YOUR GUIDE TO CANCER

TEENAGE
CANCER
TRUST

ABOUT ME

It can be useful to keep all your important bits of information in one place. Feel free to fill out the sections below with your details if you'd like to! If there's any information you're not sure of you can ask your care team to help you.

Name: ……………………………………………………………

Age: ……………………………………………………………

Diagnosis: ……………………………………………………………

NHS number: ……………………………………………………………

Treatment centre: ……………………………………………………………

Key worker name: ……………………………………………………………

Key worker contact phone number: ……………………………………

Emergency contact name: ……………………………………………

Emergency contact phone number: ……………………………………

Note: We use the word 'carer' to recognise anyone who is in the position of supporting a young person. We acknowledge that some people might not have a strong parental or carer relationship (particularly if over 18) and want to highlight that you can always turn to your care team for support.

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ABOUT US

Every young person aged 13-24 who is diagnosed with cancer will need specialised care and support to get them through it. We're the only UK charity dedicated to meeting this vital need – so no young person faces cancer alone.

We offer unique care and support, designed for and with young people. We fund specialised nurses, youth workers and hospital units in the NHS, so young people have dedicated staff and facilities to support them throughout treatment.

We run events for young people with cancer to help them regain independence and meet other young people going through something similar. And we provide easy-to-understand information about every aspect of living with cancer as a young person.

You can find out more about Teenage Cancer Trust on our website:

teenagecancertrust.org

> "Hanna (a Teenage Cancer Trust Lead Nurse) had given me a copy of this book and I read it all in about two hours before my treatment. It was so informative, and it made everything feel so normal as I knew other young people had been through this too.
>
> Nobody I know had had cancer, but reading the book made me feel that this was something I could manage to get through.
>
> It wasn't as scary after that. She also made me feel like there was no stupid questions and I could ask anything I wanted."
>
> *Lakita*

INTRODUCTION

This book has been written based on what other young people have told us they wanted to know when they were diagnosed with cancer.

Young people who have had cancer, and the clinical staff who helped them, have helped us put this together.

This guide covers some difficult topics that might be hard to read but young people have shared with us that they feel these topics are important and should be included.

We'll be honest, we wish you weren't reading this. We're sure you do too. But seeing as you are, we really hope this book will come in useful.

You've probably got lots of questions going round your head at the moment. Hopefully we'll be able to answer most of them in this guide.

If you can't find what you're looking for, always feel free to speak to your care team who'll be able to help you out.

You can use this book whenever and however you like. Some sections might be relevant to you now, others might not be. Feel free to share it with family and friends too, especially if you think it might help you explain to them how you're feeling and what you're experiencing.

Stick it in your bag. Fill in the sections for your notes from page 199. Scribble in the margins. Use it to write down the contact details of people you meet during your treatment on page 2.

Being diagnosed with cancer doesn't suddenly stop you being you – so as well as explaining the medical stuff, we've covered a lot more here too: from working through your emotions, to speaking to your friends, to dealing with changes to your appearance.

Of course, this book can't replace your care team, and they should always be your first point of contact if you're worried about anything or have any questions.

But we hope it'll help you get your head around what's going on. We're here to do everything we can to help.

Want to know more than we can fit in this book? We'll let you know throughout this book where you can find more detail online.

We have lots of really useful information on our website:

teenagecancertrust.org

TEENAGE
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Take care of yourself, and let us know any thoughts you have about this book by emailing us:

healthinfo@teenagecancertrust.org

You can find all our information online too, just scan this QR code or visit **teenagecancertrust.org/info**

YOUR STORIES

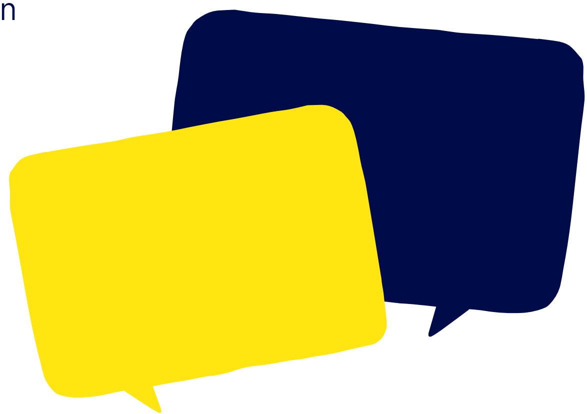
Every cancer experience is as unique as the person going through it.

Reading young people's cancer stories can be inspiring, moving, and provide support for those facing diagnosis or treatment.

Throughout this guide you'll see quotes from young people who have been supported by Teenage Cancer Trust as they share bits of their stories, in their own words.

If you'd like to share your story of your experience of cancer with us too then we'd love to hear from you.

Email us at: stories@teenagecancertrust.org to find out how you can be involved.



YOUR DIAGNOSIS

YOUR DIAGNOSIS

The moment when you're told you have cancer can turn your whole world upside-down.

Everyone reacts differently, and there's no right or wrong way to respond. However you're feeling now is completely fine. You might feel numb, confused, angry or scared. You might feel overwhelmed and struggle to focus on everyday life. Or you might feel relieved that you know what's wrong. It will take time to get your head around this.

It's really important to remember that you're not alone. There is lots of support available to help you cope and you'll meet plenty of people whose job it is to help you get through this.

So, if you have questions or you need help with something, don't be afraid to ask. If you forget the answer or don't understand it's absolutely OK to ask again. Your care team are used to explaining things a lot of times. It can be hard to take in lots of information in one go, especially when it's complicated medical information.

Don't feel embarrassed or worry about asking too many questions, no one will mind and it's good to make sure you understand what's going on.

“A few days later I went back for another blood test and when the results came back, I was told they urgently needed to do a bone marrow biopsy to rule out the risk of it being leukaemia. In those few seconds, my world came crashing down around me and I went into total meltdown. Initially it was a shock as I couldn’t quite find the words to express what was going on in my head, but after a few moments, it hit me.”

Lily

You might meet other young people whose situation is really similar to yours and other young people whose experience is completely different. It's important to remember that every young person's experience of cancer is different and everyone's experience is equally valid.

Take a moment

It can feel impossible to focus on anything else when you find out you have cancer, but pausing for a minute and reminding yourself of the facts in this section might help you breathe a little easier.

You're not alone

No one will feel exactly the same as you. But there is a huge amount of support available and there are lots of other young people who are living with cancer too.

It's not your fault

We'll keep telling you that throughout this book. A lot of young people think they might be to blame when they find out they have cancer, but that's not the case. Your carer and friends often feel guilty too – but they've not caused this either.

There's no 'normal' way to feel

Everyone reacts differently to a cancer diagnosis – there's no right or wrong way to respond. So whatever you're going through, remember that it's completely understandable. And try to be open about your feelings if you can; bottling things up probably won't help.

Hope can be powerful

Hang on to hope. No matter how tough things get, hope can be powerful. So never give it up.

What is cancer?

You probably have hundreds of questions on your mind right now. This book should answer a lot of them, starting with some of the ones we hear the most.

There are more than 200 different types of cancer, but they all come down to the same thing: cells acting differently.

Our bodies are made up of billions of cells – they're our building blocks.

Normally, cells only grow and divide to make more cells when the body needs them. This keeps the body healthy, because damaged cells get replaced quickly.

But things don't always go to plan.

New cells are produced when they're not needed, and this can cause a mass of tissue called a tumour to develop. Other types of cancer, like leukaemia, don't form tumours at all, but affect the bone marrow (the spongy stuff inside your bones that produces blood cells) or the blood.

Types of tumour

Tumours are often described as 'benign' or 'malignant'. The benign ones aren't cancerous. The malignant ones are.

Benign tumours tend to grow more slowly and are less likely to come back if they've been completely removed. They very rarely spread to other parts of the body, but if they haven't been completely removed they can sometimes start growing again after treatment.

Malignant tumours tend to grow faster. They sometimes spread to other parts of the body and may come back after treatment.

> “People say that once they hear the word ‘cancer’ that you switch off and don’t hear anything else, which I think is what my mum did.
>
> But I was the opposite. I was hyper aware and asked what we needed to do.
>
> I felt reassured to know there were good treatment options.”

Ellie

When people have brain tumours they're not always described as benign or malignant but might instead be given a grade between one and four. Grade one and two tumours are called 'low grade' and grade three and four tumours are called 'high grade'.

Search: 'types of cancer' on our website to find out more.

How did I get cancer?

Cancer is a lot of things, but it's not your fault.

There are some things that can increase the risk of getting cancer, known as 'risk factors'. Maybe you're worried about things you've done, like smoking or drinking or taking drugs. These things do have links to cancer, but there's almost no chance of them causing cancer in young people. But the simple, seriously unfair, truth is that cancer can just happen.

Cancer itself is actually pretty common. Around one in two people in the UK will be diagnosed with it at some point in their lives. But what's less common is getting it when you're young.

People aged between 13 and 24 make up fewer than 1% of cancer cases diagnosed in the UK each year. But remember, there are others out there going through the same thing as you right now – and we're here for you.

Can cancer be cured?

Yes, in some cases. If your doctor tells you you're 'in remission', that means you're no longer showing the signs or symptoms of cancer. Cancer treatments are improving all the time too, as more research is done into what causes it and what can get rid of it.

But sometimes cancer can't be cured. A lot of factors affect this – like the type of cancer you have, where it is and how advanced it is – but that's never an easy thought to deal with.

It's OK if you feel scared, in fact it's very common. Your doctor will tell you the truth about your situation, so if you want to know more, just ask. And remember that there's lots of support available, so you never have to face cancer alone.

Will it hurt?

We're always going to be honest and realistic. Some of your treatments – or the side effects of those treatments – might hurt.

Your doctors and nurses can help you manage any pain you have, so it's important to let them know if you're hurting. Painkillers can make it easier to keep doing the things you enjoy.

Who can I talk to?

Cancer can be hard on your mind as well as your body, which is why we've dedicated a whole section of this book to 'Your feelings', starting on page 103.

You can talk to whoever you feel comfortable talking to. That might be your friends, your family, your doctors and nurses, a psychologist or counsellor, or other young people who have cancer.

It's up to you – but speaking to people can sometimes really help you deal with issues. So if you're usually the strong silent type, it might be a good idea to think about who you feel comfortable talking to and approaching them to have a chat about how you're feeling.

How long does treatment take?

There's no definite answers to lots of these questions. Everyone is different, everyone's cancer is different and everyone's treatment plan is different. You might meet people who have the same type of cancer as you but are having less treatment – or more. There's no set formula – as we've said before, everyone's different and everyone's cancer experience is different.

Your medical team will look at your individual situation and write a treatment plan that's right for you and your specific diagnosis. It's really important to understand what's planned and why, so don't be afraid to ask any questions you might have. And remember: it's your treatment, so you've got the right to be involved.

Getting the right information

When it comes to your cancer treatment, there's no such thing as a silly question – and you can never ask too many questions.

If there's something that's worrying you or something you're not sure about, ask your doctors or nurses.

It's your body, so you've got every right to know what's going on.

You might want to find out every detail or you might want to only know the basics. It's totally up to you, there's no right or wrong option. You can also change your mind. If you start wanting to know more as your treatment goes on, just let your care team know and they'll be able to answer any questions you might have.

If you don't feel comfortable asking some questions in front of your carer that's absolutely fine. You can ask to speak to your care team on your own.

Speaking to doctors and nurses

It's OK to feel nervous before asking questions. Plenty of people feel awkward discussing their bodies and their feelings. And you might feel worried about what you could find out.

It can help to:

- Write down what you want to say beforehand. You can make use of the notes section at the back of this guide to write things down before, during or after your appointments so you can keep all the information in one place
- Share as much information as possible about any symptoms or changes you're experiencing – little details might seem insignificant to you but can make a big difference. This is important whether it's a face-to-face appointment or if you're speaking to your doctor over the phone or via email, try to include as much detail as possible
- Take a friend or someone from your family with you, or maybe someone from your care team. Whoever you choose, make sure it's someone you feel comfortable with who knows what you want to say and ask. You could also ask them to make notes for you if you want to concentrate on what the doctor is saying
- Be open and honest – remember that doctors and nurses talk to people about all kinds of problems all day, every day. They won't judge you or make you feel embarrassed for asking what you might think are awkward questions
- If you don't understand something you're told, you can ask your doctor or nurse to repeat it or explain it in a different way
- Everyone on your care team should listen carefully and answer all of your questions. If you feel like you're not being listened to, say so or ask to see someone else

Information overload

It can be hard to take in everything you hear, especially if you're feeling stressed or worried. You'll probably meet a lot of doctors and nurses and they might use a lot of unfamiliar words, so we've included a glossary on page 186 which explains what some common cancer words mean.

It can be surprising how quickly you get used to the language being used and you might even start using it yourself, but it's still a good idea to use some of the tips below.

- Write down the answers to your questions – there are pages for your notes at the back of this book or you could use the notes app on your phone
- If you don't want to worry about making notes, you can record your appointments and conversations on your phone so you can listen to them later and make sure you haven't missed anything. Don't forget to ask people if they're happy to be recorded, though!
- If you're finding something difficult to understand, you can ask the doctor or nurse to explain it in a different way or even draw what they're talking about if it would help
- Keep this book handy so you can double-check anything you don't understand! You can also take it with you to appointments or meetings with your nurse or Youth Support Coordinator if there are bits you want to talk through with someone

We've got a list of questions at the back of this guide on page 194 which might be useful to look through before your appointments.

“When I was diagnosed, the doctor used lots of technical terms that I didn’t understand… my Teenage Cancer Trust Nurse, Meg, took me into a room afterwards and chatted to me.

It was helpful having her there as she immediately explained everything in a really simple way.”

Josh

A quick note about the cancer registry

When you're diagnosed with cancer in the UK some information is collected about you in a registry. Each country has its own cancer registry.

They collect the following information:

- name and address
- age
- gender
- date of birth
- type of cancer
- when and how you were diagnosed
- what treatments you have had

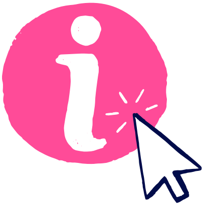
Your hospital passes on your information automatically, unless you ask them not to. The NHS and other organisations use this information for your care, or for health and social care planning or research. Like all medical records, there are strict rules to keep the information safe and secure.

Talk to your care team if you've got any questions about the registry. If you want to opt out, you'll need to contact the registry in your part of the UK. Your care team can give you details.

Use the internet carefully

Finding out more about cancer and your diagnosis can give you a better idea of what to expect and help you make better decisions about your treatment. But before you start searching online, remember to be careful.

There's a lot of good information out there, but there are also plenty of scare stories – and it's easy to get sucked in and worry yourself unnecessarily.



> “Rosa, Teenage Cancer Trust’s Clinical Liaison Nurse Specialist, took my dad and I into a room and told us about her role and how she could help us. That included answering any questions I had and giving me a big stack of information, which was fantastic as it covered all of my questions.”
>
> *Hannah*

These are our top five tips for good searching:

1. Use websites you trust

A lot of information online is out of date or just plain wrong. So try and stick with websites you know you can trust. You can always ask your doctors and nurses for recommendations. And it's a good idea to look for the PIF Tick logo. This means all information has been through a thorough process before being put online and has been checked by a range of experts. You can find out more about the PIF Tick and what it represents on their website **pifonline.org.uk**.

We've got a long list of trusted organisations who provide brilliant information on our website.

Search: 'useful contacts' on our website to find out more.

2. Don't believe everything

We'd love there to be a miracle cure for cancer. But while cancer treatment is getting better all the time, it's still the case that if something seems too good to be true, it probably is.

When you find an article or blog that looks useful, remember to ask yourself who posted this story and why. If you're not sure whether it's a reliable source of information or not, you can always ask a friend or family member to have a look too, or you can check with your care team.

3. Remember that everyone is different

There are a lot of very powerful stories and blogs online written by people who have cancer now or have had cancer in the past. Reading them can be a great way to feel less alone and to find out what treatments are really like.

Lots of people also choose to share their experiences on social media platforms like TikTok and Instagram. If you don't feel like reading then watching a video of someone sharing their story can be a nice way to break this up.

But remember that everyone has a different experience of cancer. People are diagnosed at different stages. The same treatments work better for some people than others. Your age, general health and a whole load of other things can make a difference too.

Remember: if something has happened to someone else, that doesn't mean it'll happen to you.

4. Look for balance

If you read one article, story or website that seems very negative or very positive about a particular treatment, check other websites to see if you get a more balanced picture. A lot of people have strong opinions about cancer, but that doesn't mean they're always accurate and it's good to get a balanced point of view.

5. Use the internet as a starting point

Think of the information you find online as a way to start conversations with your carer, doctors and nurses.

Ask questions about what you find online and discuss it with other people to see what they think. It might also be useful to make a note of useful websites you've found and show them to your care team on your phone in appointments to see what they think.

YOUR TREATMENT

YOUR TREATMENT

There are more than 200 types of cancer, all caused by cells in your body not doing what they're supposed to.

You can always speak to your doctors and nurses if you have questions about your diagnosis. They'll answer all of your questions and help you find more information if you want it. If you're confused by what they say, just let them know. It's really important to get answers that make sense to you.

You can find more information about specific types of cancer, including symptoms, diagnosis and treatment, on our website:

teenagecancertrust.org

Tests

Tests can become a regular part of your life when you have cancer. There are lots of different ways for your care team to check how your body is responding to treatment.

Some tests are quick and routine, others can be uncomfortable. How much you want to find out about them beforehand is up to you. Knowing what to expect can help with anything you might be worried about, but if you'd rather not know too much, you can skip to page 39. This information will always be here if you want to come back to it at another time.

What tests might I have?

Over the next few pages, we've included some details and explanations about the different types of tests you might have during treatment. You might have some, lots or none of these tests. If you have questions or want to find out more, just let your doctors or nurses know.

Biopsy

What is it?

A small sample of tissue taken from your body so the cells can be studied under a microscope for signs of cancer.

What's involved?

You'll be given pain relief or an anaesthetic before a biopsy to make sure you feel comfortable.

There are various ways of collecting the tissue sample. Depending on which cells are affected, doctors might use a hollow needle, or make a small hole in the skin, or carefully scrape cells away. It's also possible to have a biopsy during surgery. Your doctors and nurses will explain exactly what to expect in your specific situation.

The cells are then examined to confirm or rule out a cancer diagnosis.

Blood test

What is it?

Blood tests are used to monitor the amount of red blood cells, white blood cells and platelets in your blood, as these can all be affected by cancer and cancer treatment. Blood tests can also be used to measure how your liver and kidneys are working and to show the levels of nutrients in your blood.

What's involved?

Blood can be taken using a needle, central line, port/port-a-cath or PICC line. Lines and ports are tubes used during treatment to avoid having repeated injections. You can read more about them on page 46.

There are lots of different types of blood tests.

Some you might hear your doctors talk about are:

- **Absolute neutrophil count (ANC)** – Sometimes just called 'neutrophils'. Used to see how well your body can fight infection
- **Blood cultures** – Used to find out if there is an infection in your blood and which antibiotics you might need
- **Full blood count (FBC)** – Used to check the levels of red cells, white cells and platelets in your blood
- **Haemoglobin (Hgb or Hb)** Tested to check you're not anaemic or at risk of anaemia
- **Platelets** – Tested because chemotherapy drugs used to treat cancer can cause platelet levels to drop (platelets are the cells that stop bleeding). You can find out more about chemotherapy later on in this section

- **Red blood cells** – Tested because various cancers can cause red blood cell levels to drop (red cells carry oxygen through your body)
- **White blood cell differential** – Used to show the levels of different types of white blood cells in your blood
- **White blood cells** – Tested because various cancers cause the production of abnormal white blood cells (white cells fight infection)

Bone marrow biopsy

What is it?

Bone marrow is the soft, spongy tissue that's found inside some of your larger bones. During a bone marrow biopsy (sometimes also called a 'bone marrow aspirate'), a sample of your bone marrow is taken and examined under a microscope.

You might have a few bone marrow biopsies during your cancer treatment.

They help doctors to monitor the production of blood cells in your body, which is one way of tracking how your treatment is going. Sometimes very specialised tests are also performed on the bone marrow.

What's involved?

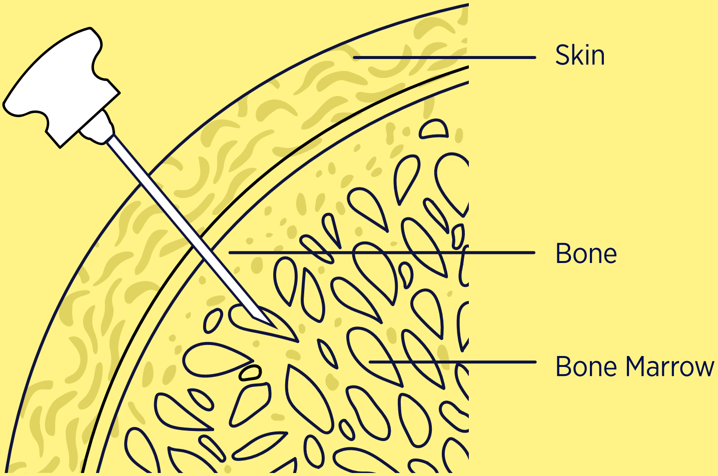
You'll be given pain relief or an anaesthetic before a bone marrow biopsy and then asked to lie on your side on an examining bed.

If you're given sedative medicine to help you relax, you'll quickly fall asleep and won't feel the biopsy. You might feel a bit washed out for a few hours afterwards as the sedative wears off.

If you're not given a sedative, you'll be given a local anaesthetic using a needle. The needle might sting but then the area will go numb.

A biopsy needle is inserted into your pelvic bone and a small amount of bone marrow is pulled out using a syringe.

Bone marrow biopsy



Once that's done, you might also have a small sample of bone taken. That's done using a different needle in the same part of your skin. They'll put a small bandage on afterwards to stop any bleeding, it's usually only a small amount.

It usually takes a few days for the results of a bone marrow biopsy to come back. In those first few days, your back might feel sore. Painkillers can help with this, so it's important to let your doctors or nurses know if you're achy or in pain.

Bone scan

What is it?

Bone scans can show up unusual things in your bones much earlier than X-rays, so they're sometimes used to test for bone tumours or to find out if tumours elsewhere in your body have spread to your bones.

What's involved?

Before a bone scan, you're given an injection of a small amount of radioactive liquid which is completely harmless.

Your bones absorb this fluid and then show up on a scan in areas where anything unusual is happening. This can include areas where there is a tumour or an infection.

After you're given the injection you usually need to wait a couple of hours to have the scan, so it's a good idea to take something with you to help pass the time. You'll be asked to drink plenty of fluids to help flush the injection through your body.

The scan usually lasts around an hour. You need to lie still while a camera moves around you. You might need to change position a few times, and you can usually have someone with you during the scan.

After it's done, you need to drink a lot of water to flush out the radioactive liquid. It's usually a few days until the results are ready.

CT scan

What is it?

A CT (Computerised Tomography) scan (sometimes also called a CAT scan) is used to create detailed cross-sectional pictures of your body from various angles. It can show exactly where a tumour is and how big it is.

What's involved?

During the scan, you usually lie on your back on a flat bed. A large tube, which produces X-rays, is then rotated around your body. You're usually moved continually through this rotating beam. You'll need to remove any jewellery beforehand.

CT scans are quick and completely painless, but you will need to lie very still to make sure the medical team can get a good scan. They normally last between five and ten minutes. You might be given a contrast solution (a liquid that's given to you either as a drink or via an injection) to help the different parts of your body show up more clearly on the scan.

The technician running the CT scan machine will be in a separate room, but you can talk to them using an intercom. It's worth checking with your care team whether you'll be allowed someone in the room with you when you're having your CT.

If you do have someone with you they'll need to wear a lead vest to protect them from the X-rays created by the CT machine.

The scan results will be used to build up a detailed picture that is then examined by a radiologist (a specialist in interpreting scans). You won't get the results straight away but your care team will be in touch with the results when they come through.

If you need to have a CT scan and you're confused about how it works and what to expect speak to your care team who can show you what the machine looks like before your scan.

ECG

What is it?

Certain chemotherapy drugs can weaken your heart muscle, so an ECG (electrocardiogram) is used to check that your heart is working well.

What's involved?

It's painless and usually takes about five minutes. During the test, electrodes (small, flat metal discs) are attached to your arms, legs and chest. Wires from these electrodes are connected to an ECG machine that records the electrical signals produced every time your heart beats.

Echo

What is it?

An echo (echocardiogram) is an ultrasound of your heart. Ultrasounds use high-frequency sound waves to show images of the inside of your body.

What's involved?

Someone will run a small microphone, called a probe, over the skin of the area that they're looking at. They'll put some gel on your skin first so the probe can move smoothly, this might feel cold but you won't feel any pain. Echoes are normally done by a doctor, radiographer or sonographer.

Hearing test

What is it?

Some chemotherapy drugs can affect your hearing. If these drugs are recommended for you, you'll have a hearing test before and during treatment to check for any changes to your hearing.

What's involved?

Doctors use various hearing tests to measure how your ears and nerves respond to sounds at different volumes and frequencies. This might involve wearing some headphones while the doctor plays different sounds at different levels. All of the tests are painless. An 'audiogram' is then produced – this is a graph that's used to record the test results.

Lumbar puncture

What is it?

A lumbar puncture is a test to check the fluid that circulates around your brain and spinal cord. This is usually done to check for cancer cells but can also be used to look for signs of infection or to measure the levels of certain chemicals in the fluid. Chemotherapy is also sometimes given through a lumbar puncture needle – this is called 'intrathecal chemotherapy'.

What's involved?

You'll usually be given a local anaesthetic before a lumbar puncture. This numbs the area before any fluid is taken.

You'll probably be asked to lie on your side with your legs curled up slightly. Your doctor or nurse will then put a hollow needle into your lower back and take a few drops of fluid from the space around your spinal cord.

After the test, the fluid is examined under a microscope for signs of cancer or infection.

Your doctor or nurse might ask you to lie flat for a few hours after the test to stop you getting a headache. If you do get a headache, painkillers should help so make sure you let your care team know if you're in pain.

MRI

What is it?

An MRI scan (Magnetic Resonance Imaging) is used to create cross-sectional pictures of your body and can show some types of tumours.

What's involved?

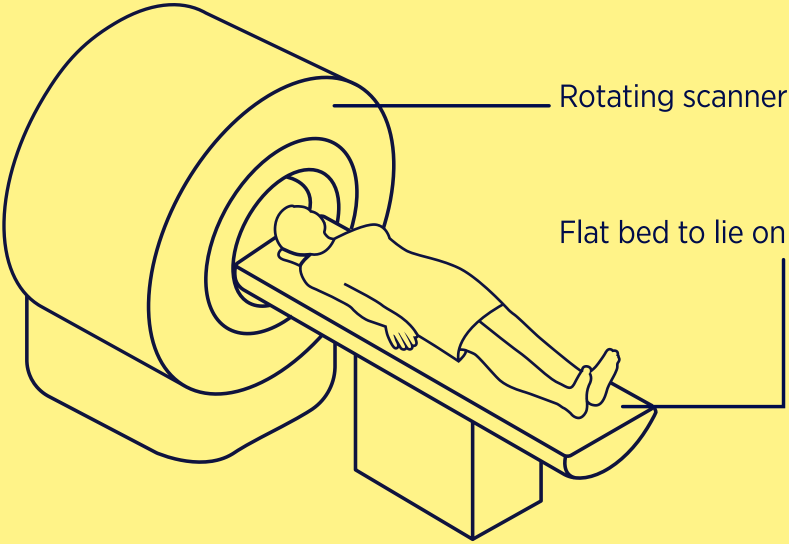
An MRI takes place in a large, tube-shaped machine. You lie on a flat bed inside the tube during the scan. You'll need to remove any jewellery beforehand.

Depending on which part of your body is being examined, you might be moved into the scanner feet-first or head-first. A radiographer (an expert in taking X-rays and other scans) then controls the scanner from a separate room. You can talk to them throughout the scan, and they can see you on a TV screen.

An MRI scan usually takes between 30 and 90 minutes. You will need to lie completely still. It can be noisy – you might hear humming or banging sounds, and you'll be given headphones or earplugs – but it's painless.

You might be given a contrast solution during your MRI. This will either be a drink or an injection. The liquid helps the radiologist to see the different parts of your body more clearly.

Scanning machines



PET scan

What is it?

A PET (Positron Emission Tomography) scan produces detailed 3D images of the inside of your body. It can show if any unusual lumps you may have are cancerous, whether cancer has spread and if cancer treatment is working.

What's involved?

You'll usually be asked not to eat anything between four and six hours before a PET scan, and you might also be asked to avoid caffeine for 24 hours beforehand.

You'll need to remove any jewellery beforehand.

Before the scan starts, you'll be given a radioactive substance called a 'tracer', either via an injection or by breathing it in as a gas.

The tracer gives off radiation that shows up on the PET scanner, and takes 30-90 minutes to travel around your body.

Once that's happened, you'll be asked to lie on a flat bed, which will then be moved into a circular scanner, which looks similar to an MRI or CT scan machine. You'll need to stay still during the test, which usually takes 30-60 minutes.

After the test, you'll need to drink plenty of fluids to flush the tracer out of your body. It can take a few days for your doctors to see the test results.

X-rays

What are they?

X-rays are safe in small doses. They are a type of safe, high-energy radiation, and passing them through your body means doctors can see tumours, bones and changes to organs and tissues.

What's involved?

Depending on which part of you is being X-rayed, you might need to strip down to your underwear and put on a gown. You'll need to take off any jewellery in the area that's being X-rayed too.

You can eat and drink what you like beforehand, unless you're having a barium X-ray, in which case you'll need to drink some barium. This is a white liquid that shows up on X-rays and can help doctors look at your stomach, bowel and other parts of your body.

The radiographer controls the X-ray machine and will make sure you're in the right position. It's very quick and easy and once the X-ray is done you can get dressed and head home or back to your ward. Your results will be sent to your doctors to discuss with you.

"I didn't leave the house much at all because I didn't want to catch anything and risk delaying my treatment.

Because I wasn't seeing many people, it helped to be treated around people my age and be able to chat with them.

Being with people in a similar situation allowed me to know that it wasn't just me. It wouldn't have been the same if they were older."

David

Common cancer treatments explained

Cancer is treated in lots of different ways – and getting your head around your treatment plan can feel overwhelming. This section should help you understand the main options.

When it comes to cancer treatment, there's no one-size-fits-all solution. Treatments are changing and improving all the time, and your doctors and specialists will work together to decide what's best for you. You might have one type of treatment or a combination of different types.

But whatever your treatment involves, it's really important that you understand what's planned and why – so never be afraid to ask.

Chemotherapy (Chemo)

Chemo uses drugs, called 'cytotoxics', to kill off the cells that cause cancer.

There are lots of different types of chemo. It works by attacking and destroying fast-dividing cells – which are exactly the kind of cells that spread cancer around your body.

But it also means that chemo attacks other, healthy, fast-dividing cells, like hair cells – which is why it can cause side effects like hair loss. You can find out more about other possible side effects on page 62.

When is it used?

Chemo is sometimes the only treatment you're given, but it's also used alongside other treatments, like radiotherapy.

It can be used before surgery to kill cancer cells and shrink tumours or after surgery to prevent cancer returning.

It can be used as a medicine to help you feel better if your cancer is very advanced.

What's involved?

Chemo is often given in cycles. This means you have treatment for a certain amount of time, and then stop the treatment for a certain amount of time before this process is repeated. The time in between drug treatments helps your body to recover from the effects of the chemo.

You might be given one drug or a combination of drugs, depending on the type of cancer you have. There are different ways to have chemo – you might be given the drugs via an injection, an infusion into a vein (known as an 'IV infusion') or as tablets or medicine. You can find out more about IV infusions on page 46.

How long does it take?

The length of your chemo treatment depends on the type of cancer you have. You might have daily, weekly or monthly treatment, and treatment can last for anywhere between a few months and several years depending on your diagnosis.

Radiotherapy

Radiotherapy uses radiation in the form of high energy X-rays to treat cancer cells.

It's also sometimes used to ease symptoms caused by cancer.

When is it used?

Radiotherapy can be used at different points during your treatment, depending on the type of cancer you have. You might have it on its own, instead of surgery or as well as other treatments.

It can be used before surgery to shrink a tumour before it's taken out, or it can be used after surgery to treat any cells that may have been left behind.

This reduces the chances of the tumour coming back.

Chemotherapy can be given before or after radiotherapy, or at the same time.

How does it work?

Radiotherapy damages the DNA in cells. Cancerous cells find it more difficult to repair themselves, which means they die as a result of this damage. DNA in healthy cells is also damaged in the process, but they can repair themselves.

The treatment is as accurate as possible to avoid damaging any healthy cells.

Types of radiotherapy

There are lots of different types of radiotherapy, some are internal and some external.

Internal radiotherapy involves delivering radiation directly to the tumour, using either radioactive liquids, tablets, injections or implants. Some of these carry on giving out radiation, so you might need to stay in a hospital room by yourself for a few days until radiation levels reduce.

External radiotherapy uses a type of X-ray that goes inside the body and can treat organs or bones.

Proton beam therapy is a different type of external radiotherapy. Proton beam therapy delivers energy to a very specific point which means the radiation can accurately target a tumour without affecting too much of the healthy tissue around it.

This isn’t suitable for everyone, and it’s currently only available in certain hospitals. If proton beam therapy is the best option for your treatment, your care team will talk to you about this, including how it will work and where you might have to have it done.

How long will it take?

The amount of radiotherapy you need depends on your diagnosis.

For external radiotherapy it can range from one to 35 treatments.

Treatment can be as quick as 15 minutes each day, but more complicated treatments can take up to an hour.

If you're having internal radiotherapy your care team will let you know how long you will have to stay in hospital.

Surgery

Surgery is used to treat cancerous tumours.

If your cancer hasn't spread, surgery might be the only treatment you need. It's used to cut out a tumour and a small amount of healthy surrounding tissue – to make sure as many cancer cells as possible are taken away. Sometimes chemo and radiotherapy are used after surgery to kill any remaining cancer cells.

What's involved?

The type of surgery you have depends on the type of cancer you have. Some cancers can be treated using keyhole surgery, when a surgeon inserts a camera into your body and removes the tumour looking at footage on a TV screen. For other cancers they might have to make a bigger incision (cut) to remove the tumour.

Your surgeon and care team will talk you through everything beforehand, and you'll have a general anaesthetic so you won't be awake during the operation.

How long does it take?

The length of your operation depends on the type of cancer you have and where it is. Sometimes if a surgeon finds your cancer has spread more than expected, your operation might take longer than planned. But your doctors will let you know how long it will last – and how long it might take you to recover, too.

Immunotherapy

Immunotherapy is a newer form of treatment.

It helps your own immune system recognise and kill the cancer cells. You might be offered immunotherapy in combination with other treatments.

What's involved?

There are different ways of taking these drugs, depending on your cancer. It could be by injection, through a drip, as a tablet or even as a cream on the skin.

How long does it take?

Treatment could be every day, week or month – again, it depends on your cancer. You might have treatment in cycles – with breaks in the treatment so your body can rest, respond to the treatment and build up healthy cells.

Bone marrow transplants and stem cell transplants

Transplants are used to help your body recover after high-dose chemotherapy, or to replace your bone marrow cells with healthy bone marrow from another person.

Bone marrow is the stuff inside your bones that makes blood cells. Stem cells are the cells made by your bone marrow, that develop into blood cells. Higher doses of chemo are more likely to kill cancer cells but will also damage more of your bone marrow and stem cells. So you're given a transplant of bone marrow or stem cells to replace what's destroyed by chemo.

What's involved?

High-dose chemo usually takes five or six days but it can be longer or shorter. You might also have radiotherapy to kill any remaining cancer cells. Your bone marrow or stem cell transplant happens after that.

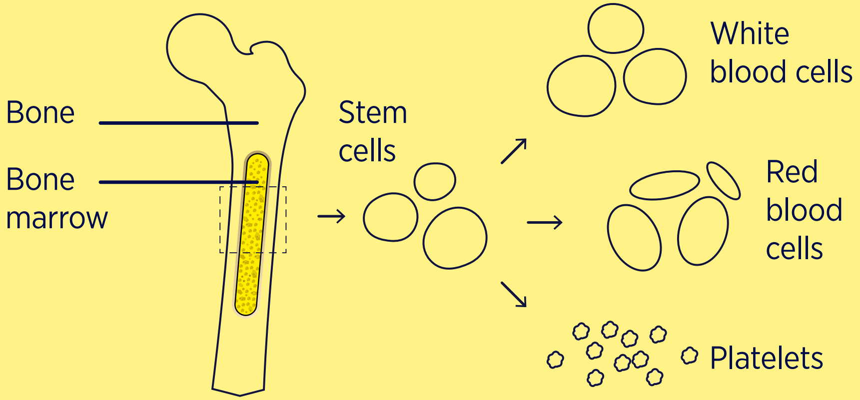
Types of transplant

The type of transplant you have depends on lots of different things, like the type of cancer you have and any treatments you've already had. Your doctors and nurses will talk everything through with you beforehand – and if you have any questions, just let them know.

Staying in hospital

Because your immune system will be weakened by the transplant, you'll stay in a single room in hospital for a few weeks where you won't be in contact with many people so you have less chance of picking up an infection. You can't have many visitors and it can get pretty boring, so you might like to decorate your room with photos and bring home comforts and things to keep you occupied, like books and films.

Bone marrow transplant



Steroids

You might be prescribed steroids alongside other treatment. These are usually ‘corticosteroids’.

Steroids might be used to treat the cancer itself or they can be used to reduce symptoms or side effects while you have another kind of treatment.

They might be tablets, a liquid you drink, or an injection. You usually take them for a few days or weeks.

You can find out more about the potential side effects later in this section.

Complementary therapies

Complementary therapies are used alongside the conventional treatments described above.

Examples of complementary therapies include art therapy aromatherapy, acupuncture, herbal medicine, massage therapy, meditation, visualisation and yoga.

They’re not intended to cure your cancer, but that doesn’t mean they won’t help you feel better. It’s really important to talk to your doctors and nurses about any complementary therapies you’re thinking of using, though, because some might not mix well with certain medicines, including chemo drugs.

It’s also important to know the difference between complementary therapies and alternative therapies. Alternative therapies are used instead of conventional treatments like chemotherapy and radiotherapy – and many are unproven.

If you are thinking about using alternative therapies, you should talk to your care team. Your doctors and nurses will be able to advise what’s best for you.

Questions to ask

Never be afraid to ask questions! When you're talking about treatments with your medical team, you might like to ask:

- Exactly what type of treatment is being recommended?
- How long will my treatment last?
- What side effects might I have and how can I reduce them?
- What is the treatment meant to achieve?
- How effective is my treatment likely to be?
- Are there any other treatments that might work?

What's an IV?

There's a good chance that during your cancer treatment you'll need various medication and liquids to be delivered straight into your bloodstream.

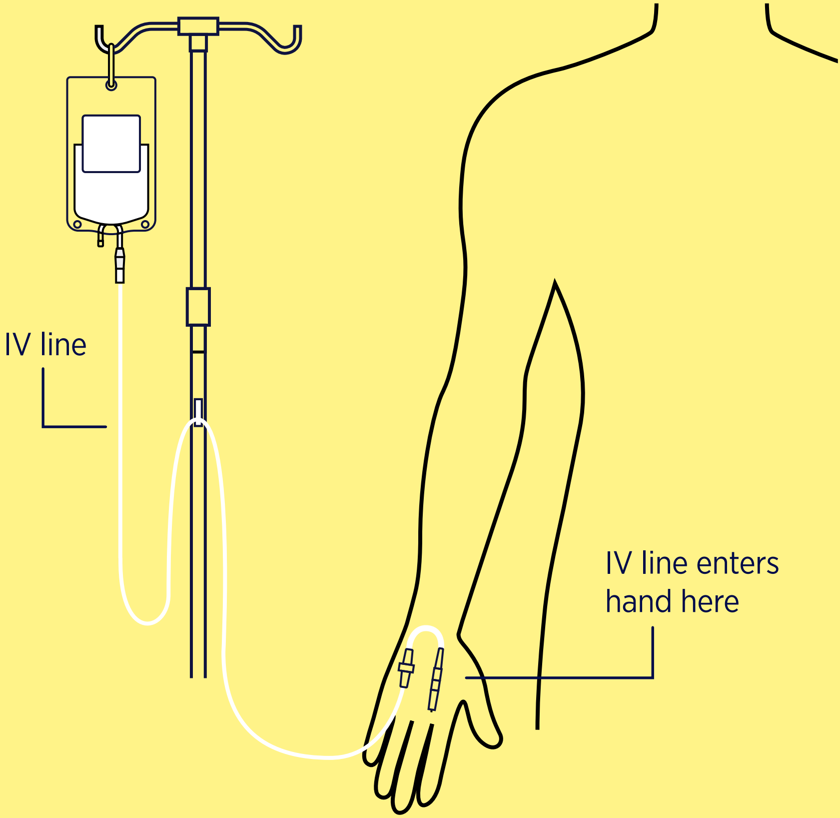
You might need antibiotics, chemo drugs or blood products (transfusions). And you'll probably need to have lots of blood tests to check how you're doing, too.

Your doctors and nurses could do all of these things by giving you lots of different injections. But usually you'll have an IV line inserted instead.

IV is short for intravenous, which means 'into the veins'. And the good thing about having a central IV line is that it's connected directly to one of your major veins, so you avoid multiple needles being used. Instead, all drugs and fluids are given to you from this one line. Blood can be taken using the line too.

There are different ways of doing this. You might be given a central line – Hickman lines, Port/Port-a-caths and PICC lines are all types of central line. Or you might be fitted with a flexible tube called a 'cannula'.

IV line



Hickman lines

A Hickman line is a long, soft, thin tube inserted under the skin so that one end lies in a vein just above your heart, with the other end lying outside on your chest. You'll have a local anaesthetic, so you won't be able to feel this being done. The other end of the tube splits into smaller tubes, which hang outside your body. These are used to give you drugs and fluids.

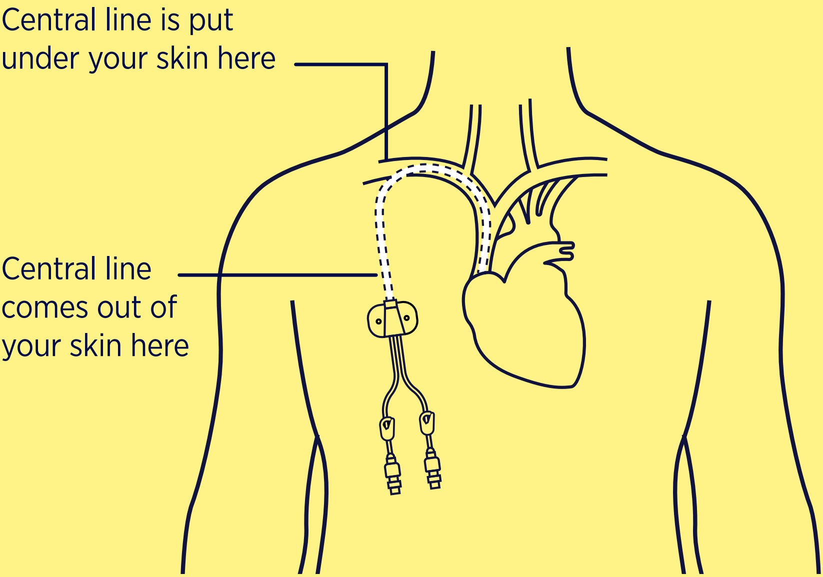
It might all sound a bit scary, but it's a really clever piece of equipment – and it can be a better option than lots of injections.

Taking care of a Hickman line

Your Hickman line is designed to stay in place, so you don't need to worry about it coming out while you move around or sleep. But you do need to be careful not to get it wet. Your nurses will let you know how to keep it dry when you have a bath or shower, and they might recommend you don't go swimming. They'll also show you how to change the sterile dressing.

You'll hopefully get used to having your Hickman line in quite quickly, and if you have any questions about what you can and can't do or how to keep it clean then you can ask your care team.

Hickman line



Port/port-a-cath

A port/port-a-cath is similar to a Hickman line. Instead of having lumens outside your body, though, the end of the line is completely under your skin. It's another way for your medical team to get drugs and fluids into your system without using lots of injections in different places.

How does it work?

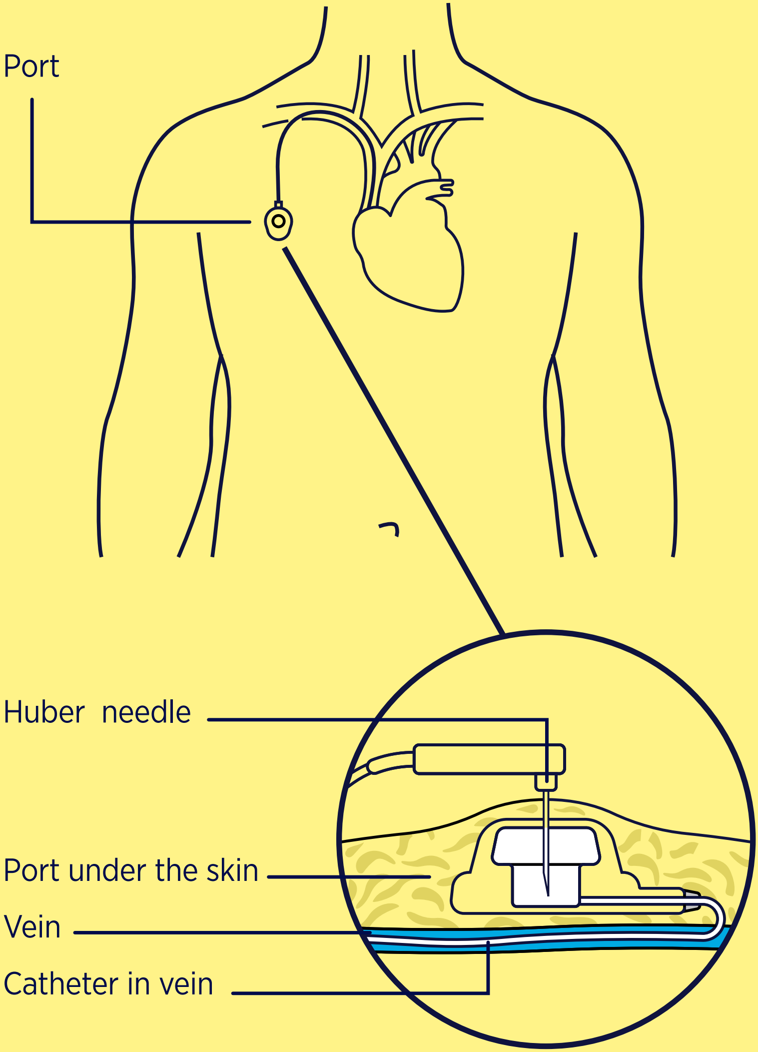
You'll be given either a general or, more commonly, a local anaesthetic. A tube is then inserted into a vein near your heart and connected to a small device, which is implanted under your skin (you'll be able to feel a bump where the device is). The device is very small, only around 2–4cm in diameter.

A special needle with a tube attached to it (called a Huber needle) is then used to give you drugs and fluids through the box, and to take blood samples. The needle can be removed after your treatment.

To begin with you can use an anaesthetic cream to numb the skin above the box before a Huber needle is put in, but the skin soon gets very tough, so you won't feel much.

If you have a port/port-a-cath fitted, you can still swim and shower and you don't need to worry about sterile dressings. It just needs to be flushed out occasionally to avoid blood clots and infections.

Port/port-a-cath



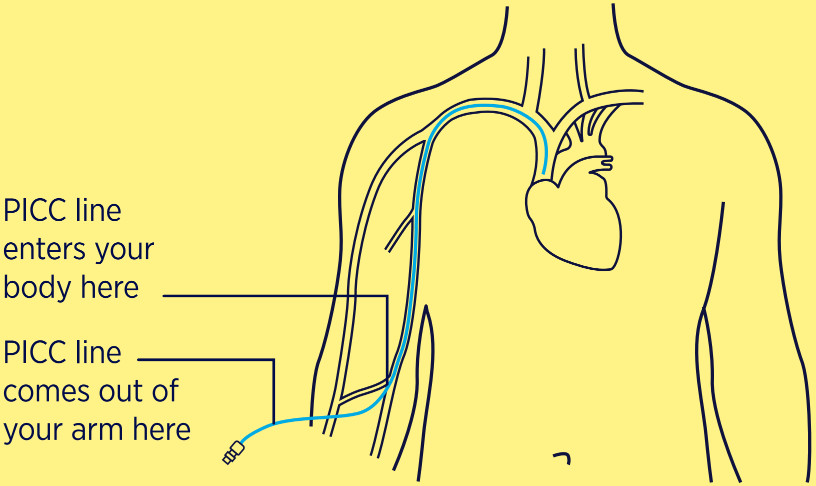
PICC line

A PICC line (Peripherally Inserted Central Catheter) is another type of central line that's used to give you medication and fluids. It's a thin tube, about 60cm long, that's inserted into your upper arm and passed into a vein near your heart.

You're given a local anaesthetic before it's fitted, so you won't feel anything.

A PICC line can be left in for several months and is often used for short-term treatment or until you have surgery to have a more permanent central line or port-a-cath fitted.

PICC line



Cannula

Depending on your treatment, you might not need a permanent central line. But you probably will need some IV procedures, and these will usually be done using a cannula.

A cannula is a small tube that's put into your hand or arm. It can only stay in for a few days, but may still be used as part of your cancer treatment.

Getting used to your IV pump

If you're given medicine and fluids through an IV line, that line will be connected to an IV pump, which keeps everything flowing into your veins at the right rate. The drugs and fluids are usually hung on a pole that's connected to the pump.

IV poles are on wheels so you can move around during your treatment. Some pumps are designed so you can carry them around in a small bag.

If you don't have an IV line...

Even if you don't have a central line or a cannula, you may still need to have blood tests taken through a needle in your arm.

It's not usually too painful, but don't be afraid to let your doctors and nurses know if you're not a fan of needles. Your care team can give you an analgesic (pain relieving) cream that can help to numb the area, and reminding them to switch between your arms if you're having regular injections can help too.

Will treatment hurt?

It's probably one of your biggest questions. And unfortunately the truth is that some of your treatments and some of the side effects might hurt.

That doesn't mean you're going to be in pain the whole time or that every treatment you have will hurt. But it does mean that you probably will experience some pain during your treatment.

It's important that you tell your doctors and nurses if you're in pain. Painkillers can really help ease the pain and discomfort, and will help you keep doing the things you enjoy. Everyone experiences pain differently, so try not to compare how you're feeling with other people. And don't be tempted to tough it out – it might make things harder.

Causes of pain

Unfortunately, there are times when you might feel pain. Tests including biopsies, lumbar punctures and bone marrow tests can be painful. You'll have an anaesthetic or painkillers before any of these, but they might still cause you some discomfort.

Treatments including chemotherapy and surgery can be painful. Chemo can sometimes cause side effects like mouth sores, constipation and joint pain, and the place where you've had surgery can be sore after the anaesthetic has worn off.

Radiotherapy can also have a number of side effects. These side effects are most likely to depend on where in your body your cancer is and therefore where you have had the radiotherapy. You can ask your care team for more information on the type of side affects you might have after radiotherapy.

Tumours can be painful if they press on your bones, nerves, spinal cord or organs – although treatment should help to reduce this pain.

Dealing with pain

There are lots of different ways to relieve any pain you might experience. The most important thing is to mention it to your doctors and nurses, who will talk you through potential options. It can be useful to make a note of when and where you're in pain and how long it lasts for. You can use the notes section at the back of this book to keep track and then share with your care team.

Pain management is an important part of your treatment, so you're given the drugs that are right for you, and when the pain stops, you stop taking them.

Dealing with treatment

There might be parts of your treatment that make you feel stressed. Maybe you don't like needles. Maybe you don't like hospitals. Whatever it is, feeling anxious is nothing to be ashamed of. In fact it's very common.

It can really help to talk about it. Your care team and support team will be able to help you with techniques to manage anxiety and approach treatments differently. They can also help you to think about what helps you to relax and how you can incorporate these things into your treatment.

You could try:

- Listening to music
- Taking someone with you who's good at distracting you
- Trying meditation or relaxation techniques
- Speaking to a psychologist or counsellor
- Using analgesic cream to numb your skin if you're worried about having an injection
- Hypnotherapy to help relieve stress and anxiety
- Speaking to an occupational therapist who will be able to help you to identify and overcome any difficulties you may be experiencing
- Speaking to a physiotherapist who will be able to help with any physical problems you might be experiencing as a result of cancer and its treatment

Everyone involved in your treatment wants to make things as easy as possible for you. So if you need support, just ask for it. You never have to face cancer alone.

Having your say

Cancer can leave you feeling totally out of control – that's completely understandable. Your treatment is about you, so don't be scared to ask questions and be honest with your care team about how you're feeling, both mentally and physically.

You might feel really overwhelmed at times, especially if you find yourself in a whirlwind of doctors and nurses all talking about your treatment using jargon you just can't get your head around.

If you have questions or want to know about other options or just want people to slow down and talk you through what's happening in normal language, say so.

Writing down questions beforehand can help. We've got a list of suggested questions you might like to ask on page 194 and you can use the notes section from page 199 to write things down.

Maybe you want to delay your next round of chemo until after an exam. Maybe your friends want to come and see you but they can't make it during normal visiting hours, your care team might be able to arrange for them to come another time. Maybe you want to leave hospital for a couple of days to go on a school or college trip.

Whatever you're wondering and however you're feeling, you can speak to your care team.

It can be hard to speak up, but it's usually one of those things that seems much worse in your head than it actually is. The people around you are there to support you and you should let them know what's important to you if you can.

Making decisions

It's absolutely fine if you want your carer to make all of the decisions about your treatment.

You might also want to have your say but struggle to get your carer to listen to you. They're probably worried and want to do what seems best, but it can be frustrating at times.

If you find yourself in this situation, try to let them know how you feel. If you are over 16, it's usually possible for you to make decisions about your treatment without your carer's input.

But it's usually better for everyone if you all discuss the options together. So gently remind your carer that you're an adult and that you'd really like to have a say in your treatment too.

Search: 'consent to treatment' on **nhs.uk** to find out more.

Clinical trials

Doctors, scientists and researchers are constantly working to discover new cancer treatments and to improve the ones that already exist. They do this by running clinical trials and you might be given the option to take part in one.

What are clinical trials?

Clinical trials are a type of research used to find out if new treatments and techniques (or a new combination of standard treatments) are more effective than the ones that already exist. They do this by giving people the new treatment and keeping track of how they respond to it. It's a really important part of developing new and improved treatments.

Clinical trials might test:

- New drugs
- New types of radiation therapy
- New surgical methods
- New ways to combine treatments
- New treatments like gene therapy

You might be given the option to take part in a clinical trial as part of your treatment. If you are given this option, you can ask as many questions as you need to and weigh up the pros and cons before you decide if you want to be involved.

Search: 'clinical trials' on **cancerresearchuk.org** to find out more.

“London is around four and half hours away, compared to Bristol being two hours away, but it is one of only four hospitals in three countries delivering the clinical trial, so I didn’t hesitate at going for it.”

George

Is it safe?

Clinical trials happen at the end of a long, tightly controlled process. Doctors and researchers will only suggest you take part in a clinical trial if they think it's right for you.

All clinical trials are designed to be as safe as possible, and young people tend to be involved in 'Phase 3' trials. These trials compare new and existing treatments to see which ones work best.

Many of the standard treatments for cancer started out in clinical trials, and many people now have a better quality of life thanks to knowledge gained during clinical trials.

Search: 'clinical trials' on **nhs.uk** to find out more about the different phases.

Is it worth it?

It's completely up to you whether you want to take part in a clinical trial.

It's important to remember that the treatment you are given during a clinical trial may or may not be better than existing treatments. That's what the trial is designed to find out.

You'll be closely monitored, probably more so than normally during cancer treatment. This means any changes to your health will usually get picked up quickly.

By testing new treatments, you're also helping to improve the care given to other young people with cancer in the future.

What's involved?

Phase 3 trials usually involve hundreds of people in lots of different places. A computer randomly splits everyone into two groups.

Half of the people will be in the trial group and will be given the new treatment. The other half, called the ‘control group’, will be given the best treatment that’s already available. The results are compared to see which treatment is most effective. Neither of the treatments will have a negative effect or make you more ill.

You won’t know which group you’re in and being involved in a trial means you might need to have more check-ups than normal, and these might last slightly longer. You might have more blood tests, scans and other tests too.

If your doctors think the trial isn’t working for you, they’ll take you off it. And, if you’re not happy, you can withdraw at any point. Your doctors will understand, it won’t affect the rest of your treatment and you won’t be asked any awkward questions.

Where do clinical trials happen?

Clinical trials take place in lots of different hospitals so you might not need to travel a long way to take part in one. However, some trials do only take place in big centres – particularly if they involve rare cancers or use new drugs. Taking part in one of those trials might mean you have to travel away from home to take part.

Can I ask questions during the trial?

Definitely. The research team has a duty to make sure you understand what’s going on. So ask as many questions as you can think of. You’ll be given the contact details for someone you can talk to at any time as well so make sure you make use of that if you have questions or concerns.

Is a clinical trial right for you?

Only you can decide if you want to get involved in a clinical trial. Our advice? Ask as many questions as you like. Write them down before appointments so you don't forget anything – you can use the notes section in the back of this guide to keep track of everything. Find out exactly what's involved. Talk it through with people close to you. Make sure you understand what's involved. And don't rush into a decision.

Remember, it's not a problem at all if you choose not to get involved.

Alternatively, if you're interested in getting involved in a trial but it's not been mentioned, talk to your doctors. They might know about a trial that would be suitable for you.

There are different phases of clinical trials and they are usually classified between 0-4.

Side effects

Now you've read about the different types of treatment you might have, you probably want to know how they're going to make you feel. In this section you'll find lots of information on possible side effects and how to manage them.

Your body will react to cancer treatments. It's important to remember that everyone reacts differently, but you might experience some pretty unpleasant side effects on the way to getting better.

The type of side effects that you have depends on a lot of things, including the type of cancer you have and the type of treatment you're having. You might experience short term or long term side effects.

Everyone experiences cancer differently, so try not to compare yourself to other people.

It can be helpful to have an idea of what might happen. So take a look through this section and remember to ask your doctors and nurses if you've got any questions.

Short-term side effects

Some of these can be pretty uncomfortable, but they usually go away once your treatment is finished.

Feeling sick

Some chemo and radiotherapy treatment can leave you feeling sick. Nausea usually starts a few hours after treatment – and can last for quite a while, sometimes up to a week. Treatment will affect everyone differently, let your doctors and nurses know if you do feel sick. There are different medicines that can help and might stop you from throwing up, tell your care team if you still feel sick and they might be able to try another option.

If you do feel sick after chemo, then the tips below might help you manage it:

- Avoid your favourite foods. If you eat them when you're not feeling well, they might make you sick and put you off eating it in the future. It's best to hold off until the nausea has passed and you can enjoy it properly
- Keep a sick bag/bowl handy
- Eat small, frequent meals and snacks – big meals can be hard to tackle and feeling really hungry can make you feel worse
- Chop up food into small pieces so it's easier to swallow
- Eat your main meal whenever you feel best, even if that means eating things at strange times
- Avoid foods that smell strong

- Choose drinks that will give you a boost like milk or fruit juices, they can also help with any funny tastes you might have in your mouth after chemotherapy
- Take it easy and relax after you've eaten
- Eat with other people to take your mind off your food if you're feeling sick
- Get plenty of fresh air
- If you start to feel like you might be sick, taking deep breaths can really help

Eating during treatment

Some treatments can affect your appetite and cause you to put on, or lose weight.

If you have problems with your appetite, weight gain, weight loss or anything else to do with eating, you can always ask your care team to refer you to a dietician.

If you're losing weight...

Your medical team will suggest ideas that could help you gain weight. You could try:

- Eating foods that have a lot of calories like ice cream, cheese, milkshakes or yoghurts
- Concentrating on getting plenty of protein-rich food – like beans, eggs, fish, meat and nuts
- Your dietitian might also prescribe a special nutritional drink which is high in energy to help with weight loss

If you're gaining weight...

Some treatments – particularly steroids – can cause you to put on weight. If you do put on a few pounds during cancer treatment, though, it's really important that you don't avoid eating to try and stop putting any more weight on. Weight gain during treatment is usually temporary, and right now your body needs energy to help fight your cancer.

"The second chemo drug made me feel really nauseous and sometimes even just having a shower was a big achievement and I would lie on the sofa for the rest of the day."

Amy

You might find you put on weight in particular places. Some people get chubby cheeks, for instance. This can be really frustrating, but dieting won't change this because it's a side effect that continues during treatment.

If you do put on weight, it's OK to feel a bit self-conscious. But focus on getting through the treatment. You can ask to speak to a dieititian who can review your diet and help you plan what to eat. They'll also take into account the type of cancer you have, your dietary requirements and whether you're struggling to eat certain things.

Try to focus on:

- Eating healthily. This can help you to avoid long-term weight gain (rather than weight gain caused by your treatment)
- Filling up on plenty of fruit and veg
- Drinking lots of water
- Being active when you can. You don't have to go to the gym, but when you feel up to it, it can help simply to be up and about doing everyday things
- Wearing clothes you feel comfortable in
- Talking about how you feel. Let people know if you're worried about your weight – keeping your feelings to yourself usually makes them worse

Trekstock support people in their 20s and 30s who have had cancer and have lots of information on nutrition and getting active. Find out more on their website **trekstock.com**

Fatigue

Some cancer treatments – especially chemo – can leave you feeling really tired and totally wiped out, this is called fatigue. Even after your treatment is finished, you might feel really tired. It can be frustrating, but try and be patient.

Give yourself time to recover. Eat well. Sleep when it's safe to. Go to bed around the same time each night. Don't overdo it. And let other people help you out.

Being active can really help to combat tiredness: sometimes just going out for a walk can make you feel more awake.

It might be hard to believe but often, the more you do, the more you feel able to do – so take it easy, but give it a try. If you're feeling very tired, you might find your mood is affected. It's pretty common to feel low if you've not got the energy to see friends or do what you usually enjoy doing. If that sounds familiar, you don't need to struggle in silence. Turn to page 108 for some ideas for dealing with low moods.

MOVE Charity supports young people with cancer who want to get back into activity and exercise. Find out more at **movecharity.org**

Mouth problems

Chemo can cause mouth ulcers, and you might have a sore mouth and/or throat during and after treatment. This can also temporarily affect how some foods taste.

Painkillers can help and your care team might suggest using a liquid pain relief specifically to help with any discomfort. Eating ice lollies can also help relieve pain, but try and avoid ones with sour citrus flavours like lemon, lime and orange as they might make your mouth feel worse, try red ones, which are usually berry flavours. Try to avoid crunchy food and very hot or cold drinks.

It's important to take care of your teeth and gums – so brush very carefully using toothpaste and a soft brush. Sometimes using a children's toothbrush can help, and some mouthwashes can come in handy if you find it painful to brush or if your gums bleed.

Check with your care team before using mouthwash though as they may be able to prescribe a specific one to help.

If you're finding it really difficult to swallow, your doctors might recommend using a nasogastric tube. That's a thin tube that's put into your nose, down your throat and into your stomach. Having it put in can be a bit painful, but it only takes a few minutes – and it means food can be given to you through the tube in liquid form, so you don't need to swallow it.

Hair loss

Even if you're expecting it, this one can be a shock.

You might lose your hair if you have chemotherapy. Radiotherapy can also cause hair loss on the specific part of your body where you've had the treatment. In both cases, it happens because the treatment kills fast-dividing cells. Cancer cells and hair cells are both fast-dividing cells, and the treatment can't tell them apart.

Not everyone loses their hair – if your hair doesn't fall out, it doesn't mean your treatment isn't working.

It's not only the hair on your head that can be affected. Your eyebrows, eyelashes, underarm hair and pubes might fall out too, but it all usually starts growing back a few weeks after your treatment finishes. It sometimes looks different though, and can be thinner, thicker, curlier, straighter or a different colour.

Dealing with hair loss can be tough, because every time you look in a mirror you're reminded of it. But these ideas might help:

- If you've ever wondered about trying a new look, now's the time
- If your hair could fall out, think about trying out the clippers or the hair dye before it does. You could get your friends over to do the shaving and dyeing
- If you've got long hair, experiment with shorter hairstyles now. It can make hair loss seem less of a leap
- Try out scarves, hats, turbans or whatever suits you best
- If you do lose your hair, try and learn to love your new look. Show the world that bald is beautiful
- Find some support groups who can put you in touch with other young people who've lost their hair. It's a good way to get tips from other young people in the same position
- Ask your nurse or Youth Support Coordinator about places that can provide wigs for you. The NHS and various charities can arrange this
- It might be hard but try to remember that hair loss is only temporary – and once you're done with treatment, you can decide what you want to do with your hair from now on

Look Good Feel Better run workshops to provide practical advice about changes to skin, eyebrows, eyelashes, hair, nails and body confidence, find out more on their website **lookgoodfeelbetter.co.uk**

Cancer Hair Care also offer a free hair loss advice service which is run by trained NHS Clinical Specialists. Find out more on their website **cancerhaircare.co.uk**

Chemo brain

It's not a medical term, but some people say during chemo they feel spaced out, sleepy, and that they struggle to concentrate and remember things. It's often known as 'chemo brain' or 'brain fog', and it's usually caused by medicines that you're taking.

If you feel like this, keep yourself safe. You shouldn't drive or do anything too physically draining. It can help to keep a journal of when you take your medicines, too, so you get a better idea of which ones might be causing you problems.

And using a diary or putting reminders in your phone can be helpful if your memory isn't as good as it normally is. A pill box can also help organise your medication and help you keep on top of when you need to take certain things. The symptoms tend to improve once you stop treatment, but they can occasionally last for some time.

If you're worried about the way you're feeling, talk to your care team.

> “Because I was upset, Dad told me that when he shaved my hair, I would be allowed to shave his in return. We were going to do this together.”
>
> **Jake**

Infection

This is often caused by your immune system being low, sometimes called ‘neutropenia’ or ‘being neutropenic’. It’s one of the most serious side effects of chemotherapy.

Symptoms of an infection can include:

- A temperature above 38°C
- Your skin feeling hot to touch
- Feeling cold or shivery
- Achy muscles
- Tiredness
- Stinging or pain when you go to the loo
- Diarrhoea
- A headache
- Confusion or dizziness
- Pain when swallowing
- A sore mouth
- Coughing or shortness of breath
- Pain, redness, swelling or any discharge from a cut or near your IV line
- Pain that you didn’t have before your treatment

If you think you have any of these symptoms or suddenly feel very unwell during chemo treatment (even if you don’t have a temperature), you must seek medical help as soon as possible.

If you wake up during the night with any of these symptoms don’t wait until the morning, it’s important to get help straight away.

When you start your treatment, your care team will explain this to you and will let you know what to do if it happens, which hospital to go to and who to contact. It’s a good idea to write this information down so you have it ready if you need it.

Other short-term effects

- Diarrhoea
- Irritated skin
- Spots
- Achy, flu-like symptoms
- Breathlessness and dizziness
- Bruising or bleeding easily
- High blood pressure

If you experience any of these you should let you care team know. They will be able to help you with medication to ease these side effects.

Search: 'side effects' on our website to find out more.

Late effects

There is a chance you could still get side effects after your treatment is finished. This doesn't happen to everyone and it doesn't mean your cancer is back – but it can be frustrating and scary.

You might hear these called 'late effects', 'late side effects' or 'long-term side effects'. They're actually slightly different.

Long-term side effects start during or shortly after treatment and don't go away within six months of treatment ending. They might eventually go away, or they might be permanent.

Late effects are a delayed response to treatment, and you can get these months or even years after treatment.

Whichever ones you have and whatever people call them, they can be really annoying and seem completely unfair. In this section, we'll use the phrase 'late effects' to cover both types – because what we're really talking about here are symptoms that carry on after treatment, regardless of when they started.

Remember: not everyone gets late effects!

Why do people get late effects?

Late effects happen because some cancer treatments, including surgery, radiotherapy, bone marrow transplants and some types of chemo, can do damage to healthy cells as well as cancerous ones. This can cause problems that take months or sometimes years to appear.

What happens?

Potential late effects vary depending on what kind of cancer you had, where it was, how it was treated and how old you were. Your doctor or nurse will let you know which effects (if any) have been associated with your cancer. And at the end of your treatment, you should also be given a treatment summary that explains any potential late effects and lets you know what to look out for. If you're not given one of these it's good to ask for one. You'll have regular check-ups, too, to increase the chances of picking any side effects up early.

What can you do?

Late effects can be really hard to deal with, but it can help to identify and deal with them as early as possible. To help with that it's important you:

- Ask your doctor or nurse if you're likely to have late effects
- Go to your follow-up appointments and tell your doctors about any problems you're having
- Keep a detailed record of your cancer treatments and your care plan – if you haven't got a care plan you can ask your doctors and nurses about it. This can help doctors you meet in the future who weren't involved in your cancer treatment. You can also use the notes section in the back of this guide to write any other details down that you think are important too

- Look after yourself – a healthy lifestyle (eating well, exercising, not smoking) can reduce the impact of late effects

If you do experience late effects, it might help to look at our tips for coping with difficult emotions on page 108.

When to call your care team

Your doctors and nurses will let you know any potentially serious symptoms to look out for during your treatment. If you get any of these, get in touch with your care team as soon as you can.

A lot of us aren't great when it comes to calling the doctor. We ignore things. We make excuses. It's really important you don't do this while you're having treatment – if you notice something unusual, tell someone.

Your doctors and nurses will let you know any symptoms that might suggest there's a problem. If you get any of these – and even if you're not sure – it's time to get on the phone. Delaying will make things worse.

What to look for

Your doctors and nurses will give you a specific list of symptoms to watch for, but you might need to call your hospital if:

- You have a temperature of 38°C or above
- You're bleeding (including nosebleeds, bleeding gums or blood when you go to the loo)
- You notice you're bruising more easily than normal
- You have red or purple spots on your skin
- You have a headache
- You start coughing
- Your appetite changes
- You vomit a lot
- You have less energy than normal
- You start feeling vague or confused
- You start going to the loo more or less often

- It hurts when you go for a poo, or there's blood
- You have a sore throat, rash or earache
- You get a pain that you haven't had before or that gets worse
- You get any new lumps

If you get any of these symptoms, you don't need to wait for your next appointment. Just call and speak to one of your doctors or nurses.

Fevers

Having a fever can be a sign that you've got an infection, and getting an infection during cancer treatment can be a problem.

That's because your immune system might be low, so you'll struggle to fight the infection on your own. If that's the case, you'll need antibiotics as soon as possible.

If you feel feverish, call your doctor, nurse or the hospital straightaway. Don't wait until the morning if it's late at night, and don't take any medicine until you've spoken to someone.

If someone you know gets an infectious disease during your treatment, for example chicken pox or measles, you should check with your doctors and nurses whether it's safe for you to see them.

Your care team

You'll be treated by a team of experts who specialise in different areas of cancer treatment.

All of these people have an important role to play. But there will probably be quite a few of them, and they often have job titles that are difficult to remember.

The next few pages will help you understand who does what and who will be involved in your treatment.

After you’ve read through you can go to the back of the guide and make a note of the names of all the people you’re being treated by to help you remember.

Clinical nurse specialist (CNS)

An expert nurse who focuses on cancer treatment. Your CNS can give you advice and practical support, and they’ll be there for you if you need someone to talk to. They might describe themselves as your ‘key worker’.

Consultants

Specialist doctors who are experts in particular areas of medicine. For example, oncologists are consultants who specialise in tumours, neuro-oncologists are consultants who specialise in brain tumours and haematologists are consultants who specialise in the blood.

Dietitian

An expert who can review your diet and help you plan what to eat. Dietitians will take into account the type of cancer you have, your dietary requirements and whether you’re struggling to eat certain things.

General practitioner (GP)

Your GP is your regular doctor and was probably the person who referred you for cancer tests in the first place. There’s a good chance you’ll stay in touch with your GP throughout your treatment, as they can help you make decisions about things like where you want to be treated.

Occupational therapist

Cancer can affect your ability to participate in life as you usually would. Occupational therapists work alongside you during your journey, to help you to identify and overcome any difficulties you may be experiencing.

Palliative care team

The people whose job it is to relieve your cancer symptoms and help you manage pain. Palliative care doctors can also work with the rest of your care team to help you and your family deal with the impact of cancer on your feelings and emotions.

Sometimes people think palliative care is only for people who aren't expected to be cured, but really it's any treatment that's given to relieve symptoms – at any time during your care.

Pathologist

A doctor who studies body tissues to look for signs of cancer and other diseases. Pathologists will examine tissue samples taken during biopsies and other tests.

Pharmacist

An expert in the medicines used to treat cancer. Pharmacists can let you know more about any drugs you need to take, as well as talking you through potential side effects.

Phlebotomist

A specialist in taking blood. Phlebotomists are trained to collect blood for testing without hurting you or disturbing your treatment. If you have a central line, though, your blood will usually be taken from your line by a nurse.

Physiotherapist

Experts in helping with physical problems that may be caused by cancer and its treatment. For example weakness, loss of movement, walking difficulties or breathlessness. Physiotherapists can help you regain movement and strength, as well as supporting you to stay active and continue with everyday activities.

Psychologist and/or counsellor

A trained professional who can help you deal with difficult emotions, challenges in relationships, decisions about your treatment and worries about the future. Cancer happens to all of you, not just your body. It affects your emotions, your thoughts and your relationships with the people around you, so psychologists and counsellors can be a vital part of your team.

Radiologist

An expert at reading scans. Radiologists will review and interpret any X-rays, CT scans, MRI scans and PET scans that you have, to look for signs of cancer and to see how your treatment is going.

Radiotherapists and radiographers

Experts who give radiotherapy treatment and control the machines used for X-rays, CT scans and MRI scans. Radiotherapists and radiographers will explain what to expect before scans and treatment, and you'll be able to talk to them during treatment too.

Social worker

A trained professional who can help you and your family adjust to life during and after cancer treatment. Social workers can help with a huge range of practical and emotional issues, from dealing with finances to talking to your carer to working through any problems at school, college or work.

Speech and language therapist

An expert who can help you talk and communicate. If you have mouth cancer, throat cancer or a brain tumour and your speech or swallowing is affected, speech therapists will help you learn to communicate again.

Surgeon

If you need an operation to treat your cancer, a specialist cancer surgeon will be in charge during the operation. Your surgeon will explain what to expect and check on your progress after the operation.

Youth Support Coordinators

Funded by Teenage Cancer Trust, Youth Support Coordinators are there to provide emotional support and help you relax in hospital. They make sure you have plenty of chances to socialise and connect with people your age, as well as giving practical help on things like changes to the way you look and going back to school, college or work.

Staying in hospital

You might not have spent much time in hospitals before, and maybe you've never stayed overnight. But as you start your cancer treatment, it's likely you'll need to get used to regular hospital visits – either as a day patient (when you go home in the evening) or you might need to stay in overnight for a few days or more.

You can find out more about what to expect from life on a hospital ward, including lots of tips from other young people with cancer on our website.

Day case/ ambulatory care

Some units have ‘ambulatory care’. This is where your care is given as a day case and overnight you stay in a patient hotel near the hospital, or at home if it’s close enough. A bed is always available should you need to come in as an inpatient.

Cultural differences

You might find that there aren’t many people from your cultural or religious background in the hospital. We know that for some people this can make it harder to talk about symptoms or problems.

If you find yourself in this situation, you can raise it with your care team. Your hospital will have staff whose job it is to support people from different backgrounds, and all staff have a responsibility to provide the same care to everyone.

If you would prefer to be seen by a male or female doctor, you can ask if this is possible. You might also be able to take someone with you to appointments if you’d like that support.

If English isn’t your or your family’s first language, translation services are available. If you would like a translator to come to your appointment, let your care team know and they can arrange this for you and you won’t have to pay. You might need to give them some warning, so it’s good to check with them how far in advance of an appointment you need to let them know.

It’s also possible to use translation services over the phone. It’s really important you understand what you’re being told, so feel free to ask as many questions as you like until you feel confident you understand what you’re being told.

Ready to leave

If you've been in hospital for a while, you've probably spent plenty of time thinking about going home. But when the day comes to leave, it can actually feel pretty scary.

In hospital there are lots of doctors and nurses around to help out when needed which can make you feel safe. When you go home you're leaving that behind, along with your hospital routine, which might leave you feeling slightly anxious. If you do feel like that, don't worry: it's totally normal to be a bit worried when things change.

Remember that your medical team will only send you home if they're completely happy that it's the right time for you to go. And all that support is still there for you if you need it – just call the hospital if you're worried about anything.

It can help to:

- Pin the hospital phone number somewhere obvious at home and save it to your phone contacts
- Keep your clinical nurse specialist or key worker's phone number handy – remember you can use your phone and the space at the back of this guide to keep a note of important numbers
- Ask a clinical nurse specialist to come and visit you at home
- Talk openly to your family once you get home, letting them know what you'd like them to do and what you'd like to do yourself
- Make a plan and keep it somewhere that can be accessed easily so everyone at home knows what to do and who to call if you're not well

Once you head home after being in hospital, you might spend less time thinking about the physical side of things – treatments, tests, appointments – and you might find the emotional stuff suddenly hits you.

No matter how much you want to be well again, it's still not easy to go back to being at home and adjusting to daily life. Head to page 108 to find out more about how coping strategies can help you deal with your feelings.

Moving to adult services (transition)

There might come a time when you need to move from services designed for children or young people to services designed for older adults. This is also called 'transition'. That might mean moving from a children's ward or a young person's ward to an adult ward, or it might mean seeing doctors and consultants who specialise in treating adults.

Whatever it means, it can feel pretty scary, especially if you've been on one ward or seen the same doctors and nurses for a while, but try not to worry – you shouldn't be rushed. If you do feel things are moving too quickly and it's making you anxious, talk to your care team. They will help you understand what's going on and feel more in control.

Age groups explained

Where you are treated depends on a lot of things – like where you live and what type of cancer you have. But the general NHS rules are:

- If you're under 16, you'll be treated on a children's ward. Although if you're 13 or older, you may also be treated in a young people's unit

- If you’re 16-18, your treatment is likely to be provided at a Principal Treatment Centre (PTC) for young people. This might not be the hospital closest to your home, but it’ll be the place where you’ll get the best treatment. The exception to this is if you need very specialist care, like specialist surgery. If that’s the case, your treatment may need to take place at a hospital or unit that’s not part of a PTC
- If you’re 19-24, you should have the option to be treated at a young people’s PTC, but you can also choose a hospital that has been approved to provide cancer care for young adults

You’ll only be moved from one place to another when you’re ready, so these age groups are only a guide. Talk to your doctors to find out more about your situation – and remember that there’s always plenty of support available for you, whatever age you are.

When does transition happen?

There’s not a specific time when this will happen. Your doctors and nurses might have an idea of when you’re ready to move, but you need to be involved in that decision too, so it won’t happen overnight. Be open about how you’re feeling and try to talk through any concerns.

Preparing for transition

Moving into adult services can feel like a big step and you might have some questions about how it will work.

To prepare yourself it can be useful to:

- Chat to your doctors and nurses and ask them to explain anything you’re not sure about. Don’t worry if they’ve explained things before – they know this stuff is complicated and you’ve got plenty on your mind

- Find out what support is available to help you through the transition to adult services. Hospitals often employ staff to make the move as easy as possible
- Ask your carer to involve you in things they usually take care of – like booking appointments, sorting out prescriptions and asking questions about your treatment
- Have appointments (or part of appointments) by yourself, without your carer
- Make sure you know who to contact in an emergency and what counts as an emergency
- Talk to your care team about how your diagnosis could affect you in the future

It can seem like a lot to take in, but there's no rush. Getting more involved in your treatment can actually help you feel more in control.

Talking to your parent or carer

This can be a tricky time for carers. It can be frustrating if they're struggling to hand over responsibility to you, but it's probably not because they don't trust you. Letting your kids do things for themselves for the first time is hard, and it can take time for your carer to adjust as roles change.

If you're feeling stifled, try to have an honest conversation about it. It's a good chance for all of you to be open about how you're really feeling. Chances are they're trying to do what they think is best, rather than trying to annoy you. And it might be that you're all reacting to the changes that transition brings, so try and be understanding.

There's more information about handling relationships with your carer on page 128.

Choosing where to go

You might be able to choose between different hospitals, clinics and other services. If that's the case, your nurses and doctors will chat to you about what's available at each of them. It's a good idea to go for a visit too so you can get a feel for the places and see whether they seem right for you.

What's different?

Once you're in adult services, doctors will expect you to know more about your condition and you'll be responsible for turning up for appointments, taking your meds and so on. There's no need to panic though – if you start learning and taking control before the transition, it'll be second nature by the time you move.

Adult wards do look different to children's wards and units for teenagers and young adults. They can feel different too, especially if there aren't many younger people there. But hospital staff might be able to put you in touch with young people on other wards, and you might be able to invite your friends over. Even if you feel a bit lost at first, pretty soon your new surroundings will feel totally familiar.

Questions to ask

- What's the plan for my transition?
- What will be different about adult services?
- What support is there to help with the transition?
- Do I have a choice of which hospitals and services I can use?
- Can I visit wards and services for a look around before choosing?
- Do you know any young people I can talk to about moving on from services for teenagers and young adults?
- What do I need to know before moving to adult services?

Staying healthy

Looking after yourself can make a real difference to how you feel, especially when you're living with cancer.

Eating well

A healthy, varied diet is important, because it gives your body the energy it needs to fight cancer.

We've already talked about how to manage nausea and eating during treatment on page 63 as well as running through weight loss and weight gain on page 64.

Whatever your experience is, try not to let food get you down. It's important to try and eat plenty of:

- Fresh fruit and veg
- Quality proteins (like beans, eggs, fish, meat and nuts)
- Carbohydrates (like bread, pasta, potatoes and rice)

As we've said before, try to eat what you can, when you can.

Physical activity and movement

Physical activity and regularly moving your body are good ways to look after your body and mind during and after cancer treatment. There might be times when exercise is the last thing on your mind, so don't push yourself. If you're feeling wiped out during treatment, your body needs to recover and it's important to give it the time to do that.

But on the days you do feel better, being active can give your body and mind a boost. Set yourself small, achievable targets and give yourself credit for what you can do, rather than setting your expectations too high. It's better to do something manageable than nothing at all. Make sure you check with your care team before getting started. They can advise if there's any specific activities or movements you should avoid depending on the type of cancer and treatment you have.

Here are some suggestions of what you can try:

- A walk around the park
- A few squats or stretches
- Going swimming (check this is OK with your care team first, though)
- A bike ride
- A gentle exercise class – like Tai Chi or yoga

Whatever you do, there are plenty of benefits. Exercise can help you:

- Feel better about yourself
- Get together with friends
- Feel energised and less fatigued
- Get to sleep more easily
- Deal with your emotions
- Keep your bones strong
- Heal tissues and organs that have been damaged by cancer treatment

Sleeping

Cancer can leave you feeling exhausted, so you'd think sleeping would be easy. Sadly it's not always that simple. Feeling stressed or unwell can stop you from drifting off, and sleeping in a hospital isn't the same as sleeping in your own bed. Some treatments might also make it harder to sleep and you might sometimes be woken up in the night for checks or medication.

It's important to get plenty of sleep though, because it can make your treatment easier to deal with and can improve your mood and concentration too.

Here are a few tips you might like to try:

- Relax in the evenings - Watch a film. Listen to music. Do whatever makes you feel calm – and try not to overthink anything that's on your mind. Avoiding looking at your phone before bedtime can also help you switch off
- Have a routine - Going to bed and waking up at the same time every day helps your body know what to expect. Even little things like opening the curtains to let in light every morning can help
- Avoid caffeine before bed - Reach for a glass of milk or water, rather than a cup of coffee or a can of coke
- Exercise - Like we said earlier, if you feel up to it, gentle exercise will leave you feeling ready for a good night's sleep
- Write down difficult thoughts - If you find yourself lying awake thinking about the same worry or problem over and over again, try to write it down so you can come back to it in the morning. The middle of the night is never a good time to figure things out
- Don't force yourself - If you can't sleep after 20 minutes, don't keep tossing and turning. Do something to relax your mind – like reading or listening to music or the radio – and then try to sleep again once you start to feel sleepy. You might find imagining a journey you know well helps you drift off too

Avoiding illness

Some cancer treatments – like chemo and radiotherapy – weaken your immune system, which means you might be more likely than normal to get ill.

To try and avoid infection, it can help to:

- Wash your hands often and well. If you're in hospital and there's one of those illustrated guides for handwashing on the wall, follow the steps
- Avoid certain foods. Ask your dietitian for a full list
- Make sure your food is always washed and cooked properly
- Avoid spending time with people who are ill, and ask people who have been ill recently not to visit until they're better
- Use the proper sterile procedure to clean your central line, if you have one (your nurses will tell you more about this, and you can see more about central lines from page 48 onwards)

If you do think you might have an infection, let your doctor or clinical nurse specialist know straightaway. It's important to get the right treatment as quickly as possible.

Drugs and alcohol

It's important to be honest with your doctors and nurses if you smoke, drink alcohol or take drugs. They won't be angry with you or judge you but they do need to know.

It's important you understand that all of those things can have an impact on your cancer treatment. And by not drinking, smoking or taking drugs now, you can give your body the best chance of dealing with cancer.

Drugs and alcohol can:

- Interfere with treatments like chemotherapy and radiotherapy
- Make side effects worse
- Increase your chance of getting breathing problems and chest infections

- Increase your risk of other side effects, like liver problems
- Increase your chances of getting other infections, especially if you're sharing needles
- Affect the way you think, making it more difficult to cope

Be honest

Your doctors and nurses might ask if you're taking anything now or have done in the past. They're only interested in your health, so everything you say is confidential and you won't get in any trouble.

In short, if you've used legal or illegal drugs, including alcohol and cigarettes, don't pretend you haven't. It's better if the people looking after you know, and you can always ask to talk to your medical team in private, without your carer being there.

Time to quit?

Maybe you've tried to give up drinking, smoking or taking drugs in the past, but haven't quite managed it. If you want to try again it's best to discuss this with your care team first so they can help you find the best and safest way to do this.

We're not telling you to stop forever – although it'll be better for your health in the long term if you do. We just want you to know that it can make a difference to your treatment.

You can ask your care team for information about organisations you can contact for support to give up cigarettes, alcohol and drugs.

Search: 'quit smoking' on **nhs.uk** to find more information.

Sex and cancer

Remember that the legal age to have sex in the UK is 16 for you and your partner.

Having cancer doesn't stop you being interested in sex. There might be times when you don't feel at all interested in sex, and there might be times when you're feeling ill or exhausted and sex is the last thing on your mind. But on the days when you're feeling OK, you might find yourself thinking about sex and that's completely natural. The good news is that, unless your doctor tells you otherwise, you're fine to have sex.

If you're having penetrative sex, you do need to use a condom. That's really important. So stay safe and check with your doctor or nurse if there are any other precautions you should take. It might feel like a difficult topic to bring up but they're medical professionals who talk about things like this all the time and they're there to help you with any questions you might have, so make sure you bring up anything that's on your mind.

Sex and chemotherapy

If you're having penetrative sex and you or your partner is having chemo, always use a condom – even for oral sex and even if you're using other contraception. That's because it's possible for men and women to pass on chemicals from chemo drugs during sex.

So keep protection handy – and use it for at least a couple of weeks after you've finished treatment. It's important to not become pregnant while you're having chemo.

Search: 'contraception' on **brook.org.uk** to find out more.

Losing interest in sex

This is common and can happen for lots of reasons, including hormonal changes, tiredness, anxiety and just not feeling great about yourself.

You might find your confidence takes a hit and you feel less comfortable being physically intimate with people. Losing interest in sex can be a side effect of radiotherapy and certain drugs too.

Often once your treatment is over you'll probably start to feel like having sex again. But if you're still not as interested in sex a while after you've finished treatment, it can be helpful to talk to a psychologist or counsellor.

Talk to your partner about how you're feeling and any worries you might have.

Let them know what you're going through. Listen to what they're thinking about too, as they might also be worried.

If your treatment has had an impact on your hormones you might be referred to an endocrinologist, they specialise in glands and hormones and can offer advice.

You might be feeling pretty unsexy but that doesn't mean your partner has stopped finding you attractive. And remember there's plenty you can do to enjoy each other's company without having sex.

Physical changes

Cancer and cancer treatment can cause various changes to your body that might affect your sex life.

You might find it hard to get hard.

Getting an erection can be difficult if:

- Cancer, or cancer treatment, has damaged nerves and blood vessels in your pelvis
- You've had surgery to your prostate, bowel, testicles, bladder or rectum

- You've got low levels of the hormone testosterone. Testosterone can be reduced by radiotherapy or surgery to your testicles, or by treatment to the pituitary gland in your brain
- Stress and tiredness can also have an effect.

If this happens to you, don't be embarrassed to talk about it. To your doctors and nurses it's just another medical conversation, and one they've had plenty of times before – and you can ask to speak to a man if you'd prefer. They'll be able to help you understand things that might help.

You might find it hurts to come.

This can happen if part of your penis called the urethra gets inflamed during radiotherapy. This usually stops happening a few weeks after treatment. In the meantime, you might want to avoid having sex.

You might not come when you have an orgasm.

This is called a dry orgasm. Some surgery for testicular or prostate cancer might cause this. Some people say that it doesn't change the way an orgasm feels; others think it can make things feel a bit less intense.

You might find your vagina is dry.

This is caused by low levels of the hormone oestrogen, and can make sex painful or uncomfortable. Various treatments, including radiotherapy to your pelvis and chemotherapy, can reduce your oestrogen levels. Your doctor or nurse will let you know if there are tablets or gel that are suitable for you to use. Water-based lubricants, which are available at pharmacists, should help too – just make sure you choose a lubricant that is safe to use with condoms.

Surgery might affect parts of your body linked to sex.

If you need to have surgery as part of your cancer treatment, you might find that your body image is affected and you feel less like having sex – particularly at first. Surgery on parts of your body including your testicles, breasts, ovaries and vulva might change the way you feel about sex too, or might make it more difficult to have sex. Having a limb amputated can also impact how you feel about sex. If you're worried about any of these things, try and let your doctors and nurses know.

Fertility

Fertility means your ability to have children. When you're young and diagnosed with cancer, you need to think about lots of things you probably haven't thought about before.

Even if kids are the last thing on your mind right now, in the future you might feel differently. And there are things you can do now to increase your chances of having a family in the future.

Whatever your sexuality or gender identity, you can always speak to your care team about your fertility. They should be able to answer any questions you have about how treatment may impact your fertility, and the options available to you now and in the future.

Treatments can affect fertility

Chemotherapy and radiotherapy can affect your fertility, and so can surgery on parts of the body involved in reproduction – like ovaries and testicles.

Plenty of people have these treatments and go on to have kids – but it's important to talk to your doctor about the likely effects of your treatment.

The details

If you have testicles, cancer treatments can sometimes impact your fertility by:

- Affecting your sperm production
- Affecting the production of hormones involved in reproduction
- Damaging nerves and blood vessels in your groin, making it difficult to get an erection or come.

If this could happen to you, it might be possible to freeze your sperm now in a sperm bank – making it more likely that you could still have a family in the future. You can find more information on sperm banking on the next page, and you can ask your doctor any questions you might have.

If you have ovaries and you've started having your periods, cancer treatment can sometimes impact your fertility by:

- Affecting the production of hormones involved in reproduction
- Affecting your ovaries
- Damaging the lining of your womb, or requiring your womb to be removed if you have certain types of cancer

It's also possible for chemotherapy to put you into early menopause (the menopause is the time women stop producing eggs).

If any of these things could happen to you, it might be possible to freeze embryos (eggs that have been fertilised), eggs or tissue from your ovaries to use in the future. You can find out more about egg freezing later in the guide, and you can always ask your doctor any questions you might have.

“I knew I wanted children in the future, but I hadn’t thought about it that much and I didn’t know it could be taken away from me.

Luckily, I had time to preserve my fertility, but I put so much pressure on myself as I thought it could be my only chance to have children.”

Amy

Periods

Your periods might stop or become irregular during your treatment, but this doesn't mean there's no chance of you having children. Periods often come back after treatment is over. Chat to your doctor or clinical nurse specialist about this if you're worried.

Early menopause

Another potential side effect of cancer treatment is that you might experience early menopause. The menopause affects people with a uterus and ovaries. It's what happens when your periods stop and your ovaries no longer make any eggs. This usually happens when you're around 45-55 years old but it can also happen earlier as a result of cancer treatment.

You might experience early menopause if you have had your ovaries and uterus removed, radiotherapy in an area that included your ovaries or you if you've had some specific chemotherapy drugs.

Menopause symptoms include:

- Irregular or no periods
- Low mood or anxiety
- Painful bones and joints
- Headaches
- Weight gain and/or bloating in your stomach area
- Irregular heart rate
- Hot flushes and night sweats
- Vaginal dryness and painful sex

If you have any of the symptoms above, it doesn't mean you're definitely going through early menopause but it's always worth noting any changes and new symptoms with your care team so they can keep track of what's going on. They'll be able to support you and offer some solutions for coping with the effects of the menopause.

Pregnancy

Being diagnosed with cancer when you're pregnant can be really worrying. It's important you speak to your care team about your pregnancy and treatment plan.

It's not a good idea to try to have a baby during cancer treatment, as the treatment could harm your baby. If you do have sex during treatment, make sure you use protection. You can chat to your doctor or nurse about the best type of contraception for you (they talk about things like that every day, so there's no need to be embarrassed).

It's usually best to wait a while before trying to get pregnant after treatment, so check with your doctor or clinical nurse specialist if you're thinking about starting a family.

Mummy's Star is a charity dedicated to supporting women and birthing people diagnosed with cancer during pregnancy or within 12 months of giving birth.

You can find out more on their website **mummysstar.org**

Search: 'pregnancy' on **macmillan.org.uk** to find out more.

Fertility testing

After cancer treatment, you can have tests to check your fertility levels. It's worth thinking carefully about this and maybe chatting to someone close to you about how you would deal with any bad news you might get. You might prefer not to be tested, or to wait until you're a bit older.

And remember that infertility caused by treatment can be temporary – so your first test result isn't necessarily a final result. It's a good idea to wait at least six months to a year following treatment to check fertility to give your body time to recover.

Questions to ask

When you talk to your doctor about fertility, you might like to ask:

- Will treatment affect my fertility?
- Will it affect my fertility permanently or temporarily?
- Is it possible to store my eggs/sperm?
- Will the treatment affect my periods?
- What contraception is best to use during treatment?
- What fertility treatments might be possible after treatment?
- How long after treatment should I wait before trying to get pregnant?
- Are there any other treatments that might work?

For more advice and information on having safe sex and other questions go to **brook.org.uk** or speak to your care team.

How does egg freezing work?

People have their eggs frozen so they can use them in the future to fertilise with either their partner's sperm or donor sperm so they can get pregnant.

Even if you have your eggs frozen it doesn't mean you will have to use them later in life if you want to try for a baby. You may still be able to conceive naturally if your fertility hasn't been affected by treatment.

Having your eggs frozen involves stimulating, collecting, freezing and then storing your eggs. This process normally takes about two weeks.

You'll need to inject yourself with hormones to encourage the eggs to grow outside of your normal cycle – you can do these injections at home, you won't need to go to your doctor's or the hospital and you can ask someone to help you do this.

Sometimes there might not be time to have your eggs frozen before you start treatment. This might be because you need to start treatment as soon as possible. Even if this is the case you may still be able to talk to a fertility specialist to understand the impact of your treatment and your choices.

Search: ‘egg freezing’ on our website to find out more.

How does sperm banking work?

People have their sperm ‘banked’ or stored so they can use it in the future. This could either be to inseminate their partner, or as part of the IVF (in vitro fertilisation) process where the sperm is used to fertilise an egg outside the body and then it’s transferred into the womb as an embryo.

You may not need to use your banked sperm in the future if your sperm count isn’t reduced by your treatment.

Sperm banking is usually done by masturbating and ejaculation. You can do this at the fertility clinic in a private room or you might be able to do this at home and bring it into the lab. It can help if you haven’t masturbated in the few days before giving a sample. If your sperm count is very low you might have to give multiple samples. Your sperm will then be kept frozen until you’re ready to use it.

Search: ‘sperm banking’ on our website to find out more.

How long can eggs and sperm be kept frozen for?

You will need to give written consent to make sure your eggs, embryos and sperm are used and stored in a way that you're happy with.

You can store your eggs, embryos or sperm for up to 55 years, but you will be asked to renew your consent to storage every 10 years. It's really important that your clinic has your up-to-date contact so you can renew consent every 10 years. If you move house, make sure you let them know. If a clinic cannot contact you then your eggs, embryos and sperm may be disposed of. This is even if you consented for more than 10 years storage.

Search: 'storage' on hfea.gov.uk to find out more.

YOUR FEELINGS

YOUR FEELINGS

You might experience all kinds of emotions after being diagnosed with cancer, as well as during and after treatment.

Sometimes you might not even be sure what it is you're feeling or why. But the main thing to remember is that there's no right or wrong way to feel. Whatever you're going through, it's absolutely normal. Everyone's cancer experience is different, and everyone's cancer experience is equally valid.

Your emotions

It can be tricky to let other people know how you're feeling, especially if you usually like keeping things to yourself. You might prefer to ignore your emotions and hope they'll go away.

Unfortunately, keeping feelings bottled up can sometimes make things worse. It can make you act differently too. So as hard as it can be, finding a way to express what you're going through is an important part of dealing with it.

If you struggle to talk about your emotions, it can help to write them down or even to talk to yourself about them. Remember, you can use the notes section at the back of this guide to write down anything you want.

You might be feeling...

- **Shocked** - Even if you suspected something was wrong, hearing a doctor mention cancer for the first time can be a real shock. You might have struggled to focus or not really have heard what the doctor was saying. You might have cried or felt exhausted. These are all very common reactions to shock
- **Scared** - There's no shame in feeling afraid. No matter how old you are, cancer can be scary. Talking to someone and telling them you're afraid can feel like a massive weight off your chest.

  If you're worried about anything, it often helps to try and find reliable information about what you're going through so you understand what to expect. See page 23 for more tips on finding trustworthy information.
- **Uncertain** - Not knowing what's going to happen is one of the toughest things about cancer. It's easy to feel overwhelmed, but it can help to focus on the things you can control, like looking after yourself and eating well
- **Angry** - Cancer isn't fair. And it's totally natural to feel angry because of that. The fact that it's not your fault probably won't make you feel any better either.

  It's important to try and find things that soothe you and calm you down, instead of bottling it up. It's not unusual to feel seriously fed up when you have cancer.

  But there are some tips on more helpful ways to deal with anger:

  Exercising - If you're feeling physically OK, a jog, walk, swim or bike ride can really clear your mind and help you work through your anger

Writing down what you're feeling - This isn't for anyone else but you, so don't worry about how you're writing it. Getting everything out and down on paper can help clear your mind

Having a good cry - All of these ideas basically come down to releasing what's inside. If you feel like crying, don't hold back – let it all out

Talking to people - Being honest about your emotions can help your anger

Learning self-help techniques - Cognitive Behavioural Therapy (CBT) can really help you to deal with difficult emotions, like anger

You might also be feeling...

- **Sad** - There are lots of reasons you might feel sad when you have cancer.

  Changes to your body, losing your hair, changes to your health, lifestyle and relationships can all affect your mood.

  It can help to think about what usually makes you feel better – like calling your friends or listening to music – so you can do those things if you start to feel low.

  And remember that sadness usually comes and goes. If it feels constant and overwhelming this could be a sign of depression. Depression can be treated, so it's important to ask for support. See page 124 for more information about depression.

- **Frustrated** - You might feel like you've lost your independence, which can be particularly annoying if you're used to doing things for yourself. Having to take advice all the time can be tough too.

It can be a good idea to let people know if you need some space or don't need help – chances are they might not realise. And you'll probably feel better for letting your feelings out too.

- **Guilty** - It doesn't make any sense, because you've not done anything to cause cancer, but the truth is that people feel guilt for all sorts of reasons after a cancer diagnosis. It's easy to get caught up in thoughts and feelings of guilt, but try to remember – this isn't your fault.

  And don't be surprised if people in your family feel guilty too – that's also not unusual. You might even find that knowing you feel the same way actually helps. Acknowledging guilt can be the first step in letting it go.

- **Embarrassed** - It's not easy dealing with some of the changes cancer and cancer treatment can cause. You might feel embarrassed if your body changes or if you can't do things you used to do. You might feel like people are staring at you, or you might not know how to answer questions about your cancer.

  Have a think about what you're happy to tell people. People usually ask questions either because they're genuinely interested or because they're feeling embarrassed themselves. You could even use the notes section at the back of this guide to write down some answers to questions you think you might get, so you're prepared to answer them.

- **Jealous** - It can be tough seeing your siblings, partner and friends going out and doing the stuff you'd love to be doing. If you are feeling jealous, try and talk it through with them. It can help to let them know you'd like it if they still invited you – and that you'll be there whenever you feel well enough.

- **Lonely** - Being surrounded by people doesn't mean you can't feel lonely and there might be times when you feel like no one understands what you're going through.

  If you are feeling lonely it can really help to talk to other young people who have had cancer. Everyone is different, but you'll probably have plenty of experiences in common. Remember that you can always speak to a member of your care team, they might be able to put you in touch with some other young people in a similar situation.

Good days and bad days

There's a good chance people will tell you how important it is to stay positive. It's one of those bits of advice that people say because they care but which don't always help.

So while it is worth trying to stay optimistic if you feel able to, don't worry if you feel miserable sometimes. It's natural to have good days and bad days.

No one expects you to wake up with a smile on your face every day. In fact, having a good cry and a moan can sometimes leave you feeling a lot better.

Coping strategies

A coping strategy is basically anything you do to make yourself feel less stressed. We use them all the time without necessarily giving them a name. And because cancer can be pretty stressful, it's a good idea to have plenty of coping strategies in place. Have a look at these suggestions, and there's space to write your own in the notes section at the back of the guide.

“Nicola, my psychologist, also taught me a technique called ‘Worry Time’ where I was only allowed to think about things at a certain time of the day and for a set amount of time.

This stopped me spending all day stressing about it.”

Beth

- **Learn about cancer** - Some people feel better knowing everything they can about their diagnosis because then they know what to expect. Others would rather take it step by step. Whichever you are is totally fine and completely your choice.
- **Ask questions** - If you're not sure about anything, ask your doctors and nurses for an explanation
- **Talk** - From a good rant to a good cry, speaking to people is usually better than staying silent
- **Have some control** – There are lots of parts of having a cancer diagnosis that are out of your control. Getting involved in decisions about your treatment – from when you want to be woken up to what you want to eat – can help you feel more in control
- **Do the things you used to do** - It's easy to forget about seeing friends or watching films or doing whatever you love – but the normal, everyday stuff is really important. You don't need to stop living life because you have cancer
- **Get creative** - Write a blog, buy some paints, take photos, mess around with a guitar, take up the drums – whatever puts a smile on your face
- **Get organised** - Set goals and have a weekly to-do list – just don't take on too much
- **Laugh** - A good laugh can make you feel better, so spend time with friends and family who put a smile on your face, or keep your favourite comedies close by
- **Exercise** - A few laps of the pool or the park can help your day seem brighter, and even doing a few stretches in bed can help.

Don’t worry if you sometimes don’t feel up to it, though – and remember to check with your doctor or nurse before starting any exercise

- **Self-care** – Pampering yourself on the outside can make you feel better on the inside
- **Try something new** - Learn an instrument. Try a new sport. Give meditation a go. If you’ve got more free time and you’re feeling OK, why not make the most of it?
- **Sleep** – Sleeping well is a big part of feeling well and dealing with your emotions. Turn to page 89 for some ideas that might help if you’re struggling
- **Have a routine** - Getting up, going to bed and eating at the same time each day can help your life feel less out-of-sync
- **Accept help** - It can be annoying when people constantly want to help, but it can also make your life easier. Why not think of things you can suggest when people ask, like doing the laundry or picking up your favourite magazine?
- **Treat yourself** - It’s really important to cut yourself some slack and be kind to yourself. We’re talking chocolate, a curry, getting your nails done, a massage (check with your doctor or nurse before getting any treatments), the cinema, a game of FIFA – whatever makes you smile
- **Join a support group** – Talking to young people who know what it’s like to deal with cancer treatment can help you feel less alone

Top tip: Make the time to do something you enjoy doing every day, even if it’s just 60 seconds of something small.

Grief and loss

We often only talk about grief and loss in terms of people dying, but there's more to it than that. Cancer can alter your life in lots of ways that make you feel a sense of loss.

During your treatment, you might feel a sense of loss if:

- You look different
- Your body doesn't work like it used to
- You lose your hair
- Your confidence and self-esteem take a hit
- You lose touch with friends or feel left out when you're with them
- You break up with a partner
- You spend time away from school, college or uni
- You leave your job
- Your ambitions and job plans change
- Your treatment affects your chances of having children
- You feel like you're suddenly growing up very fast
- You have to cancel plans

Signs of grief

Grief is a totally natural response to loss. In fact, grieving can help you deal with the losses you're going through.

Everyone experiences it differently, but possible signs of grief include:

- Having trouble sleeping
- Wanting to sleep a lot
- Having sad dreams or nightmares
- Eating a lot or not eating enough
- Feeling really down and crying a lot
- Avoiding things and places that remind you of how things were
- Wanting to be alone
- Feeling angry or agitated

- Longing for how things used to be
- Feeling empty
- Drinking or taking drugs to hide your feelings

Coping with grief

There's no right or wrong way to deal with feelings of loss and grief. Everyone reacts differently, so try to avoid comparing yourself with other people.

It's all natural – and even if you're struggling and it's hard to believe right now, dealing with grief does get easier. That thing people say about time being the greatest healer is true.

In the meantime, try to avoid putting a lid on how you're feeling. Expressing your emotions can be a powerful way of dealing with them. It can help you change things that are making you feel loss too. So find a friendly shoulder to cry on if you need to.

Where to find support

Teenage Cancer Trust

Our nurses and Youth Support Coordinators have a lot of experience of helping young people deal with grief. They will always be happy to talk to you. They can also put you in touch with clinical psychologists who have lots of techniques and ways of talking that can help people with their grief and feelings generally.

Young Lives vs Cancer

Young Lives vs Cancer support young people from 0-24 with a cancer diagnosis. They also have social workers who are experts in working with young people and their families and helping them handle the challenges that come with a cancer diagnosis. **Find out more on their website younglivesvscancer.org.uk**

Samaritans

The Samaritans can provide confidential support 24 hours a day by phone or email. **You can call them on 08457 90 90 90 or visit samaritans.org**

Childline

Childline have lots of information on their website about your feelings, friendships and relationships, home life and work and school life. They also have a helpline and online chat where you can speak to a counsellor - these are both available 24 hours a day, seven days a week. **Find out more on their website childline.org.uk**.

The Mix

The Mix is a support service specifically for people under 25. They have information on sex and relationships, your body, mental health, alcohol and drugs, housing, money, work and education and crime and safety. They have an online community where you can connect with other young people and they also have a free, confidential helpline and counselling service. **Find out more at themix.org.uk.**

Top tip: You don't have to pay attention to people who tell you to 'get over it', 'move on' or 'cheer up'. Deal with grief in your own way and your own time.

“Losing my hair upset me a lot.

Many think that it’s just girls that take hair loss hard, but all cancer patients do.”

Jake

Body image

If you have cancer, there can be times when your body hardly seems like your body anymore. But whatever happens, it's important to remember that you're still you.

Worrying about your appearance is completely natural. We get insecurities about our bodies at the best of times and it can be tough if cancer or cancer treatment changes the way your body looks or feels, or how it works.

It's about how you feel

It might sound strange, but evidence shows that the way somebody feels about their appearance doesn't always relate to how they look.

What matters is how you feel about it and how you approach it. This is where psychologists, clinical nurse specialists, Youth Support Coordinators and your care team can be useful (as well as your support network).

There's a lot of professional help available, so if you're worried about anything, don't keep it to yourself.

Things to know:

- It's completely understandable to feel less confident or even unattractive if your appearance changes with treatment – whether that's losing hair, changes to your weight or your skin, or if you've had surgery
- It's OK to mourn the loss of how you looked before – it is a loss, so why shouldn't you feel some grief
- Do anything you can think of to help yourself feel more confident. For example, if you feel anxious about people looking at you when you go out, take a friend with you
- Don't forget about your strengths and the things you like about your appearance – take some time to think about these things often

- Remember a lot of changes to your appearance will be temporary
- If you know your appearance is going to change – for example losing your hair – you might want to write yourself a letter to read when this happens. People often include things like their strengths and things they want their future selves to remember when they feel upset.
  It can help to imagine you are writing this to a friend going through it
- It's understandable to feel worried and less confident about meeting friends or going out. But if you become very anxious about this or stop doing the things you want to do, tell someone in your care team early on.
  This is because the more you avoid doing certain things, the harder they can become – and your team can suggest some very effective tricks you can try to make this easier for yourself.
- Some people can develop something called body dysmorphic disorder (BDD). This is when the way they feel about their appearance becomes so distressing that they are unable to function properly in their day to day lives. This is not common but if you're worried about it, speak to your care team or youth support worker so you can get the right help. Mind, the mental health charity, have more information on this

Search: 'BDD' on **mind.org.uk** to find out more.

Changing Faces is a national charity that supports anyone with a scar, mark or condition on their face or body. They provide mental health, wellbeing and skin camouflage services and work to transform the understanding and acceptance of visible difference, and campaign to reduce prejudice and discrimination.

For more information on their services go to **changingfaces.org.uk**

If someone close to you dies

Sometimes cancer treatment isn't successful. And if you build close relationships during your treatment with other young people who then die, it's a horrible thing to have to deal with.

You'll have so much on your mind already and now you need to try and cope with losing a friend. It's not fair and it's not easy.

You will get through this. It's not going to be easy but with the right support over time things will get easier.

It might help to remember that there's no right or wrong when it comes to grief. It's not a test or a competition. All that matters is what feels right to you to get through this.

You might be feeling:

- Sad, in a way that makes you feel empty and unable to smile
- Lonely, because you've lost a close friend who was probably an important source of support
- Afraid, because it's hard not to start thinking the worst about your cancer when you're feeling low
- Guilty, because you're still here and your friend isn't

- Angry, at cancer, at the situation, maybe even at your friend for leaving you behind

Coping with loss

It's important to remember this isn't your fault. Nothing you could have done would have changed this.

If you feel up to it, try and open up about your grief. You can talk to someone close to you who you trust, or there are lots of professionals out there who can help. You can talk to your doctors and nurses or, someone you don't have a relationship with – like a clinical psychologist or a counsellor. And you can contact specialist organisations that employ experts in coping with loss and grief:

- **Child Bereavement UK** has a confidential helpline (**0800 02 88840**) and offers advice at **childbereavementuk.org**
- **Childline** offers guidance and support all day, every day on **0800 1111** and at **childline.org.uk**
- **Cruse Bereavement** have a helpline you can call **(0808 808 1677)** and talk to a volunteer trained in lots of different types of bereavement. If you don't feel up to chatting on the phone you can also speak to an expert grief counsellor on their online chat too. Find out more at **cruse.org.uk**.

  Cruse also operate **hopeagain.org.uk** which is especially for young people who are dealing with grief, it has message boards so you can share your experiences with others
- **Winston's Wish** provide emotional and practical bereavement support to young people, and also those who look after them. Find out more on their website **winstonswish.org**

You could also try writing your feelings down. Expressing what you're going through can be the first step in dealing with those emotions.

The main thing is not to deny there's anything wrong. If you're struggling, say so. Bottling things up doesn't make them go away.

It might help to:

- **Go slow** - Don't expect too much of yourself too soon. If you need time, take time
- **Say goodbye** - Funerals are painful, but they can be a release too. And if you can't go to the funeral, you can always create your own way of saying goodbye – like visiting somewhere your friend would have liked and saying a few words about them or leaving flowers or a letter
- **Talk about your friend** - Or if you don't want to talk, don't be afraid to think about them. Write letters or poems. Make a book with photos of them in. This can be a nice way of remembering why you enjoyed their company and the good times you spent together.
- **Laugh** - You'll probably feel guilty at first, but you're not offending anyone by cracking a smile or having a laugh
- **Ask for help** - If you need it, there's always support available

Losing someone can also make you think more about your own situation. That's very common. But try to remember that everyone experiences cancer differently. And if you do find yourself getting anxious, try to speak to someone about how you're feeling. There are lots of people who will be happy to listen. You really don't have to face this alone.

Who to talk to

There are lots of people you can turn to for support – from your friends and family to people who are trained in talking about how you're feeling, like nurses, Youth Support Coordinators, clinical psychologists and counsellors. It can take a few tries to find the right person, but it's worth making the effort.

Try to talk to someone who:

- You trust
- Listens to you
- Is there when you need them
- Keeps things private if you want them to be
- Is honest
- Won't judge you
- Won't try to solve everything
- Won't tell you they know how you're feeling

You could try:

- **Family** - If you have a close relationship with your family you might feel most comfortable chatting to them. Whether it's your parents, siblings or other relatives like aunts, uncles, cousins or grandparents. Try to be clear when you need their support and when you'd rather be by yourself
- **Your doctors and nurses** - They're not only there to talk about physical problems – they can also help with the emotional stuff. They look after young people with cancer every day and have a lot of experience in helping young people work through their worries
- **Friends** - Sitting down and talking through your fears and frustrations with trusted friends can help you deal with your emotions – and help you feel more like your old self, too
- **Partners** - If you have a partner, they can offer a shoulder to cry on or laugh on, depending on what kind of day you're having

- **Teachers** - If you get on well with one of your teachers and trust them, don't be afraid to contact them to ask for a chat
- **Religious and community leaders** - If you're a member of a religious group or a youth group, you can always chat to one of the leaders there
- **Psychologists and counsellors** - During and after treatment you'll be able to talk to professionals who are trained to help you deal with fear, anger and whatever else you're feeling. You can talk to them about anything, so it's a good way to be 100% honest and to have a no-holds-barred vent, as well as learn some new ways of thinking
- **Support groups** - There are various organisations that can put you in contact with other young people who have or have had cancer. While everyone has a different experience, chatting to people who've been through similar things can still be really helpful. Lots of groups are also good fun and very social, so you might find you make new friends

Search: 'useful contacts' on our website to find out more.

- **Online support** – You can find support groups, blogs and forums online too. This can be a great way to read and share stories and experiences, and you can usually post anonymously if you want to. It's important to remember that you can't always trust everything people post, though, so be careful

Visit: thinkuknow.co.uk for tips on internet safety, and see page 17 of this book for more about finding reliable information.

Anxiety and panic attacks

Feeling anxious is very common for people going through cancer. If the anxiety is really intense, you might have a panic attack.

If you're having panic attacks tell somebody in your care team because a psychologist can help you deal with them.

Having a panic attack can be a really unpleasant experience, but the good news is that talking therapy can really help treat them. Panic attacks can happen at any time. They are often triggered by a particular thought, image or smell, but sometimes they feel as if they just come out of nowhere.

Panic attacks can respond incredibly effectively to some basic techniques.

You might find your own ways to deal with anxiety, but here are some ideas that could help:

- Learn an effective breathing technique - you can ask your care team or psychologist for suggestions on how to do this
- Avoid caffeine, alcohol and smoking - these can cause your heart rate to quicken which people often experience as a symptom of anxiety, so this can start someone feeling on edge
- If you can, do some exercise you enjoy - this is a very good way of getting your body to relax
- Start practicing calming visualisations - picture images or scenes that make you feel relaxed and safe
- There are some really powerful apps out there that a lot of people find useful in helping them with anxiety - ask your care team for suggestions

Understanding depression

People experience depression differently, but if you have a few of the symptoms below for more than a couple of weeks, or if they keep coming back for a few days at a time, it's important to reach out for support.

Depression can change:

- **Your mood** - You might feel sad, helpless or moody most of the time. You might struggle to concentrate. You might feel like there's nothing to look forward to. And you might stop enjoying the things that usually make you happy
- **Your behaviour** - Crying a lot is a common sign of depression, and so is feeling like you can't be bothered to do anything. You might start to lack confidence in yourself, too, and become quiet or withdrawn. And you might feel like doing things you know aren't good for you, like smoking, taking drugs, getting drunk or harming yourself
- **Your body** - You might eat or sleep too much, or not eat and sleep enough. And you might start feeling sick or exhausted a lot of the time

Dealing with depression

If you are feeling depressed, your doctor can recommend various treatments that might help. A lot of them involve talking – to clinical psychologists, to counsellors and to other people in support groups. Medicine is sometimes used too.

There are also various things you can do to help yourself. If you feel up to it, exercise can lift your mood. It releases endorphins (chemicals that can make you feel positive) and can leave you with a real sense of achievement: just make sure you set yourself small, realistic goals.

Staying in touch with people close to you can help too. And so can making a conscious effort to break the cycle of negative feelings.

If your depression is severe, you could find yourself experiencing suicidal thoughts. If that happens to you, it's vital to get help. Tell a member of your treatment team as soon as possible, and if you're ever concerned for your safety, go to A&E or call 999.

You can get in touch with the Samaritans for help 24 hours a day, every day on 116 123.

Remember: Your support network and care team are there for you. Try to be honest with them and share how you're feeling.

Religion and spirituality

Living with cancer can make you ask some pretty big questions, even if you've not really thought much about them before.

If religion already plays a part in your life, you might find it's a real source of comfort and support for you during your treatment. Having faith can help you feel better about what's happening, and you might feel comfortable talking to people at your place of worship about cancer too.

But you might also find that the opposite is true, and that you start asking more questions about your faith and your beliefs. That's also completely understandable. Lots of people find cancer makes them see things they'd previously taken for granted in a slightly different light.

It can be a tough time, especially if your family are religious and you find yourself struggling with your faith. Try and be honest about what you're thinking and how you're feeling.

Talk to people you trust about it. Religious leaders speak to people about these kinds of issues all of the time, and they won't be angry or judge you if you bring them up.

Exploring religion

If you've not been particularly interested in religion before, it can feel strange to start wondering about gods and faiths, but it's quite natural to start asking yourself all those why-are-we-here? and why-did-this-happen? type questions.

If you do find yourself being drawn towards a particular religion, you might find it's a huge support. Religion sometimes helps people make sense of confusing and difficult situations.

And even if you feel religion isn't really for you, you might start thinking about other types of spirituality. Again, we'd recommend searching out a good listener and talking to them about these things.

It's all about respect

If you're staying on a ward or cancer unit, you might meet other people who believe strongly in a certain religion or have strong views about spirituality. It's important to respect their beliefs and the way they're dealing with cancer treatment – as we've said before, everyone handles this time differently.

This can be a difficult time to get your head around. You might find it useful to chat to them about their faith and what it means to them, too.

Remember: everyone deals with cancer differently. The only thing that should matter to you is how you deal with it.

YOUR LIFE OUTSIDE HOSPITAL

YOUR LIFE OUTSIDE HOSPITAL

When the people close to you find out you have cancer, they'll probably feel a lot of the same things you did. They might not know how to respond and act differently – when you'd really like them just to be normal.

Dealing with relationships

Suddenly relationships that have been natural can feel strange and strained. But keeping friends and family close is important – and being honest and open can really help.

Remember, we use the word 'carer' to recognise anyone who is in the position of looking after a young person.

We acknowledge that some people might not have a strong parental or carer relationship (particularly if over 18) and want to highlight that you can always turn to your care team for support.

Cancer can put any relationship to the test, and a cancer diagnosis can feel just as overwhelming for your carer as it does for you. This list might help you think about what they are dealing with in case they start acting differently.

They might be feeling:

- Shocked, scared and angry
- Worried about you, and about your siblings
- Tired and short-tempered
- Distracted, because normal things don't seem so important
- Helpless, because they can't just sort this out for you
- Isolated, because their friends might not be sure how to help
- Stressed, about things like getting time off work or paying the bills

They might be over-protective of you. They might not seem like themselves (which probably means they're trying to put on a brave face). But whatever they're doing, it'll be their way of trying to cope.

Going backwards?

If you get cancer as a teenager or in your early twenties, you can suddenly find yourself spending a lot more time with your carer – just when you were getting used to spending a lot less time with them. And losing that independence can be tough for everyone.

You might need your carer for emotional support or for practical things like driving to appointments or cooking food. You might need to move back home or to ask for help with things you'd definitely rather do by yourself, like getting dressed or having a shower. And you might need your carer to help out financially too, which can be difficult if you're used to having your own money and paying your own way.

Changes like these can make you feel frustrated and smothered and possibly a bit embarrassed. It can seem like you're going backwards, and you might feel like your carers are fussing or nagging or treating you like a child.

If they are being over-protective, it's probably because they're worried about you, but it's still a good idea to let them know how you're feeling. Otherwise it's hard for them to know what they can do to help you.

Taking control

Sometimes you might feel too exhausted to do anything for yourself, but it can be really important to try and hold on to your independence and play a part in decisions that affect you.

Your carer may feel like they know what's best, and it can be tempting to let them take control. If that works for you, that's fine, but there might also be times when you want to be involved too. Learning about your cancer and your treatment can help you feel more confident about having your say. If there are things you don't want to know about – like the details of a procedure – just let people know before they start explaining things.

If you feel like you're not being listened to, try to talk to your carer calmly about what you'd like to change.

You might talk about:

- Who will go to your appointments – you might want a family member or friend to go with you, or you might prefer to go alone
- How you will be involved in decisions about your treatment
- How to keep doing the things you enjoy
- How you'll stay in touch and tell your family and friends what's happening. Maybe you want to communicate by phone or text, rather than

having them with you the whole time

- Why it's important to be left alone when you need space
- How to keep everyday life as normal as possible

Your care team will have helped young people deal with these issues plenty of times. If you think talking to your family or friends could be tricky, it might help to chat to the people who are looking after you first – they can offer advice and might be able to help you have any difficult conversations.

How you feel

Sometimes you might not want to tell your carer if you're feeling scared, depressed, stressed or just in need of a hug. Maybe you're nervous about making them worry even more.

But if you bottle things up, you usually end up feeling lonely or ready to explode. Or both.

If your family doesn't often talk about emotions, you might find it helps to write down some notes about how you're feeling in the notes section at the back of this guide and share it with your carer for them to read in their own time. They'll understand how you feel – without you feeling uncomfortable and trying to find the right words on the spot.

A lot of families find it helps to get support from someone outside the family. Psychologists, counsellors and your care team at the hospital know a lot about the impact of cancer and can help you, your carer and your siblings talk honestly about how you're feeling. You're all trying to figure your way through this, and talking about it honestly usually makes you feel a lot better.

“Spending that much time with my mum was nice and it brought us closer.

We joked that we had the party room as sometimes we’d put music on and have a mini party.”

Abigail

Keeping the connection

Calling, texting and messaging can all help you stay connected with family and friends. But sometimes, spending time together in person makes all the difference. Maybe you plan a day trip away from home, or an hour or two out of the hospital ward to get a change of scenery.

Siblings

Whatever your relationship with your brothers and sisters is usually like, you might find that cancer makes things a little different.

You'll probably find that lots of things don't change between you. What makes you laugh about them will probably still make you laugh. What annoys you about them will probably still annoy you.

It might bring you closer as you deal with this together.

Your brothers and sisters can be a useful link to your friends, school or college, and you might find yourself spending more time with them than you're used to.

But it doesn't always work like that. If you'd already moved out when you were diagnosed, it can be tricky if you need to move back home, for example. As you're trying to get your head around being back in your old home, they'll be going through the same thing, adjusting to you being back in the space.

You might find they suddenly get really overprotective and it can feel like they're acting like an extra carer. Or they might go quiet and not mention your cancer at all. Either way, it can be pretty tough to deal with and get your head around.

If you're in hospital for a while it can also put a strain on things. You might find your brothers and sisters don't want to come and visit.

Or it might start to feel like you don't have as much in common anymore, because you're not going to school or college together or spending much time together.

Why are things changing?

It's always strange if relationships you've taken for granted start to change.

Your brothers and sisters will probably be feeling a lot of the things that you're feeling. And if they start behaving differently, it might be because they're struggling to deal with that or trying to keep things as normal as they can for you.

You might find your brothers and sisters feel:

- **Scared** – No matter how strong they pretend to be, they'll be worried about you – especially if they feel like your carers aren't telling them everything or if they don't quite understand what's happening
- **Angry** – They might feel left out or annoyed because they're being asked to help out around the house more or because all of the attention is on you – and they might be angry at themselves for feeling like that
- **Jealous** – It probably sounds strange but you might be getting a lot of attention, and they may not be. It can seem unfair and that might make them feel jealous
- **Guilty** – When your siblings are out having fun, don't be surprised if they're feeling bad because you can't do the same. It's also not unusual for brothers and sisters to say cruel things they don't mean and then feel guilty about that. That doesn't mean they don't care about you: it's a pretty common way to respond if you're worried or upset
- **Lonely** – If you and your carer are spending a lot of time in hospital,

your brothers and sisters will probably miss you and miss the way things were. Their friends might drift away too, because they don't know how to react, and that can be a pretty lonely experience

- **Worried** – Sometimes brothers and sisters might think they've done something that's caused your cancer. It's important to let them know that's not possible. Nothing they – or you – did made this happen

It can all feel pretty complicated. But, as we've said before, the simple truth is that talking helps. Even if you've got the sort of relationship where you don't usually speak about feelings and emotions, just sitting down and being honest with each other can be a big step forwards.

It won't necessarily get things back to how they used to be, but it usually really helps to clear the air.

Friends

Your friends might be amazing during your cancer treatment – saying and doing all the right things and generally being very supportive and helpful. But cancer can put pressure on any relationship, and sometimes even the closest friendships can change.

Having your friends around you while you're dealing with cancer can be a massive source of comfort. You might feel like they're the people who know you the best, and you can probably be totally honest with them too.

But sometimes people find that even their closest and oldest friendships start to feel strange and strained. There are lots of practical reasons why that can happen. You might need to spend time away from home in hospital, for instance, or you might not be able to do the same things you used to do.

But a lot of the time friendships drift apart. Your friends might not know what to say. They might worry about saying or doing the wrong thing, and you might not be seeing each other as much as you used to which can make things difficult too.

You might find that your friends are asking themselves lots of questions, like…

- What am I supposed to do?
- What if I say the wrong thing?
- How can I help?
- Is it OK to visit or should I stay away?
- Should I talk about cancer or not mention it?
- Should I talk about other things or will that make me seem selfish?

Talking through some of those questions can really help clear the air, and so can letting people know how much their friendship means to you.

It might help to:

- Ask people to keep calling, texting and inviting you to things
- Explain you sometimes might take a while to reply
- Make sure you contact them too
- Let your friends know what they can do to help
- Let them know if you're happy to answer questions

Even if you can't always go out and do the things you used to do together, seeing your friends when you feel up to it can give your mind a rest from thinking about cancer. So let them know if you're happy to hear about the usual day-to-day stuff you would normally chat about, otherwise they might think it's too trivial to bother you with.

And try not to worry about moaning when you're with your friends, people understand that things are tough for you right now.

Remember...

There might be times when your friends annoy you, especially if you're feeling ill or irritable because of your treatment. It's only natural and it probably happened before you had cancer too.

But instead of getting angry with them, try to remember that:

- **Sometimes people don't know what to say** - so they stay quiet or say things without thinking
- **Sometimes people ask silly questions** - it's only because they're interested
- **Your friends aren't deliberately trying to annoy you** - so if they do something that gets on your nerves, try to talk it through calmly
- **Your friends might not realise just how bad you're feeling** - so they might assume you're feeling happier or stronger than you actually are
- **Your friends have their own lives** - so try not to get upset if they talk about school, college or whatever – it can actually give you a nice chance to think about something else

Drifting apart

It might be that you get closer than ever to some of your friends during cancer treatment. Having people to listen to you, make you laugh, talk things through and give you a shoulder to cry on can be just the support you need.

But you might also find that you end up losing touch with people. Some of your friends might not be able to understand what you're going through, and might end up distancing themselves.

They might even be jealous of the attention you're getting. It might be that your perspective on life changes, so you struggle to relate to people like you used to.

If this happens, try not to let it get you down. Friendships change all of the time – cancer or no cancer. You'll probably find yourself building new relationships, especially if your outlook on life is changing or if you meet other young people living with cancer.

And what matters most is spending time with people who make you feel good – whether you've known them for a long time or not.

Partners

Dealing with partners can be difficult at the best of times. Throw cancer into the mix and things often get even more complicated.

If you're in a relationship while you're going through cancer treatment, it can bring you closer together, helping you realise just how much you mean to each other.

But it can also push you apart, as you might struggle to communicate like you used to about what you're feeling and what's going on.

Whatever happens, remember you're both reacting to a really tough situation – and you're both probably feeling a lot of the same emotions. It's never easy, but sharing what you're going through – and trying not to criticise or blame each other – can stop you drifting apart.

You might feel like you're a burden, or your partner might really want to support you but not know how. Stuff like that doesn't come out easily unless you talk about it.

“My friendship with Katie is one of the most positive things to come out of my experience.

It’s great having someone else in my corner; she’s another cheerleader for me.”

Ellie

“Meeting Ellie was such a relief as we have the same worries, and we can chat about them without making people feel guilty.

You feel bad moaning about cancer to people who don’t have it; if you suffer, they suffer. So, you sometimes put a brave face on things.”

Katie

Things that might happen

Every relationship is different, but these are a few things that can sometimes happen after a cancer diagnosis.

- **You get closer** - Lots of couples find their bond gets stronger during treatment
- **Your partner seems distant** - Sometimes people respond to news they really don't want to hear by blocking it out. If this happens, it can seem like your partner is ignoring you or doesn't want to talk about cancer. That can be pretty painful
- **Your partner smothers you** - On the other hand, you might find your partner suddenly won't let you do anything for yourself, leaving you feeling suffocated and helpless
- **You seem out of sync** - There might be times when you feel glass-half-full but your partner feels glass-half-empty. Sometimes the opposite might be true. This can put a strain on both of you – but try to remember it's OK to feel differently about things
- **You worry about how you look** - If your body is changing, you might be scared that your partner won't be attracted to you anymore
- **You worry about the future** – If your fertility is affected by your treatment then what that means for the future might weigh on your mind too
- **You feel guilty** - No matter how many times your partner tells you it's not true, you might still feel like a burden. And that can make you worry that they feel stuck with you or are only with you out of sympathy
- **You change** - If your outlook on life alters during treatment, you might find you grow apart from your

partner. It can happen in any relationship – whether you have cancer or not

- **Your partner can't handle it** - Sadly this does sometimes happen. Your partner might feel they can't deal with this right now and choose to move on
- **You can't handle it** - This happens too. Some people just feel they lack the energy for a relationship during cancer treatment and decide to call it a day

Honesty is the best policy

It's true. Hiding things causes arguments. Being honest might make for tricky conversations, but at least it gets any issues off your chest.

So if you've got any doubts about how your partner is feeling or how you're feeling, get them out in the open and try to talk things through without blaming or criticising each other.

Make sure you listen too, rather than pressuring your partner to feel a certain way.

And remember that being diagnosed with cancer doesn't mean cancer is now the only thing in your life.

Remember to:

- Talk about all the other stuff you've always talked about
- Plan time to just be together
- Laugh together and cry together, if that's how you're feeling

What to tell a new partner

It's up to you when you decide to tell a new partner that you have cancer. You might want to wait until things seem to be getting serious, or you might want to be honest and open from the start.

Whatever you do, remember it's not something to be ashamed about. Your partner may even know someone who has been through something similar.

"My partner has made it so much more manageable; I can't put it into words when I try to explain everything she has done for me and been there for me, I can't find the words to fully explain it.

I never expected her to be as good as she was. The way she looked after me, I'd never expected anyone to be there like that especially at this age."

Michelle

If your body has changed because of your cancer treatment – if you've had a breast or testicle removed, for instance – you might want to talk about that before you get too intimate. It's not always the easiest conversation, but it can help you feel more comfortable. And it means you can both have a little time to get used to how that makes you feel.

But however you decide to talk about cancer with your new partner, it can help to:

- Pick a time when you are both relaxed
- Think about what you want to say beforehand
- Be honest about how you're feeling and encourage your partner to be honest too

And, if you're feeling worried, turn to page 147 for a little more advice on telling people about your cancer diagnosis.

Telling your kids

If you've got children, you may want to try and explain to them what's going on – and you don't need us to tell you that that's not an easy conversation.

When you're young, your brain is like a sponge. You soak up everything that's going on around you – even if you don't exactly understand it.

So if you've got children, chances are they'll figure out fairly quickly that something is up – especially if your appearance is changing. For that reason it's worth trying to do what you can to explain it to them as early as possible. It'll help them make sense of the changes they notice, too.

The good news is that children often want to learn, and if you explain things in a simple way, they'll understand. If you're open and honest with them, chances are they'll be open and honest with you too about how they're feeling.

Planning the conversation

There's no point denying it - telling your kids you have cancer is a horrible thing to have to do, and they will probably be very worried by what they hear.

But by thinking carefully about what you want to say and how you want to say it, you can make the conversation less painful.

You might find it helps to:

- **Tell them you love them**, because there aren't many things that provide more comfort than that
- **Explain things step-by-step**, so they can come to terms with your diagnosis and treatment gradually
- **Be honest** - they'll work it out pretty quickly if you're holding things back
- **Encourage questions** and ask your children to be open about how they're feeling
- **Reassure your children** that this is nobody's fault and that they won't catch your cancer
- **Ask them to repeat what you've said** - so you can check they've understood it

There are books you can use to help you explain what's happening, you can ask your nurse or Youth Support Coordinator if they have any copies or can point you in the right direction of where to find them. There might also be play specialists at your hospital who work with children and can help with these conversations too.

The **Little C Club** has lots of resources to help you talk to your children about cancer. Go to their website for more information: **littlecclub.com**

What to expect

Children react in all sorts of ways. They might become clingy, insecure or withdrawn, or they might start playing up to get more attention. You might find they go through stages of acting in all of these ways.

It can help to try and spend as much time with them as you can, or to ask friends and relatives to spend extra time with them if you're not around. Simple things like playing with them, going for a bike ride or walking to the park can make both of you feel better. Finding ways for them to help out and get involved in your treatment can be a good idea too.

And don't be afraid to let them know if there are times when you could really do with a hug. Your children can be a huge source of support – and can usually put a smile on your face – if times get tough.

Talking can be tough

Throughout this guide we've been encouraging you to open up about your feelings. But what if you struggle with that?

Lots of people like to keep to themselves, and that doesn't suddenly change after a cancer diagnosis. You're still the same person you always were.

But talking really can help, and going through this alone might make it harder. The trick is to find a way to talk that works for you.

For starters, try to remember:

- There's no right or wrong way to talk about cancer
- Finding the right person to talk to can make a big difference
- Being scared that you'll upset people can mean you hold things back when they really want to know the truth, so being honest is important – even if it's tough

Tips for talking

It’s totally up to you what you talk about, how you talk about it and who you talk to, but these ideas might help to make conversations a bit easier:

- People might avoid talking about cancer because they’re not sure if you want to, so it’s a good idea to let them know if it’s OK, or if you don’t want to talk right now
- It can help to start by explaining what you’d like to talk about and if there’s anything you’d rather avoid
- Writing things down can help – it can guide your conversation and if you don’t feel up to talking, you could write a letter for people to read in their own time
- There might be silences and people might get upset. That’s OK, so try not to let it worry you. Take a few breaths, have a cup of tea or a glass of water and see if you feel ready to keep chatting. If not, don’t force it. Take a break and try again later
- Some people prefer to talk while they’re doing something else, so that all the attention isn’t on them. If that sounds like you, think about times that might work – like when you’re in the car, out shopping or watching TV. Or if you prefer to talk somewhere private and quiet, choose somewhere you feel really comfortable
- Try not to worry too much beforehand – conversations often seem much worse in your head than they actually turn out to be. Often, talking about this stuff makes everyone feel better

If talking is too tough

If you really don't feel able to talk, don't worry – there are plenty of other ways to let people know how you're feeling.

Here are some ideas for how to manage this:

- Send a text, email or write a letter
- Take photos, draw pictures or send songs that sum up how you're feeling
- Leave a sign on your bedroom door
- Write a blog to let everyone know what's on your mind
- Some people might find it helps to make use of social media channels like YouTube, TikTok or Instagram to document how they're feeling
- Keep a diary, to get your thoughts out even if you don't want to share them with anyone else

If your family is really struggling to talk, it can also help to speak to someone whose job it is to help people communicate. Counsellors, social workers, Youth Support Coordinators, doctors and nurses will all be able to give you lots of practical ideas and clinical psychologists are experts in helping people have tricky conversations, so don't be afraid to ask for help. Even if it feels weird at first, involving someone who's not so close to the situation can help everyone relax.

Choosing who to tell

Talking to your family and close friends about cancer is hard enough, but what about telling people you know less well – like your classmates, teachers or people you work with?

At this time it's normal to ask questions like:

- Do I have to tell everyone?
- How will people react when they find out?
- Do I want that person to know?
- Am I going to keep this from people?

The truth is that your treatment might make it hard not to say something. If your appearance changes, for example, avoiding awkward questions can be tough.

But whatever happens, who you decide to tell is your choice – and it can help to weigh up the pros and cons before deciding who to tell.

You might decide to talk to people because…

- Keeping cancer to yourself can be stressful and tiring, whereas being honest can be a relief
- Telling your teachers or manager can make it easier to get extra support at school, college, uni or work. This might include having time off for appointments, changing your work hours or avoiding things like heavy lifting or using machinery because you might not feel able to keep doing your normal job safely
- You might feel tired or struggle to concentrate because of your treatment, and explaining why can be more straightforward than making something up or avoiding answering questions

You might decide not to talk to people because…

- You're worried about getting a strange reaction and being treated differently
- You haven't got the energy to keep repeating the same story and answering the same questions
- You don't feel comfortable discussing your health, especially if your cancer is affecting a part of your body you wouldn't normally talk about
- You want to keep school, college, uni or work as a place where you're not defined by cancer
- You feel like it's nobody else's business

However you feel is completely fine and totally understandable. It's your body, your life and your decision who to tell. It's worth bearing in mind that if you don't tell your employer, they don't have an obligation to make reasonable adjustments for you at work – you can read more about that on page 156.

How to tell people

It's up to you - you might want to tell people separately or in a group. You might want to go for a walk or find a quiet classroom or meeting room. You might want to talk about everything or keep your explanation short.

It's your cancer, and your choice. There are some questions it can help to think through before telling people, though.

- **How much information are you happy to share?** You could write this down beforehand – you can use the notes section at the back of this guide and you could even share this with people if you don't feel comfortable talking out loud
- **What do you want to say?** It can help to practise on your own first
- **How do you feel about people telling others?** Let them know if you don't want it to go any further. Bear in mind that most people will want to tell at least one other person, usually because they're feeling worried or upset and want to talk things through
- **Are you happy to answer questions?** Some people might have a lot. Others might feel a bit shocked and not say much. Either way, it can help to let people know that you're OK for them to ask

- **Is there anything people can do to help?** It's often the first question people ask when they find out, so have a think about any practical support you need and things like how often you'd like people to be in touch

It can be a tricky conversation, but it's often much more straightforward than you expect. It's also not unusual for relationships to grow stronger after people find out about a cancer diagnosis. But don't feel any pressure to tell anyone you don't want to.

Education

What happens with school, college, apprenticeships or uni during treatment? Here's what you need to know about cancer and education.

If you're a full-time student, your doctors and nurses might recommend you take some time off school, college, apprenticeships or uni to help your recovery. This can sound like a great idea at first but can quickly feel quite weird.

The good news, though, is that there are plenty of options to prevent you from losing touch with your studies completely – and plenty of ways to make your return to school less stressful, too.

Staying in touch

It can help to try and keep up with some work even if you're not able to stay at school, college, your apprenticeship or uni full-time. Doing things you're used to doing can help you feel more positive, and so can keeping in touch with your teachers, tutors and people in your classes. Chat to your teachers or tutors about what's possible for you to do, but try to avoid taking too much on and getting stressed.

Letting people know

Your school, college, apprenticeship provider or uni can only provide support if they know what's going on. So while it's up to you who you tell, it's usually a good idea to let your tutors know about your diagnosis as soon as possible. You can always make it clear you don't want them to tell any other students or particular staff members.

Schools can help you keep up. Colleges often have support services and can get funding to help you. Unis can make adjustments or postpone your studies. And you might be able to get help via the Disabled Students' Allowance (DSA), too. But all of these things can take time to get sorted.

Search: 'disabled students' allowance' on **gov.uk** to find out more.

Learning at hospital or home

If you're in compulsory education (which means you're 18 or under) and staying in a children's cancer ward or teenage and young adult unit, you might be able to study while you're there. Lots of facilities have education departments that employ teachers.

And if you're 18 or under and not in hospital but not well enough to go to school, you might be entitled to home tuition or be able to study online. You can ask your social worker or Youth Support Coordinator for more information about this, or you could get in touch with your local authority.

Top tip: Staying in touch with your school, college, apprenticeship or uni can help life seem more normal – even if you're simply emailing tutors or meeting up with friends.

> “I was in hospital for five weeks. The hospital had teachers, so I had 45 minutes to an hour lessons on Maths and English.
>
> School then broke up for seven weeks, so I didn’t miss too much.”
>
> Bobby

Ready to go back?

Once you're feeling well enough to start studying again, chat to your doctors and nurses. They'll help you work out what's possible and give you advice on what to expect.

It's also a good idea to get in touch with or visit your school, college or uni, so you can let your teachers know how you're doing and how they can help. If you don't want to do this yourself, you can always ask your carer or a friend to go with you – or ask your carer to go instead.

Helping people understand

You might also like to ask your teachers to talk to your class before you go back, so people have an idea of how your treatment has gone and how you are now. It can help you avoid having to answer the same questions multiple times.

It might even be helpful to bring this guide with you when you go back to school and give to other people in your class to have a look through if they want to learn more about your experience. If you don't want to share any notes you've made in the back, you could always ask your nurse or Youth Support Coordinator if you could have/borrow another copy to share.

We've also got lots of information on our website and social media channels which might be useful to tell people about.

Your first day back at school

Like a lot of things, your first day back might seem a lot worse in your head than it turns out to be. You might find that some people are looking at you or treating you differently, especially if you look different now. But you'll also probably find that lots of people are really happy to have you back.

It's a good idea to arrange to meet a friend beforehand, because arriving with someone else might help you feel a bit less self-conscious.

And if you look different after treatment and are worried about how people might react, you could arrange to meet up with a few people before you go back. Try to remember, too, that everyone will get used to how you look now very quickly.

If anyone does make nasty comments, let a teacher know. Dealing with bullies isn't your responsibility and it's important people know what's going on.

Keeping up

If you struggle to keep up with your work at first, don't worry. You might have missed a lot. Your treatment might have affected your ability to concentrate. You might just feel exhausted.

However you feel, your teachers will understand – and your classes should get easier as time passes.

Remember to let people know if you're going to miss classes because of appointments.

To make sure you don't get behind, you could:

- Ask a friend to take notes and share them with you afterwards
- Get the teacher to email you with any work you miss
- Talk to your teacher about which work is most important, so you can focus on that

Applying for support

If you've got exams coming up, you might be able to apply for various 'access arrangements'. This can cover things like being given extra time or having someone to write for you during an exam.

Similarly, you might be able to get ‘special consideration’. That basically means your individual circumstances are taken into account when your paper is being marked.

Lots of people apply for access arrangements and special consideration every year, for all kinds of reasons. It can help to take some of the pressure off when you’ve had a difficult experience. It doesn’t make your result worth any less – it’s just recognition that you’ve not been able to study as much as you’d normally be able to.

If you think this is something that would help you, speak to your teacher about how to arrange this.

Who to talk to

If you’re worried about your studies or you’re struggling to keep up, try not to keep it to yourself.

It might help to talk to:

- Your teachers, who are there to support you as well as teach you
- Your school, college or university counsellor or pastoral support team – these are people who are trained to listen and help you deal with problems
- Your carer, who can speak to your teachers if you’d rather not and might be able to help you get extra support
- The people taking care of you, including doctors, nurses, social workers and your Youth Support Coordinator, who might have some helpful ideas on how to cope with studying
- Your friends, who might be able to help you keep up, or might just be the perfect people to open up to about your feelings

Your job

Keeping up at work, returning after treatment or looking for a new job can be a challenge, but there's plenty you can do to make things easier.

During treatment

Legally you don't have to tell your employer if you've been diagnosed with cancer. But if you don't tell them, they don't have any obligation to make reasonable adjustments to help you.

Reasonable adjustments can include things like giving you time off to go to hospital or doctor's appointments, giving you extra breaks and letting you return to work gradually. These are all covered under the 2010 Equality Act (Disability Discrimination Act in Northern Ireland). This classifies everyone with cancer as disabled (even though you might not think of yourself as disabled).

Once you've told your employer about your diagnosis, it's illegal for them to discriminate against you. So think carefully if you're not planning on letting them know.

Search: 'equality act' on **gov.uk** to find out more.

Don't rush into anything

If you've had a cancer diagnosis and are thinking of quitting your job – don't do anything before you've fully considered your options. Take some time, speak to people close to you and work out whether that's really what you want to do. You can also speak to your employer to find out what reasonable adjustments they might be able to make to accommodate your diagnosis.

Find out more about work and your rights at **macmillan.org.uk/workandcancer**

Ready to go back?

Going back to work if you've taken time off for cancer treatment can feel like a big step forward. But it's important not to rush it – and not to expect too much of yourself, too soon.

If you're going back to your old job, your employer has a duty to make changes that could help you, as long as they're reasonable and you've told them about your diagnosis. And if you're looking for a new role, there's no reason that cancer should stop you landing the job you want.

But whatever your situation, wait until you feel ready to go back to work, then talk to your manager and your doctors or your clinical nurse specialist about what's possible, and ease yourself back in gently. Your social worker and Youth Support Coordinator can help you talk things through too.

Tips for going back to work

You might find you get tired more easily at first or sometimes struggle to concentrate. Try not to worry – that's very common. It can help to:

- **Make a return-to-work plan** - This gives you and your manager the chance to agree what you're able to do, which parts of your role you should focus on, any changes that are needed, any appointments you'll need time off for and so on. Your return-to-work plan should be flexible, and it's a good idea to review it regularly
- **Go back part time** - You could talk to your manager about working fewer days or shorter shifts, or maybe about working from home
- **Adjust your routine** - Ask if you can arrange your day around the times you feel at your best

- **Take your breaks** - Make sure you don't miss them – and relax when you have them
- **Be honest if you're struggling** - No one will judge you, and your manager might be able to make reasonable adjustments to make things easier for you
- **Go easy on yourself** - It takes time to recover from cancer and treatment, so listen to your body and don't stress if you can't do everything straightaway

The people you work with will probably be curious about your treatment and how you're feeling, so it's worth thinking about how much you want to let them know. Go to page 147 for tips on managing conversations about your diagnosis.

Speak up

Most managers and companies are brilliant at adapting to make your life easier – but some aren't. If you think you're not being treated fairly or it feels like a fight to get adjustments made, try not to stay silent. You could speak to colleagues, family or friends, and the Citizens Advice Bureau can help too.

Find out more at **citizensadvice.org.uk**

Looking for work

Searching for a new job is hard at the best of times. After you've had cancer it can seem even trickier. But if you're qualified and physically able to do a job, there's no reason that cancer should be a barrier.

In fact, there are very few reasons that an employer can question your health in an interview.

It's OK for employers to ask about your health to check if you're able to complete a task that's fundamental to the role, to make sure the recruitment process isn't discriminating against anyone, or to help them take 'positive action' (which might mean improving their recruitment of people with disabilities, for instance).

But it's up to you how much you tell any potential employer. Try and resist any temptation to be dishonest, though – being honest from the beginning will help in the long run.

And remember that while you might not think of yourself as disabled, the Equality Act and the Disability Discrimination Act consider everyone with a cancer diagnosis to be disabled. This protects you against discrimination because of your cancer – and this applies for the rest of your life, even when there's no longer any evidence of the cancer.

So if you're asked if you're disabled, you should say yes, even if it doesn't feel quite right.

Look out for the 'Disability Confident' employer scheme on job ads, too. If you meet the basic conditions for these jobs, you'll definitely be asked in for an interview.

Search: 'disability confident' on **gov.uk** to find out more.

Top tip: My Plus Students Club offers job-hunting tips, legal advice and info about companies who are committed to employing people with disabilities. Visit **myplusstudentsclub.com**

Holidays

Ready for a break? Cancer doesn't have to stop you dreaming of sun, sea and sand. You just need to think about a few more things before you go.

We're definitely not telling you that there's no way you can go on holiday before, after or even during cancer treatment. A change of scene can do wonders for you and those around you.

What is important, though, is that you speak to your medical team before going anywhere.

Having cancer might affect where you can go, when you can go and what you can do, and your doctors and nurses will be able to help you make the best choices.

Head to page 166 at the end of this section to find a handy checklist of what you need to remember before we go on holiday.

Just allow a bit more time to make any special arrangements, and follow these ten handy tips if you are thinking about travelling:

Be realistic

This one isn't always easy, but it makes sense. If you find yourself getting tired easily at the moment and can't walk long distances, now probably isn't the time to book a hiking trip. Go easy on yourself and be honest about what you can and can't do. Symptoms like fatigue, sickness, diarrhoea, increased risk of infection because of your treatment and increased sensitivity to the sun can all affect your travels, so take them into account when you're planning your trip.

Check insurance options

Getting travel insurance can be more difficult when you have cancer and can take longer to arrange, but that doesn't mean you won't get it.

Insurers have to cover the cost if you get ill while you're away or need to cancel your trip. You'll usually need to give the insurance company a letter from your doctor before they make a decision. And make sure you're totally honest when you apply – otherwise your insurance policy might not be valid.

Ask about vaccinations

To travel to some countries you need to get vaccinations before you leave. But taking certain cancer drugs can weaken your immune system, which means you can't have the vaccinations. Check with your doctor to see what's possible for you.

Search: 'travel vaccinations' on **nhs.uk** to find out more.

Plan your medication

If you'll be on medication while you're away, take enough for the whole trip – plus a few extras in case you're delayed or you lose some. If you're going away for less than three months, your doctor will be able to write extra prescriptions for you. If you're away for longer than that you'll need to get medication overseas. Some countries limit the amount of certain drugs you can take in, so if you're worried contact their embassy in the UK - you can find a full list at **gov.uk**.

It's also a good idea to get a letter from your doctor listing all the medication that you're taking. And make sure you carry any medication, syringes and medical pumps in your hand luggage so you can get to them easily. You might be worried about having things like syringes taken off you at security if you're flying, but you're allowed to carry medical equipment with you if it's essential for your journey. You will need to have a note from your doctor that explains this.

Make sure you're fit to fly

You can usually fly without problems, but there might be times when changes in pressure or the amount of oxygen in the cabin could be issues. Check with your doctor and airline before flying anywhere, and in particular if:

- You've recently had surgery
- You've had a bone marrow or stem cell transplant in the past year
- You've got low levels of platelets in your blood
- You get breathless easily

If you need to carry an oxygen cylinder with you for your flight, you'll need to contact the airline you're flying with in advance to check their rules on this.

Pack your medical records

They'll come in very handy if you need any treatment while you're away.

Speak to your travel company

Some travel companies and airlines have medical officers who will be able to give you advice about your journey. They'll be able to organise things to make your trip easier too – like early plane boarding, the right meals for you and a wheelchair if you need one.

Get a GHIC card

If you're travelling anywhere in the EU, or to Norway, Lichtenstein, Iceland or Switzerland, apply for a UK Global Health Insurance Card (GHIC) card online. Having one of these means you can get healthcare for free or at a reduced cost in those countries.

Search: GHIC on **nhs.uk** to find out more and apply for a free card.

Protect yourself in the sun

It's really important that everyone wears sun cream, and some cancer treatments can make your skin more sensitive to sunburn, so it's even more important to keep yourself protected. Remember to cover up, pop on a hat and put on sun cream that's factor 30 or higher and remember to re-apply regularly.

Enjoy yourself

We know it can seem like a lot of admin to get all of these things sorted before you go on holiday, but once you're there, make the most of it!

Legal and money issues

There are lots of legal and money issues that can come up during cancer treatment. You might want to know how to deal with being discriminated against at work, or understand more about benefits and any other support that exists for your carers or family members. Maybe you'd like to find out about help with travel costs.

Dealing with issues like this can be frustrating when you're trying to focus on your health. But the good news is that plenty of organisations can make it easier to find the answers and support your needs.

Top tip: If you've got legal or money questions, speak to your social worker or Youth Support Coordinator first. They'll either know the answers or be able to point you in the right direction.

Money matters

The NHS will cover all of your treatment costs (unless you're receiving private care), but cancer can still make life difficult financially. You or your carers might be earning less if you've had to stop working or reduce your hours. You might need to pay for travel to appointments. Your carers might need to pay for accommodation to stay nearby if you're away from home. And costs like heating can increase too if you're spending more time indoors or feeling the cold more.

If you and your family find yourselves struggling with the financial side of things, there is a lot of help available – like benefits, grants and tax credits. There are also plenty of organisations that are very experienced at supporting people in your situation.

Search: 'useful contacts' on our website to find out more.

Dealing with discrimination

You have rights under the Equality Act to make sure you aren't treated differently because you have cancer. They mean that:

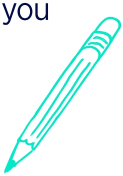
- You can negotiate for reasonable changes at work – which might include flexible working hours or time off for treatment
- You have legal protection if you feel you're being treated unfairly at work
- You shouldn't be treated unfairly at school – your school should work with you and your family to consider what's best for your education
- You shouldn't be treated differently by landlords – they can't refuse to let you a property because you have cancer

If you feel you're being discriminated against, start by talking to your manager, teachers or landlord about how you're feeling. If that doesn't sort the problem, speak to your social worker or Youth Support Coordinator, or contact the Citizens Advice Bureau.

Making a will

This is probably something you've not given much thought to before now. But if you're over 18, writing a will is a really good idea (whether you have cancer or not).

You don't need to have lots of money to make a will, it's simply a way to explain what you want to happen after your death. It can cover your possessions, who will look after your children (if you have any) and any details about your funeral. You need to make sure it's legally valid, and once you've done that you can be confident that things will happen the way you want them to.



Search: 'make a will' on **gov.uk** or 'wills' on **adviceguide.org.uk** to find out more.

Your travel checklist

Use this list to make sure you've got everything you need before you head on holiday!

- Check in with your doctor before you travel
- Check your travel insurance options
- Make sure you have the right vaccinations
- Pack enough medication (and some spares!)
- Speak to your airline or travel company
- Get a GHIC card (if you're travelling in EU, or to Norway, Lichtenstein, Iceland or Switzerland)
- Pack sun cream (minimum factor 30)
- Pack your medical records
- Keep your emergency numbers handy

YOUR LIFE AFTER TREATMENT

YOUR LIFE AFTER TREATMENT

Remission describes when the signs and symptoms of cancer are no longer visible.

'Remission' is probably the word you've wanted to hear for so long, congratulations!

When you're living with cancer and having treatment, you tend to spend a lot of time thinking about it – and about doctors, nurses, hospitals, tests, side effects and everything else that goes with your diagnosis.

When the day comes that you don't have to think about those things anymore, everything can feel a bit strange and slightly scary.

If the world seems strange at the moment, don't worry. There's nothing ordinary about life after treatment. And no matter how much you've been looking forward to it, it takes time to adjust to your 'new normal'.

What does life look like now?

You and the people close to you have come through a massive challenge. But getting over cancer doesn't happen when you get rid of the disease.

In fact, it can be hard to work out what 'normal' is now. That can be exciting, but it can be confusing too.

So give yourself time and don't rush into any decisions. It might help to think about what you want your life to look like now, rather than trying to rebuild your exact life before cancer.

Redefining your plans

Now can be a good time to look into different options for your future. It can help to talk to family, friends, careers advisers, social workers, religious leaders: anyone whose advice you trust. Writing down short or long-term goals can help too.

The most important thing is to do whatever feels right to you.

You might want to pick up where you left off with some goals, while others might need a rethink…

- If cancer has affected your body, your energy levels or your emotional state, you might not feel able to follow the plans you had before. This can be hard to adjust to, but don't rush to find a new direction. The time will come when you feel ready to think about different opportunities
- Maybe you're thinking about aiming for a totally new career. Whatever you're thinking, speaking to a careers adviser can help you figure things out
- Maybe you've got no idea what you want to do. That's nothing to worry about. This is a tough time, and no one will blame you for feeling confused. (And plenty of people live a happy life without ever really knowing what they want to do.)

You can find more information on careers, apprenticeships and training in your country on the following websites:

England:
nationalcareers.service.gov.uk

Northern Ireland:
nidirect.gov.uk/careers-service

Scotland:
skillsdevelopmentscotland.co.uk

Wales:
careerswales.gov.wales

Looking for meaning

It's not unusual to think about the impact cancer has had on you. A lot of people want to know why it happened to them, what it means and what they can learn from it.

You might feel it's left you feeling stronger and able to enjoy life more. Perhaps you prefer just to accept that it's happened and move on. Or maybe you're swinging between feeling positively and negatively about what you've gone through.

Everyone's experience is different. But if you do find yourself wanting to talk about issues like these, try your friends and family. There's a chance you'll even find they've been asking themselves similar questions.

Online forums can be helpful too, as they can put in you in touch with people your age who have been through cancer. Remember that everyone's experience is different, though.

Who am I?

That's a pretty tricky question at the best of times, but cancer can make it a whole lot trickier.

There are various reasons you might not feel quite like you used to:

- The way you look and the way you see yourself might have changed (which can affect your confidence and self-esteem)

- You might feel like your relationships with the people close to you have changed
- You might feel stronger and more mature
- You might value different things
- People might treat you differently, even if you're no longer living with cancer

It can be frustrating if people act strangely or single you out. Doing the things you used to do – like going to school or work or just spending time with friends – can help. Meeting new people can be a good idea too, if you feel up to it.

It's a confusing time, so don't rush to figure out who you are. Identity constantly changes, and after living through cancer it's not unusual to feel a bit lost for a while.

Finally, you might find it helps not to set your expectations too high. If you go back to school or work expecting everything to be just like it used to be, you might be disappointed. But if you prepare yourself for things to take time or to feel weird for a bit, it might make the experience easier.

Relationships after cancer

As we've already said, figuring out what life looks like for you after cancer can be difficult. The people close to you might also struggle too and as a result, your relationships might start to change.

Family

We acknowledge for many reasons people might not have a close relationship with their family. We want you to know that we understand this, and your care team will do the best they can to support your needs. Lots of people, especially those over 18, have close friends and they may be the ones who are supporting you through cancer.

It's likely that during your treatment, you and your family adjusted to your new reality. You might have needed more support from them than you're used to.

Now your treatment is over, figuring out how your relationship with your family or carers will work from now on can be complicated. If you're still living in your family home, you might feel like you're dancing around each other as you try and get your independence back and everyone tries to readjust.

It's a good time to experiment with who does what, and to be honest about how you're feeling. Try and find out what works best for everyone and how best to support each other. Take the time to listen to the people around you. You'll figure out what's normal now soon enough.

Friends

You might have stayed close to your friends right through your cancer treatment, so they know what's happened to you, you know what they've been up to, and all of you fit right back together now you can spend more time with them.

But it's not always that straightforward. Maybe you feel you've missed out on things or can't relate to your friends like you used to. You might feel like you've grown up faster than them or they've left you behind. Or maybe their problems and worries seem a bit trivial now and you're less interested in hearing about them.

If some friendships have become difficult, you might find things gradually feel less strained once your treatment is over. Spending more time with people and doing the things you've always done can help everyone feel more comfortable.

But it might be that some friendships don't quite click anymore. That happens too – cancer or no cancer.

If you find that you're interested in new things, you might want to try and meet new, like-minded people – maybe by joining a local club or team or by connecting with people online.

And try not to worry. Even if it feels like a lot is changing now, you'll soon get a better idea of how you want to spend your time and who you want to spend it with. Just give yourself a bit of space and time.

Partners

When we use the word partner, we are referring to people of all sexual orientations and gender identities. This is inclusive of everyone in the LGBTQ+ community.

Even if you've been with your partner throughout your treatment, you might still find that things feel slightly odd. Don't worry – that happens. Just like with your family and friends, it's all about readjustment.

It might be that neither of you have really spent much time thinking about what's going to happen once you finish treatment. Even if you've talked about the future before, the situation can seem different when it actually arrives – so it's important for both of you to work through what you want now.

When you're feeling ready, it could help to talk through:

- How you feel about your relationship now
- How you'd like your relationship to develop

That might sound pretty scary, but it can be exciting too. After all, this is your chance to start thinking about all of the things you might have been too nervous or distracted to think about before.

Taking your time

You might find some people struggle to understand why you can't just go back to being exactly how you were before. Phrases like 'get over it' and 'move on' aren't useful but that doesn't mean you won't hear them.

If you feel like people are pressuring you, try to explain that even though your treatment is over, you still need to deal with what's happened – in your own way and in your own time.

And if you notice you're finding life after cancer particularly challenging, it's important to speak to someone about that. It could be someone close to you like a family member, a doctor or nurse, your Youth Support Coordinator or a clinical psychologist or counsellor. The time after treatment can be one of the most challenging to get used to and there's nothing wrong with asking for help.

> We organise regular events that bring together young people who've had cancer. **Search**: 'events' on our website to find out more.

"When I made the difficult decision to return to university a few months after I finished treatment, still in a global pandemic, I had never felt so isolated in my life. I decided that I was going to involve myself in university groups.

For the first time, I met other LGTBQ+ people. Coming from a very small town in the west of Scotland, for a long time, I was a square peg in a round hole. But finally, I felt at home. Being able to talk about my experiences and my concerns was so uplifting."

Jamie

Worrying about cancer coming back

‘Will my cancer come back?’ is usually one of the first questions people ask themselves when they find out they’re in remission. Even if you’re feeling well and your doctor has told you that your cancer is in remission (which means you’re no longer showing any signs or symptoms of cancer), the knowledge that it could come back can be really hard to deal with.

If you can’t shake the worry that cancer could return and it stops you from doing things, it might help to speak to other people who have had cancer about how they deal with that uncertainty. Talking to those in your support network can help. It might be worth trying some relaxation or mindfulness techniques too.

Or you could talk to a professional, like a clinical psychologist or counsellor, who will help you find ways to deal with your fears and anxieties.

If cancer comes back

Sometimes, even if it’s been a long time since you had treatment, cancer can come back – either where you had it before or somewhere else. This is also called ‘relapse’. Getting that news can be devastating and prompt you to ask ‘why me?’

One of the hardest things about cancer to get your head around is that there’s a chance it could come back. For most people, every day that passes lowers the risk of that happening. But even if your doctor is 95% certain that your cancer has gone for good, it can be really difficult to stop thinking about that 5%.

There are several reasons that it can come back – but it’s never because of anything you’ve done.

If you are diagnosed with cancer again, your doctors and nurses will talk through exactly what the situation is and what treatment you might need. Cancer treatments are advancing all the time and might have changed since your first diagnosis. So don’t be afraid to ask questions or to be totally honest about whatever is on your mind.

How you might be feeling

Finding out that your cancer has come back can feel totally overwhelming, like everything you’ve already been through was for nothing. It’s completely unfair.

You might find yourself experiencing a lot of the same emotions you felt first time around – but perhaps more intensely or in a different way.

You might feel...

- **Shock** - This is only natural, especially if you’ve been feeling well and like you’ve moved on
- **Anger** – Again, this is normal. There are no two ways around it: this is not fair
- **Sadness** - You might be upset at the thought of how your life could change again
- **Fear** - You might be scared about having to go through more treatment
- **Guilty** - You might be worried about putting pressure on people again, but try to remember that this definitely isn’t your fault. Your family and friends know that and will only want you to get better
- **Confusion** – You might ask why you have to go through it all again

"My mental health was alright during the diagnosis and treatment; it was after my treatment ended that it got to me.

I went from seeing the staff every week to not going in. It's a big change as I was used to their reassurance."

Beth

Facing up to feelings like this again can be really difficult. Having been through it before won't stop you from having bad days or from wishing this wasn't happening to you again.

When treatment is unlikely to cure cancer

Sometimes cancer treatment doesn't work. We wish that wasn't the case, but sometimes doctors do have to tell people that their cancer can't be cured.

Before you read this section

Thinking about death and dying is really tough – and lots of people prefer not to think about it. So if you're not sure it'll help you to read about these issues, it might be a good idea to skip this section – you can pick the guide up again at page 186 if you'd rather avoid this information for now.

Dealing with your emotions

There's no easy way to talk or read about this. Finding out that your treatment won't work is a horrible, extremely painful situation.

Everyone reacts differently – and there's no right or wrong way to react.

People often experience a whole range of different emotions. Some emotions may come and go quickly. Others can last longer.

You might feel:

- **Denial** - Continuing to believe that your cancer can be cured and that everything will be OK isn't unusual. It can provide a lot of comfort, and means you don't have to think about what the news really means. But as time goes on, it can be harder to convince yourself that everything is fine. And denial can also stop you from doing and saying the things you most want to.

Sometimes people might think you're in denial when actually you just want to focus on other things. You may want to spend time researching a holiday you know you might not be able to take, for instance. That's fine – and it often helps to explain your approach to other people.

- **Anger** - Most people feel angry at some point. You might get angry at your doctors or nurses, or at your friends and family, or at yourself. You might feel like the whole world is against you. It's totally understandable. This is an incredibly unfair situation, and you might not be able to get over your anger completely. But finding a way to manage it will help you focus on other things. You can find suggestions for dealing with anger on page 105
- **Sadness** - You might feel really upset. That's totally natural. You might feel too low to share your feelings with others – don't let anyone pressure you into talking if you don't want to. Sometimes it can help to write difficult thoughts down

  You can read more about sharing your feelings on the next page.
- **Detachment** - It can be difficult and strange to look around and see people doing everyday stuff. You might sometimes feel like those things are pointless now, and that you can't really be bothered to do anything anymore. This is a common feeling – and often changes with time. Talking about how you're feeling often helps
- **Frustration** - You might feel completely powerless, like your situation is totally out of your control and impossible to change. It's OK to feel like this.

Not being able to do certain things if you're feeling bad can also be really annoying. But you can still get involved in decisions about how and where you are treated, as well as choosing how you want to spend your time – which can help you feel less frustrated.
Some people find it makes a big difference to stay in control of the things they are able to influence.

- **Fear** - It's only natural to have questions about death. When will it happen? Will it hurt? How long will it take? What will it be like? Will I know what's happening? You can ask your doctors, nurses, Youth Support Coordinator, youth worker, psychologist or counsellor questions, and though they might not always be able to give you a specific answer, it can still be helpful to have some information and to talk through the issues that are weighing on your mind
- **Loneliness** - You might feel that no one you speak to really understands what you're going through. And while it's true that your situation is unique, a lot of people find it helps to talk to others who have been told their treatment isn't working
- **Guilt** - You might be worried that you're causing your family and friends a lot of pain, and you might be scared about how they will cope after you're gone. Talking about these sorts of things is difficult for everyone, but if you feel able to, it can help to share your feelings. You'll probably find the last thing people close to you want is for you to feel bad about them

It's only natural to have lots of questions right now – and there's no such thing as a stupid question. So ask everything that's on your mind.

Sharing your feelings

All through this book, we've encouraged you to be honest about how you're feeling and what you're going through. We'd still encourage that now, but we also know that talking about dying is about as difficult as it gets.

You might find sharing your thoughts and emotions is just too hard, and it's important to do whatever feels right for you. A lot of us struggle to talk about death, and in some cultures it's considered disrespectful or dangerous to the person who is ill to mention dying. If this is the case for you, try to let your care team know, or ask a friend or family member to let them know for you.

This is a very personal, emotional time, so don't feel forced into doing anything you don't want to.

But if you do want to talk, it's good to talk to someone you trust who won't make things more difficult for you. You might find you just end up crying on each other's shoulders, but even that can make both of you feel a whole lot better. It's a totally natural response.

And if you want to talk but don't feel ready to speak to your family or friends, your doctors, nurses, clinical psychologist, counsellor, Youth Support Coordinator or social worker might be able to help.

There are also professional organisations that can offer support at this time – ask your care team for details.

Palliative care

Palliative care is the name given to treatment that helps you feel better, relieves your symptoms and improves your quality of life.

People often think it only refers to treatment given after you've found out that your cancer can't be cured. But palliative care doctors and nurses might be involved in your treatment right from the start, because they are simply experts in relieving pain.

Palliative treatment can involve lots of different types of medicine, like painkillers and anti-sickness medicines, as well as cancer treatments like chemotherapy and radiotherapy.

Your doctors will talk to you about which palliative care options might work best for you – and will aim to choose treatments with as few side effects as possible. Palliative care can make a big difference in helping you keep your symptoms under control, so that you can keep doing the things you want to do.

Making decisions

As time passes, you might find your feelings become less intense and more bearable. It might sound strange, but some people say they gradually adjust to finding out that treatment isn't likely to work. If that's the case for you, you might find yourself thinking about things you want to do, say or get sorted.

You might want to do things you've always wanted to do. Or you might want to spend time with the people you love, doing what you already love. Whatever you choose is up to you.

Your doctors and nurses might want to talk to you about advance care planning, to help you decide how you would like to be cared for if you become too ill to make choices.

You might not want to think about things like that, or you might like to talk through where the best place would be for you to stay, how you want to be treated and so on. Your family and friends can be involved in these conversations too – and if you're under 18 your carer will be more involved.

You might also want to talk to your friends and family about anything you'd like to happen at your funeral, about what you'd like to happen to your things – or just what you would want them to do on your birthday. You might want to let them know some of your best memories. Or you might not want to think about any of this.

But whatever you choose to focus on, don’t ever be afraid to ask questions. This is an incredibly tough situation, and getting the right information is really important as you think through what you want to do now and start making any decision for the future.

There is no right or wrong way to handle this news, and it’s important you are able to act how you want to. However you are feeling and thinking is natural and understandable.

YOUR GLOSSARY

You hear a lot of new words when you're diagnosed with cancer, so we've put together this list to help you check anything you're not sure about. You might find it helps to have it with you when you're speaking to your care team.

If someone mentions a word that isn't on this list and you're not sure what it means, you can always ask your care team and they'll be happy to explain it to you.

A

- **Alopecia** – The medical name for hair loss
- **Anaemia** – A condition, caused by a lack of red blood cells or a lack of haemoglobin in your red blood cells, which leaves you feeling totally worn out, dizzy and out of breath
- **Anaesthetic** – A drug used to stop you feeling pain. A local anaesthetic numbs a specific area. A general anaesthetic sends you to sleep before an operation

- **Analgesic** – The medical name for a painkiller
- **Antibiotics** – Drugs used to fight or prevent infection
- **Anti-emetics** – Drugs used to stop you being or feeling sick
- **Aspiration** – The removal of fluid from your body using a needle

B

- **Benign** – The medical term for a growth in your body that isn't cancerous
- **Biopsy** – A procedure involving a small amount of tissue being taken from your body so cells can be studied under a microscope. Biopsies are usually done using an anaesthetic
- **Blood count** – The number of different blood cells (white blood cells, red blood cells and platelets) in your blood
- **Blood transfusion** – A process involving blood from a blood donor being given to you through an intravenous line
- **Bone marrow** – The soft, spongy stuff in your bones that creates blood cells

C

- **Cancer** – A general term for lots of different diseases, all of which are caused by cells not behaving normally
- **Cannula** - A flexible tube, inserted into a blood vessel in your lower arm or hand, so you can be given things like blood transfusions, medicines or an anaesthetic
- **Carcinoma** – The name given to types of cancer that start in your skin or in the tissues that cover your internal organs
- **Care team** - The group of people responsible for looking after you during cancer treatment. Your care team is part of your multidisciplinary team

- **Catheter** – A small tube that's put into your body. Fluids are injected or removed through the tube
- **Central line** – A catheter that's placed into a vein near your chest. It's used to give you fluids and blood, and to take blood counts. Lots of chemo drugs are given through a central line
- **Chemotherapy** – Often known as chemo, chemotherapy is a drug treatment used to kill off cancer cells
- **Clinical trial** – A type of medical research. These can study a range of things, including the effectiveness of cancer treatments and the side effects of treatments
- **CT scan** – It stands for computerised tomography and it's also known as a CAT scan. A CT scan takes X-rays from a lot of different angles to build up detailed images of your body
- **Cytotoxic drugs** – Drugs used to kill off cancer cells. Chemotherapy uses cytotoxic drugs

D

- **Diagnosis** – The identification of a disease
- **Donor** – A person who gives blood, body tissue or organs to be used by another person

E

- **External radiotherapy** – A type of X-ray that goes inside the body and can treat organs or bones using radiation

F

- **Frozen section** – A procedure involving body tissue being taken and then quickly frozen so it can be studied under a microscope. You'll have pain relief before a frozen section

G

- **Graft** – Healthy tissue that's taken either from a healthy part of your body or from someone else and then used to replace damaged tissue
- **General Practitioner** - Or GP for short. Your GP is your normal doctor and was probably the person who referred you for cancer tests in the first place. There's a good chance you'll stay in touch with your GP throughout your treatment, as he or she can help you make decisions about things like where you want to be treated

H

- **HPV** – Human papillomavirus. Some types of HPV are linked to certain cancers, including cervical cancer
- **Haemoglobin** – The part of red blood cells that transports oxygen around your body
- **Haematology** – The branch of medicine that focuses on blood. Doctors who specialise in blood are called haematologists
- **Hormone** – Chemicals that are released by glands in your body. They affect things like your growth, mood and energy levels

I

- **Immune system** – The cells and organs in your body that combine to protect you from illness
- **Immuno-compromised** – The medical term for a weakened immune system
- **Immunotherapy** – Treatment which helps your own immune system kill the cancer cells
- **Infusion** – The slow injection of drugs, blood and other fluids into your body, usually through a cannula or central line

- **Internal radiotherapy** – The delivery of radiation directly to a tumour, using either radioactive liquids, tablets, injections or implants
- **Intravenous (IV)** – Drugs, blood and other fluids that are given to you directly into a vein

L

- **Leukaemia** – The name given to various types of cancer that begin in your bone marrow and affect white blood cells
- **Localised cancer** – Cancer that hasn't spread to other parts of your body
- **Lumen** - A narrow tube used to give you fluids. If you have a Hickman line fitted, it's connected to lumens that hang outside your body and are covered in a sterile dressing
- **Lymph** – A clear fluid that flows through your lymphatic system and fights infection by collecting unwanted bacteria and viruses so they can be filtered out through your lymph nodes
- **Lymphoma** – The name given to various types of cancer that start in your lymphatic system.
- **Lymphatic system** – A network of thin tubes that runs throughout your body, transporting lymph and fighting infection. It forms part of your immune system
- **Lymph nodes** – Glands, found in places like your groin, neck and armpits, that form part of your lymphatic system and help to fight infection by filtering out unwanted bacteria and viruses

M

- **Malignant** - The medical name for a growth in your body that is cancerous and may spread
- **MDT** - Multidisciplinary team, or the group of health professionals who work together to diagnose, treat and care for young people with cancer
- **Melanoma** – A type of skin cancer that affects cells called melanocytes
- **Metastasis** – A secondary tumour caused by cells from a primary tumour spreading to another part of your body

O

- **Oedema** – Swelling caused by a build-up of fluid in your body
- **Oncologist** – A doctor who specialises in treating cancer

P

- **Palliative care** – Treatment designed to relieve the symptoms of illness. Sometimes people think palliative care is only for people who aren't expected to be cured, but really it's any treatment that's given to relieve symptoms – at any time during your care
- **Plasma** – The part of your blood that transports blood cells and platelets around your body
- **Platelets** – The part of your blood that helps to stop bleeding by causing blood to clot
- **Primary cancer** – The place where cancer begins. If cancer spreads to somewhere else in your body, it's called secondary cancer
- **Prognosis** – The most likely outcome of a disease

- **Prosthesis** – An artificial replacement for a part of the body that has to be removed
- **Proton beam therapy** - A kind of external radiotherapy that targets cancer cells with particles called protons instead of X-rays

R

- **Radiotherapy (or radiation therapy)** – A cancer treatment that works by targeting cancer cells using various types of radiation. Sometimes radiation therapy is given from outside your body (see 'External radiation', above) and sometimes it's given from inside your body (using liquids and implants)
- **Radiation** – A type of energy that can be used to damage and destroy cancer cells. X-rays are the main type of radiation used to treat cancer
- **Red blood cells** – The cells in your blood that contain haemoglobin, which transports oxygen around your body
- **Relapse** – The return of a disease, usually after treatment and a period of remission
- **Remission** – A period when the signs and symptoms of a disease are no longer evident

S

- **Sarcoma** – The name given to various types of cancer that start in your muscles, bones, nerves, cartilage, tendons, blood vessels or other soft tissues
- **Secondary cancer** – A type of cancer that has spread from a primary cancer somewhere else in your body
- **Side effects** – Secondary, usually unpleasant, effects caused by treatments. Side effects can occur after chemotherapy, radiotherapy and surgery

- **Stem cells** – Very new cells in your body that divide to form other, specific types of cells – for example blood cells, muscle cells and skin cells

T

- **Terminal** – A word used to describe diseases that can't be cured
- **Total body irradiation** – A type of radiotherapy usually used to treat leukaemia that's given to your whole body, rather than to a particular area of cancerous cells
- **Tumour** – An abnormal growth in your body
- **Tumour marker** – A substance produced by a tumour. It's found in your blood and can help doctors understand how a tumour is behaving
- **TYA** - Teenage and young adult. TYA is often used to describe young people with cancer who are under 25

U

- **Urinary catheter** – A type of catheter that's put in your bladder and used to help you wee. People who use urinary catheters frequently learn to put them in themselves

W

- **White blood cells** – The cells in your blood that help to fight infection

Useful contacts

There are lots of great organisations out there that can answer your questions, offer advice and put you in touch with useful people.

We've put together a long list of useful contacts that could offer you help in lots of different ways.

Search: 'useful contacts' on our website to find out more.

If you can't find what you're looking for there, you can always speak to your care team who might be able to suggest other places or organisations local to you that can help.

Questions to ask

Here are some questions you might want to ask. You can use the notes section to write down the answers and any other questions you might have.

About your cancer

- How do you know I have cancer?
- What kind of cancer do I have?
- Which part/parts of my body are affected?
- How serious is it?
- What will it do to me?
- Will it spread?

About your treatment

- What tests will I have?
- What treatment will I have?
- What's involved?
- Will it hurt?
- What are the possible side effects?
- How long will the treatment last?
- Will I need to stay in hospital?
- How will we know if it's working?
- Have other young people had this treatment?
- Is there any new research that might affect my treatment, or any clinical trials I could take part in?

About your feelings

- How could cancer affect my emotions?
- Who can I talk to if I'm feeling low?
- What counselling support is available?
- What support groups could I join?

Staying in control

- Are there other treatment options that might work?
- Am I able to choose where I go for treatment?
- What happens if I don't have the treatment?
- Who will be involved in making decisions about my treatment?
- Will you include me in conversations with my carer?
- Can I talk to you without my carer if I want to?
- Can I get a second opinion about my treatment?
- Who can my family and friends talk to if they are feeling anxious?

After treatment

- What will happen after I finish my treatment?
- Could the cancer come back?
- Are there any long-term side effects?

Practical questions

- Will I be able to stay in education or keep working?
- Will I qualify for any benefits or financial support?
- Is there anything special I should be doing, eating, reading etc?

How we produce our cancer information

When you're going through cancer, we know how important it is that you have access to accurate, trustworthy and easy-to-understand information.

Young people with cancer have been involved in every stage of creating each version of this book.

They told us what information they wanted included, and they helped us review it at every stage to make sure it was as good as it can be.

We also work closely with healthcare professionals who help us make sure we include everything that young people need to know. Accuracy is vital, which is why we only use trusted sources and everything is reviewed by multiple people before it's printed.

All of which means the information in this book is right and up-to-date, so you can use it to make the best decisions about your healthcare and treatment.

Trusted
Information
Creator
Patient Information Forum

PIF TICK

Teenage Cancer Trust is an accredited member of the PIF TICK scheme developed by the Patient Information Forum.

This means we have gone through a strict assessment process to make sure that all the information we produce is accurate, age-appropriate and accessible. You can find out more about the PIF TICK on their website: **pifonline.org.uk**

Want to get in touch?

This book was first printed in 2015. Since then it has been reviewed and reprinted in 2018 and 2022. It's due to be reviewed again in 2025 but if you spot anything you're not sure about or have any questions or comments before then, you can get in touch with us: **healthinfo@teenagecancertrust.org**

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Expert reviewers

Colette Bateman, Trainee Advance Nurse Practitioner

Kam Bhatti, Teenage and Young Adult Radiographer

Vicki Cummerson, Youth Support Coordinator

Lyndsey Griffiths, Senior Clinical Nurse Specialist

Beth McCann, Senior Specialist Nurse

Jade Greenhouse, Clinical Liaison Nurse Specialist

Franchessca Sefton, Youth Support Coordinator

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The team:

Editor: Rosie Vare, Clinical Information Lead

Design: Juice

Printer: Pure Print

With support from:

Louise Soanes, Chief Nurse

James Robertson, Head of Brand and Content

Dan Henchman, Content Manager

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MEET YOUR TEAM

You can use this page to keep track of the names of everyone in your care team.

Clinical nurse specialist (CNS) ....

Consultant ....

Dietitian ....

General practitioner (GP) ....

Palliative care team ....

Physiotherapist and/or occupational therapist ....

Psychologist and/or counsellor ....

Social worker ....

Surgeon ....

Youth Support Coordinator ....

Any other details? ....

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> "The guide is amazing. It's been my trusty teacher, explaining the jargon surrounding my diagnosis, treatment, and after-effects. After my diagnosis, it was the first thing I read that really understood how I felt. It's like a friend, someone who really gets it."
>
> Kaleb

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