.

For more information about fertility, see our booklet *Relationships, sex and fertility for young people affected by cancer*. We can send you a copy for free.

You can also contact the Teenage Cancer Trust for more information on fertility. See page 107 for contact details.



'Sometimes steroids affected my mood, making me snap quickly – especially at my brother and sisters. My family knew why I was acting like this, so they learned not to take any notice when I was being grumpy.'



Cancer and relationships

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Having cancer in the family (even if you're not the one who's got it) puts a big strain on everyone – especially in the way you relate to each another.

How does cancer affect relationships?

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 and friends 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.

Any two people who communicate on a regular basis have a relationship. 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; from an email to a love letter.

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 is often a recipe for communication breakdown. All teenagers have rows with their parents – it's part of learning how to negotiate and compromise – but it can also make it difficult to talk to people.

'My illness divided the family – everyone argued all the time. There were moments when I just thought, "I don't need this." I often told them to sort it out among themselves instead of arguing in the same room as me.'

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 like a child again. It can seem like they don't have any control over what's going on.

That's why understanding exactly what's happening to you – 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 the way 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.

The next few sections look at how the people closest to you might be affected by your illness.

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

'It was hard to tell how well my parents coped with me being ill. It can't have been easy, because they still had to look after my younger brothers while my dad worked full-time and my mum stayed with me in hospital. I do know that they got support from our wider family though, as well as from the parents of other young people who were in hospital.'

Usually people will be really worried about you, and that's likely to stress them out. They want to protect you and make you well, but they realise that with cancer they don't have the power to do that. So they feel out of control, which can make them frightened.

As a result they may be over-protective, for example telling you not to get too tired, saying you shouldn't go out with your friends, or nagging you to eat your dinner. Understandably, 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 go out with anyone who's unwell.

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

Sometimes parents are already having problems. Without you being aware of it, they may have been disagreeing about money, work or other major things. Then the worry arising from your illness can add to the strain on their relationship.

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 causing upset. This is an understandable fear, but the people closest to you would generally much rather know the truth about how you feel.

'There was one point when I was really poorly after I'd developed pneumonia during chemo. I thought I was going to die, but I was too scared to talk about my feelings with my mum and dad in case it upset them. Once I'd got a bit better, my mum told me about how the doctors didn't think I'd make it. Because she had the strength to stay so upbeat when I was seriously ill but was really honest with me afterwards, I now feel like I can talk to her about anything.'

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.

7 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 various ways. Your brother or sister

may not want to visit you in hospital, behave badly at home or school, or say spiteful things. This can be hard to take, but it's a normal reaction.

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 them aware that there's support and advice available for them, such as our cancer support specialists on **0808 808 00 00**.

You may want to discuss this with your parents, together with a social worker, activities coordinator or specialist nurse.

How will it affect my friends?

'I felt okay in myself dealing with my illness, but telling my friends made it really hit home how serious it was. It hurt to see their reactions and to think that I was going to be away from them for a while. I didn't want them to worry. They were good friends though. They visited me a lot and sometimes I'd just ring them up to chat about how I was feeling.'

People often find that friendships become very strong and important while they have cancer – but it isn't always the ones you expect who give the most support. Sometimes even friends who 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.

Making new friends in hospital

Making new friends in hospital is surprisingly easy. This is because you'll meet other young people with cancer.

7 'We used to hang out together in the chill-out room where we'd play games and watch TV together. We'd all chat to each other about what we were going through. Everyone was really supportive and understanding because we were all going through the same thing.'

You can also join special young people's support groups – your nurse or the local Macmillan nurse will know about groups in your area, and you can also get suggestions from the contacts section of this booklet on pages 106–108. 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. Coming to terms with losing people close to you is another part of living with cancer.

Questions and answers

The questions on the next few pages are some of the most popular questions our Macmillan nurses are asked:

I got ill while I was still studying and I wasn't well enough to sit my exams. My treatment went on for most of the next year, so I never went back and now I don't know what to do. I suppose I'd like to get a job, but everyone keeps telling me I should get some qualifications first. Also I'm worried about working, because what if I need to take time off for hospital visits or I get ill again?

If you're 13–19, you can call the National Careers Service helpline for young people on **0800 100 900** (Mon–Sun, 8am–10pm). You can also chat with their advisers online at **www2.cxdirect.com**. 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 most effective way to tell employers about your medical requirements. 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.

I've been having chemotherapy for three months and my mum is driving me crazy with her nagging. It's bad enough when she visits me in hospital, but when I get to go home in between treatments she goes on and on about how I've got to be careful and mustn't do this or that. I know I have to take care, but I still want to see my friends and have a good time on the days I feel up to it.

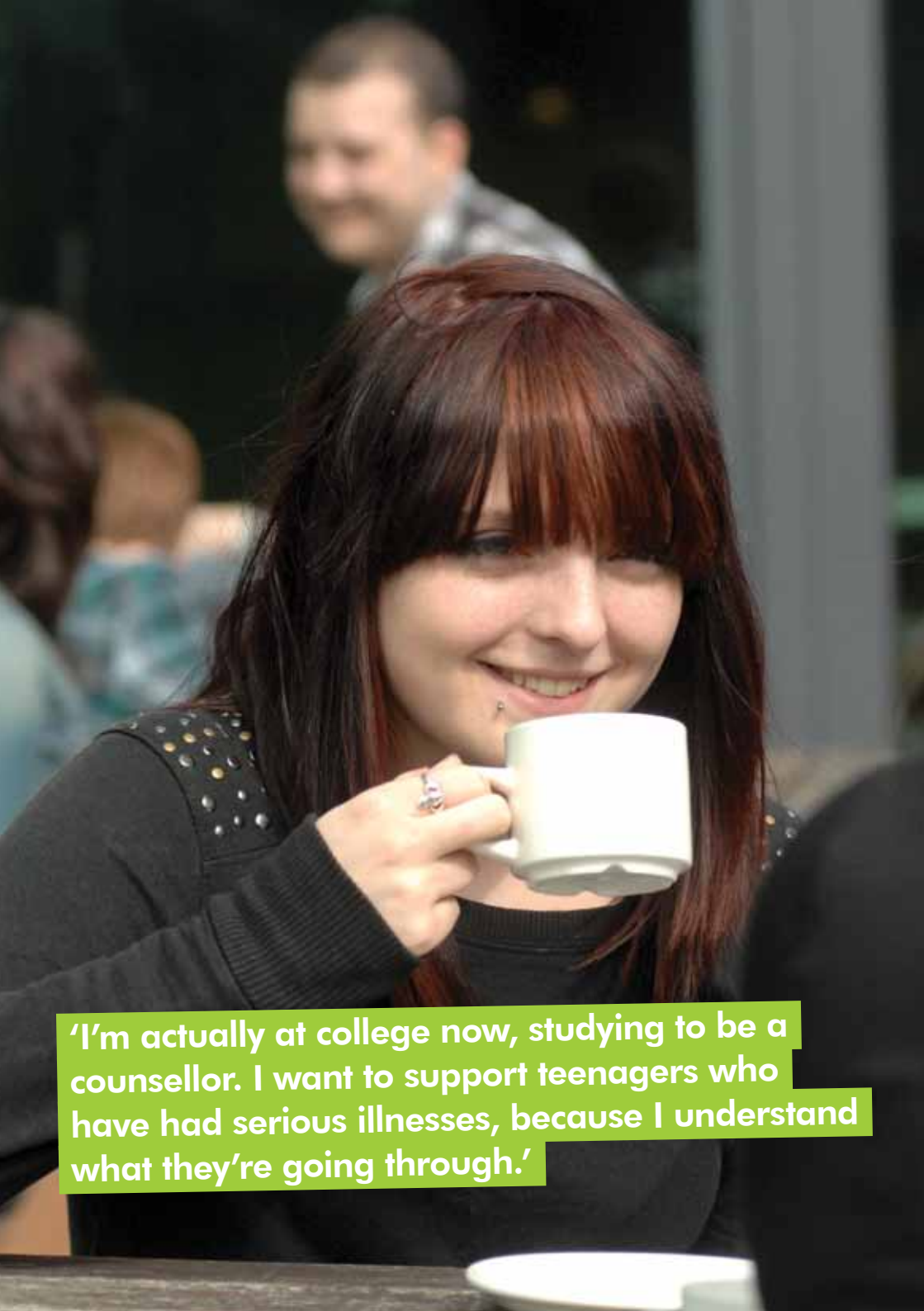
Try to remember that your mum is acting like this because she's scared. She's really worried about your health and is trying to do everything she can to protect you. For a mum this usually means holding on tight and not letting you out of her sight. Try not to get angry but talk the problems through with her. And ask one of your nurses or your social worker if they can talk to you both about the main dos and don'ts. Having a third person there will keep tempers cool and give your mum a chance to accept that it's okay for you to live as normal a life as possible in between treatments.

7 I'm at home at the moment during a gap in my treatment and recently I went out with my friends to a club. It was the first time I'd been out for ages and I met a really nice girl who one of my friends already knew vaguely. I like her and I know she's keen on me but I'm scared to ask her out because a) I'm not sure I feel up to anything, and b) I don't know what the future holds. I just don't know what to do about it.

The best approach is to be honest with her. Your life isn't normal at the moment, but there's nothing to stop you getting in touch and explaining that you like her and would like to see her again. It's quite possible she already knows about your cancer from your friend. If not, just tell her, but make it clear that as far as you're concerned being ill is only a temporary stage. Maybe you'll only manage to be friends at the moment, but as long as you're upfront about everything, you can look back knowing you made the right move under difficult circumstances.

I'm 16 and I've just been told I've got cancer. I'm really worried that it's because I used to smoke. No one knows about this except a couple of my friends. My mum would be so disappointed in me if she found out. So if I tell my doctors, would they inform her?

Smoking is linked to cancer and lots of other diseases. It's also habit-forming, which is why breaking free is such a big achievement, so well done for quitting. Even so, at 16 a former smoking habit is unlikely to have caused your cancer. In most cases, you have to smoke steadily for quite a few years before there's a serious risk. Your doctor is likely to ask if you have a history of smoking, and you should be honest as this helps them build a clear medical picture. They have to keep what you say confidential, so they won't tell your parents if you feel strongly that it would make the situation worse. If you change your mind and decide that perhaps they should know, your doctor will help explain that at your age it's unlikely to be the cause of your illness.



'I'm actually at college now, studying to be a counsellor. I want to support teenagers who have had serious illnesses, because I understand what they're going through.'



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

'I was glad to go home, but it felt strange at first. I was scared knowing that there weren't going to be nurses paying attention to me around the clock. I also missed seeing all the familiar faces from hospital.'

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. Tell your social worker through your oncology unit (or general social worker service), and speak to them 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 106–108 for details).

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.

'Although I withdrew into myself during the time I was ill, I think the experience brought all my family much closer together. When I went home after surgery on my leg, my mum dressed the wounds that had become infected. Also, my family had to help me get changed, or take me to the toilet. It wasn't particularly pleasant having to rely on them like this, but everyone chipped in and I even enjoyed having the occasional argument with my brothers because it gave me a sense of normality.'

Your parents will understandably be anxious about you and may have their own secret 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.

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 side of 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 anti-climax. 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 might 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 ring the ward and keep in touch with friends you made in hospital too.

'Since finishing treatment, I've kept in touch with friends I made through being in hospital. Some of them were diagnosed a year ahead of me, so whenever I have an off day, they can offer me a lot of support and advice based on their own experience. I can say, "Oh God, did you ever feel like this?" and they'll say, "Yep, we've been there!" I've been really grateful for having them there for me to help me cope.'

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 or portacath 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, for example your GP. The information about managing infections on pages 42–43 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. This should be discussed with you before you leave hospital, but it's also a good idea to go through it with your parents and family so that they know what to do if there's a crisis.

- Note down any important phone numbers and contacts, and 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. Never be scared of worrying them unnecessarily. They're there to help you.
- Your GP and a named community nurse should have been told that you're going home. Together they'll be responsible for your care. You should know their names and contact details before you leave hospital. Also, as soon as you get home, contact your GP's surgery and make sure they know what's happening.
- 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 for you 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 in the contacts section (see page 106–108),

but your community nurse will also have details of other local groups.

- If you have any questions or concerns about cancer, you can call our cancer support specialists on **0808 808 00 00**.

Returning to school, university or work

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. How will friends who haven't seen you for a while react to your hair loss or change in weight?

It's a good idea to try to meet up either at home or somewhere where you feel safe 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 step out into the world.

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. Either you or your parent(s) should get in touch with school, university or work before you go back and ask for an opportunity to talk this through.

Teachers and employers may not have come up against your illness before. 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, then the school or college nurse should be able to support you and help you talk to staff about anything you need. The booklet *Welcome Back* may be useful, although it's written for younger children. Contact Cancer Research UK for details (see page 106).

'My main coping strategy when I was ill was to set targets for myself. One of my key targets was to finish my degree. I've taken a lot of time off to recover after treatment, but I'm planning to go back to uni later this year. Meanwhile, I've kept in contact with my uni mates and we're even going travelling together in Thailand soon.'

8

If you're returning to work then 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 pick up where you left off. 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.

If you're unable to find work, you may be entitled to benefits. You can find out more about these by ringing Citizens Advice



(see page 106), or by visiting **direct.gov.uk** You can also call our cancer support specialists on **0808 808 00 00**. They can provide details about organisations that can give financial help to young people with cancer.

In addition, your social worker can help you make an appointment with any benefits officers and/or Citizens Advice workers who visit hospitals on a regular basis.

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 as 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 really is the best way to make sense of them, which frees you up to move on with your life.

'My outlook on life has changed and I don't take things for granted as much any more. I've learned how important it is to have your friends and family around you. My mum and dad helped look after me during chemo when I was feeling really ill, but even after treatment I know it's worth having them nearby so I can talk to them about how I feel.'

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 use it right now, it's good to know you can call upon it if your feelings change.

There are bound to be times when you feel down, so don't lose sight of the fact 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.





Your questions and notes

Here's a list of concerns surrounding cancer treatment. You might know the answers to some already, but if there's anything here you're not sure about, then talk it through with your consultant or a member of your medical team. Even if you think they've heard the same question countless times, they'll know that the answer is very important to you.

About the cancer

- Where is the cancer?
- How serious is it?
- What happens if it spreads?
- How does it spread?
- What causes cancer?
- Did I catch it from someone?
- Is it inherited?

About the treatment

- If this treatment doesn't work, what will happen?
- How long will I have to stay in hospital?
- How long will my treatment take?
- How does the chemotherapy know which cells to attack?
- What are the side effects?
- Will I lose my hair, and if so when will it grow back?
- What are the effects of steroid treatment?
- Will I become infertile?

- Will I feel sick?
- Is there anything I can take to stop me feeling sick?
- What are the hospitals like where I'll be having my treatment?

After treatment

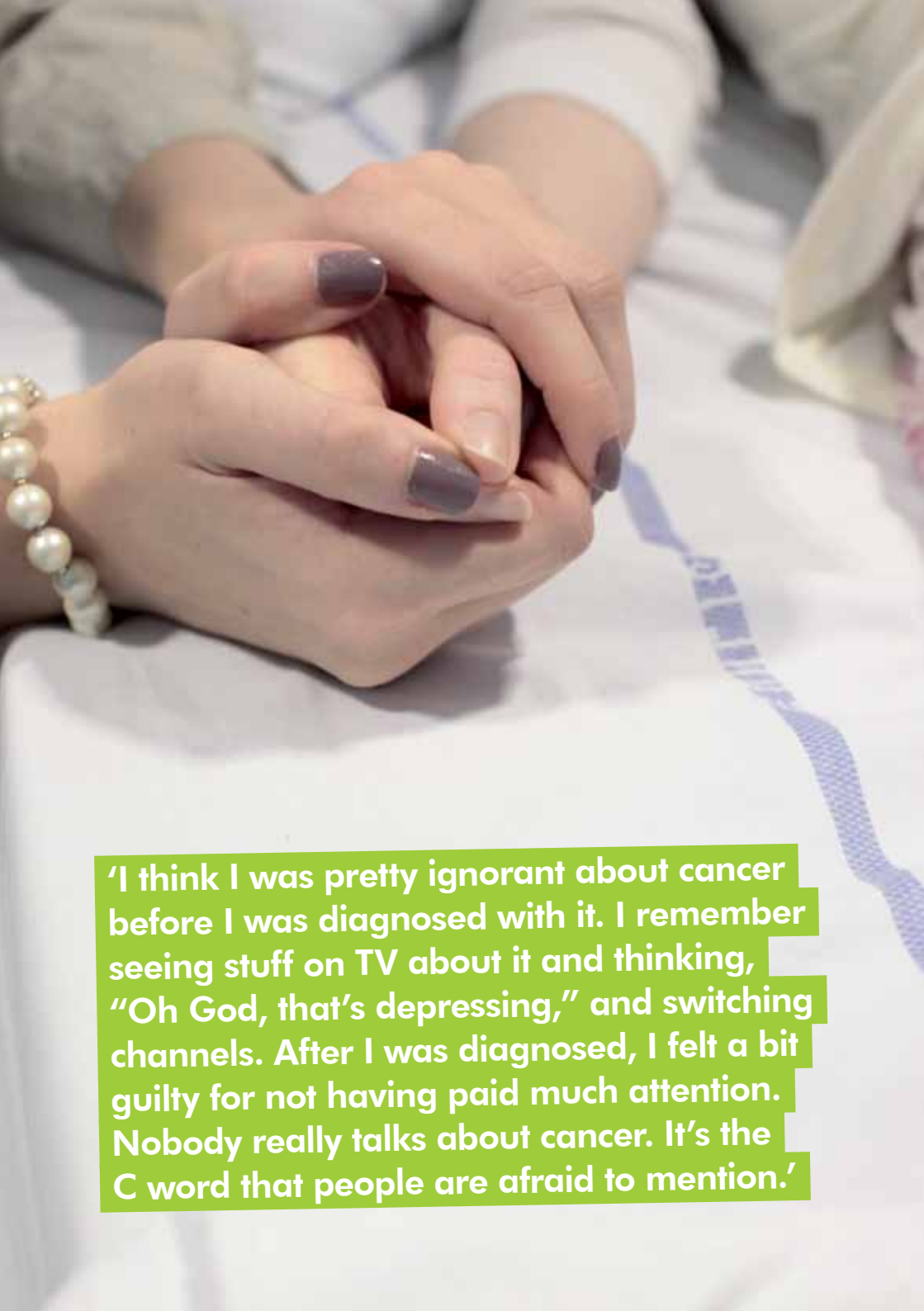
- What will happen after I finish all my treatment?
- What will happen if the cancer comes back?

Practical questions

- When am I going home?
- How will this affect my education or career?

Your questions

On the next few pages is some space where you could write down any of your own questions, and then write down the answers you receive. You might also want to use it to jot down notes or write about your experiences.



'I think I was pretty ignorant about cancer before I was diagnosed with it. I remember seeing stuff on TV about it and thinking, "Oh God, that's depressing," and switching channels. After I was diagnosed, I felt a bit guilty for not having paid much attention. Nobody really talks about cancer. It's the C word that people are afraid to mention.'



Glossary of medical terms

Anaesthetic (general) A drug that puts you to sleep while you have an operation or procedure.

Anaesthetic (local) A drug, cream or injection to make part of your body temporarily numb.

Benign Describes a tumour or growth that's not cancer.

Biopsy The removal of a tiny piece of tissue from your body so its cells can be examined under a microscope. It can be done under either a local or general anaesthetic. Sometimes just a small sample is taken with a special needle, but usually the complete lump is removed for examination.

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

Central line A thin tube inserted into your chest for chemotherapy. One end stays outside your body.

Chemotherapy A cancer treatment involving a special mix of anti-cancer drugs.

Consent Agreement to treatment.

Cytology The microscopic study of individual body cells. This is very important in making a diagnosis.

Diagnosis The identification of a patient's illness or disease – usually arrived at after looking at symptoms and doing tests.

Infertility The inability to get pregnant or make someone pregnant.

Intravenous An injection into a vein (in your arm or another part of your body).

Lesion Damage or change to body tissue that may or may not be cancer.

Lymphoma A cancer of the lymph glands or lymphatic system.

Malignant Describes a growth or tumour that's cancerous and can grow and spread to other parts of the body.

Oncology The study and treatment of cancer.

Paediatrics The medical care of children.

Portacath A thin tube inserted completely into your chest to make chemotherapy injections easier.

Primary cancer The site or point in the body where cancer first developed.

Prognosis The way a disease is likely to affect you in the future.

Prosthesis An artificial replacement for part of your body.

Radiotherapy A cancer treatment involving high energy x-rays.

Scan A computer-generated image of the inside of your body.

Secondary cancer A cancer that's spread to another part of the body.

Steroids A type of drug that can help treat cancer.

Tumour A growth or lump that may or may not be cancer.





How we can help you

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

Get in touch

Macmillan Cancer Support

89 Albert Embankment,
London SE1 7UQ

Questions about cancer?

Call free on **0808 808 00 00**
(Mon–Fri, 9am–8pm)

www.macmillan.org.uk

Hard of hearing?

Use textphone
0808 808 0121 or Text Relay.

Non-English speaker?

Interpreters are available.

Clear, reliable information about cancer

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

Macmillan Support Line

Our free, confidential phone line is open Monday–Friday, 9am–8pm. Our cancer support specialists provide clinical, financial, emotional and practical information and support to anyone affected by cancer. Call us on **0808 808 00 00** or email us via our website, **macmillan.org.uk/talktous**

Information centres

Our information and support centres are based in hospitals, libraries and mobile centres, and offer you the opportunity to speak with someone face-to-face. Find your nearest one at **macmillan.org.uk/informationcentres**

Publications

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

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

Review our information

Help us make our resources even better for people affected by cancer. Being one of our reviewers gives you the chance to comment on a variety of information including booklets, fact sheets, leaflets, videos, illustrations and website text.

If you'd like to hear more about becoming a reviewer, email **reviewing@macmillan.org.uk**

Need out-of-hours support?

You can find a lot of information on our website, **macmillan.org.uk**

For medical attention out of hours, please contact your GP for their out-of-hours service.

Someone to talk to

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

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

Professional help

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

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

Support for each other

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

Support groups

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

Online community

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

Financial and work-related support

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

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

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

Macmillan Grants

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

Find out more about the financial and work-related support we can offer at **[macmillan.org.uk/financialsupport](https://www.macmillan.org.uk/financialsupport)**

Learning about cancer

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

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





Other useful organisations

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Organisations

Cancer Research UK

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

Tel 020 7242 0200

www.cancerresearchuk.org

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

Cancer Support Scotland

Shelley Court, Gartnavel
Complex, Glasgow G12 0YN

Tel 0141 211 0122

www.cancersupportscotland.org

Offers information and support for cancer patients, families, friends, and healthcare professionals. Runs a network of monthly support groups and also provides counselling and complementary therapies.

Citizens Advice

Contact details for your local office can be found in the phone book or at

citizensadvice.org.uk

Find advice online, in a range of languages and for each UK country, at **adviceguide.org.uk** Citizens Advice provides free, confidential, independent advice on a variety of issues including financial, legal, housing and employment.

Citizens Advice Scotland

www.cas.org.uk

Irish Cancer Society

43–45 Northumberland Road,
Dublin 4, Ireland

Cancer helpline

1800 200 700 (Mon–Thurs,
9am–7pm, Fri, 9am–5pm)

www.cancer.ie

Operates Ireland's only freephone cancer helpline, which is staffed by qualified nurses trained in cancer care.

Maggie's Cancer Caring Centres

1st Floor, 1 Waterloo Street,
Glasgow G2 6AY

Tel 0300 123 1801

www.maggiescentres.org

Located throughout the country, Maggie's Centres

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

Teenage Cancer Trust

3rd Floor, 93 Newman Street,
London W1T 3EZ

Tel 020 7612 0370

(Mon–Fri, 8.30am–5.30pm)

www.teenagecancertrust.org

Builds cancer units for teenagers and young adults in hospitals, and organises support and information services for patients, their families, schools and health professionals.

Tenovus

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

Helpline 0808 808 1010

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.

Websites

Cancer in Young Adults – Through Parents’ Eyes

www.cancerinyoungadults-throughparentseyes.org

Offers support to the parents of young adults who have cancer. Contains personal accounts written by parents.

Captain Chemo

www.royalmarsden.org/captchemo

An interactive website where you can learn all about childhood cancers and treatment through quizzes and an interactive game.

**Great Ormond Street
Hospital for Children**
**[www.gosh.nhs.uk/
teenagers](http://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.

Macmillan Cancer Support
**[www.macmillan.org.uk/
cancerinformation/
teensandyoungadults](http://www.macmillan.org.uk/cancerinformation/teensandyoungadults)**

Macmillan's cancer information site written specifically for young people.

NHS Choices – Cancer Care
Choices for Young People
**[www.nhs.uk/
young-cancer-care](http://www.nhs.uk/young-cancer-care)**

Information for young people about treatment options and what it's like being in hospital.

Teenage Health Freak
**[www.teenagehealth
freak.com](http://www.teenagehealthfreak.com)**

Reliable health information for teenagers.

Youth Health Talk
www.youthhealthtalk.org

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

Disclaimer

We make every effort to ensure that the information we provide is accurate, but it should not be relied upon to reflect the current state of medical research, which is constantly changing. If you are concerned about your health, you should consult a doctor. Macmillan cannot accept liability for any loss or damage resulting from any inaccuracy in this information or third-party information, such as information on websites to which we link. We feature real-life stories in all of our articles. 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 medical editor, Dr Terry Priestman, Consultant Clinical Oncologist.

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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

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Surname

Address

Postcode

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I enclose a cheque / postal order /
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Macmillan Cancer Support

OR debit my:

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Card / Switch / Maestro

Card number

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Don't let the taxman keep your money

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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 Teenage Cancer Trust.

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

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

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

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

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

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