

**HONEST ANSWERS  
SOUND ADVICE**

**A YOUNG  
PERSON'S**

**GUIDE TO  
CANCER**



**TEENAGE  
CANCER  
TRUST**

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# HI THERE...

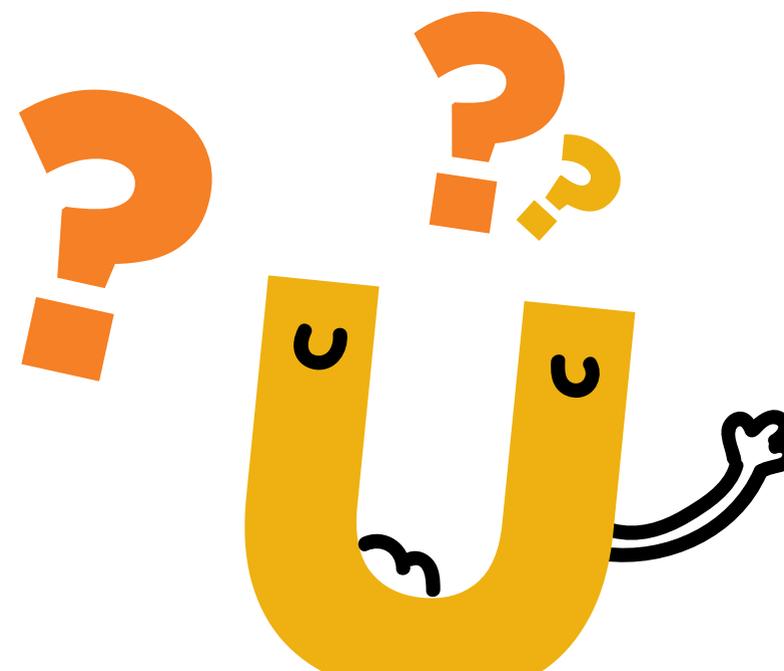
**We'll be honest, we wish you weren't reading this. We're sure you do too. But seeing as you are, we really hope this book will come in useful.**

It's based on what other young people have told us they wanted to know when they found out they had cancer. And young people who've had or have cancer helped us put it together.

You've probably got a whirlwind of questions going round your head at the moment, and getting diagnosed with cancer doesn't suddenly stop you being who you are.

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.

And, in case you have times when you just don't feel like talking, we've included some cards at the back that might come in handy.



### Why this book isn't a book

We've not really designed this to be read from cover to cover like a normal book. Instead, it'll hopefully become something you dip in and out of when you've got something on your mind. Some sections might be relevant to you now, others might not be. You might be more interested in the stuff at the back than the front.

So use it however suits you. Stick it in your bag. Fill in the sections for your notes. Scribble in the margins. Tear out the cards. Use it to write down the mobile numbers of people you meet during your treatment. We'd love this book to end up looking pretty tattered.

And while you shouldn't think of it as a replacement for your care team – who should always be your first point of contact if you're worried about anything or have any questions – we hope it'll help you get your head around what's going on, because we're here to do everything we can to help.

Take care of yourself, and let us know any thoughts about this book at:  
[information@teenagecancertrust.org](mailto:information@teenagecancertrust.org)

**The Teenage Cancer Trust Team**

**Want to know more than we can fit in this book? There are some Useful contacts on page 178.**



# FINDING OUT



REMEMBER  
**YOU'RE  
NOT  
ALONE**



# HEARING THE NEWS

**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. Whatever you're feeling is absolutely, completely, 100% natural.

You might feel numb, confused, angry or scared. You might feel overwhelmed and struggle to focus on everyday life. You might want to blame everyone you meet; from your parents to your doctors to random people on the street. You might want to go somewhere by yourself and scream 'IT'S NOT FAIR!' at the top of your voice. Or you might feel relieved that you finally know what's wrong.

There's no right or wrong way to feel, and it will take time to start getting your head around this.

But 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.

Your family and friends will want to be there for you too.

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, ask again. If you still don't understand, ask again. And if you still don't understand, well... you get the idea. Just keep asking questions until you know what you need to know.

Doctors and nurses are used to explaining things a lot of times. It's hard for people to take in more than about 20% of what they hear when they're anxious or upset – let alone when it's complicated medical info. So don't feel embarrassed or worry about sounding stupid. Just keep on asking.

And never forget – even if you're feeling lonely right now – we guarantee you're definitely not alone.

# TAKE A DEEEEEEEP BREATH

**Go on. Fill your lungs. Blow out slowly. Breathe in again. Repeat ten times, and then read this section.**

**It can feel impossible to focus on anything 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.**



## **MOST YOUNG PEOPLE SURVIVE CANCER**

It's true, and the good news doesn't end there – survival statistics are getting better all the time as new ways of treating and diagnosing cancer are being discovered.

## **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. Turn to page 178 for useful organisations that can help you hear and share experiences.

## **IT'S NOT YOUR FAULT**

Absolutely, definitely not. 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 they're all wrong. Absolutely, definitely wrong. Parents 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. For more information on talking if times get tough, turn to page 118.

## **HOPE CAN BE POWERFUL**

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

**THIS ISN'T YOUR FAULT -  
AND WE'LL KEEP TELLING YOU  
THAT THROUGHOUT THIS BOOK**

# SO WHAT IS CANCER ANYWAY?

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



Our bodies are made up of billions of cells. Brain cells. Nerve cells. Muscle cells. Bone cells. Gland cells. Reproductive cells. Everywhere you look in the human body, you'll find cells – they're our building blocks.

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

Sometimes, though, things get weird. New cells are produced when they're not needed, and this can cause a mass of tissue called a tumour to develop.

## **TYPES OF TUMOUR**

Tumours can be 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.

And some cancers, 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.

**You can find out more about some of the most common types of cancer on page 20.**

# THE BIG QUESTIONS ANSWERED



**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.**

## **HOW DID I GET CANCER?**

We've said it before and we'll say it again. Cancer is a lot of things, but it's not your fault.

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.

Spending too much time in the sun can put you at risk. So can having unprotected sex, as a virus can be passed on that can lead to cervical cancer. 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. So while there's absolutely no need for you to feel guilty right now, it's understandable if you're feeling pretty annoyed. Cancer sucks.





### **CAN CANCER BE CURED?**

The short answer to this one is yes. 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 it's also true that 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 (not that you need us to tell you that).

It's OK if you feel scared, in fact it's very common. Your doctor will be able to tell you the truth about your situation, so if you want to know more, just ask. And try to remember that there is a huge amount of support out there for you, so you never have to face cancer alone.

**THERE IS A HUGE AMOUNT OF SUPPORT OUT THERE, SO YOU NEVER HAVE TO FACE CANCER ALONE**

### **WILL IT HURT?**

This is probably one of the biggest questions on your mind. And the short answer, unfortunately, is that some of your treatments – or the side effects of those treatments – might hurt.

Some tests – like biopsies, lumbar punctures and bone marrow tests – can be painful, and you might be offered an anaesthetic or painkillers before any of these. Treatments like surgery and chemotherapy can cause mouth sores, joint pain and other types of pain too. And tumours can hurt as well, though treatment should reduce this.

Your doctors and nurses can help you deal with pain – but only if you let them know you're hurting, so don't keep it to yourself. Painkillers can make it easier to keep doing the things you enjoy.

**In pain? Don't tough it out. Let your doctors and nurses know – they can help.**

### **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 'Emotional stuff', starting on page 80.



But the short answer to this question is that 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 a support group made up of other young people who have cancer.

It's up to you – but speaking to people can really help you deal with issues. So if you're usually the strong silent type, it might be a good idea to think about becoming the strong slightly-more-talkative type.

### **HOW LONG DOES TREATMENT TAKE?**

This one isn't easy, because everyone is different and everyone's cancer is different. Your treatment could be finished after one operation or it could last for a few years. 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.

Your medical team will look at your individual situation and devise a treatment plan that's right for you. It's really important to understand what's planned and why, so never be afraid to ask. 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 stressing you out 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 – and not knowing can make you imagine the worst.

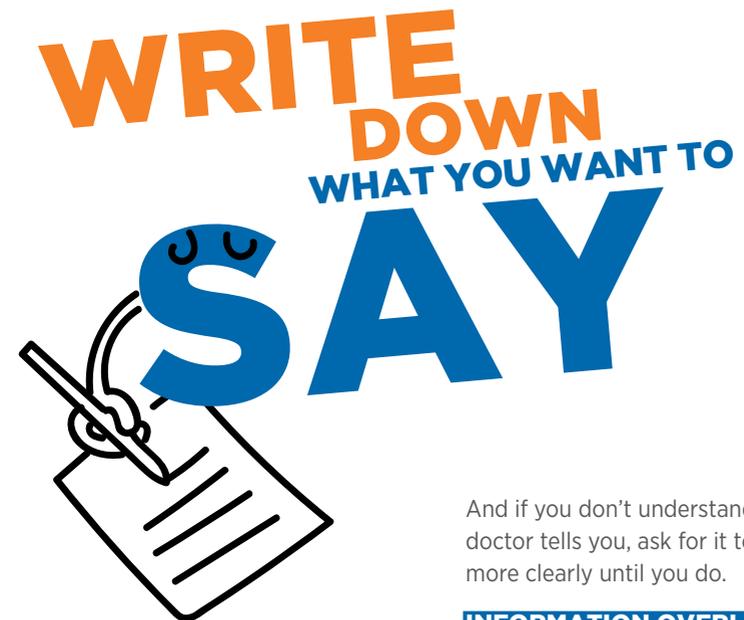
You might want to find out every detail or to keep your knowledge basic. It's totally up to you. If you start wanting to know more as your treatment goes on, just let your care team know.

If you like, you can speak to them without your parents being there. And, if you're over 16, you'll be involved in decisions about your treatment, too.

## **SPEAKING TO DOCTORS AND NURSES**

It's ok to feel nervous before asking questions. Plenty of young people feel awkward discussing their bodies and their feelings (so do plenty of not-so-young people). And you might feel worried about what you could find out.

## **DON'T JUST NOD IF YOU DON'T UNDERSTAND – ASK PEOPLE TO SPEAK IN PLAIN ENGLISH**



And if you don't understand what a doctor tells you, ask for it to be explained more clearly until you do.

## **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.

It can be surprising how quickly you get used to the lingo and even start using it yourself, but it's still a good idea to:

### **It can help to:**

- Write down what you want to say beforehand
- Share as much information as possible about any symptoms or changes you're experiencing – little details can make a big difference
- 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
- Be open and honest – remember that doctors and nurses talk to people about all kinds of problems all day, every day
- Ask your doctor or nurse to repeat anything you don't understand

Everyone on your care team should listen carefully and answer all of your questions. But if you don't feel you're being listened to, say so or ask to see someone else.

- Write down the answers you get (there are pages for your notes throughout this book)
- Record 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)
- Ask the doctor or nurse to draw what they're talking about if it's not making sense
- Keep this book handy – especially the glossary on page 154 – so you can double-check anything you don't understand!

## QUESTIONS & MORE QUESTIONS

Here are some questions you might want to ask. There's a handy space on the next page to write down answers and any more questions you think of, too.

.....

### 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?
  - Will it hurt?
- .....

### About your treatment

- What tests are you going to do?
- What's the best treatment for me?
- 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?
- What are the chances of the treatment working?
- How will we know if it's working?
- Have you given people this treatment before, and how old were they?
- 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 parents?
  - Can I talk to you without my parents 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?

# A QUICK NOTE ABOUT THE CANCER REGISTRY

When you are diagnosed with cancer some information about you is collected in a national database, called the cancer registry. 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 need to contact the registry in your part of the UK. Your care team can give you details.

## OVER TO YOU



Write your answers here, along with any other questions you think of.

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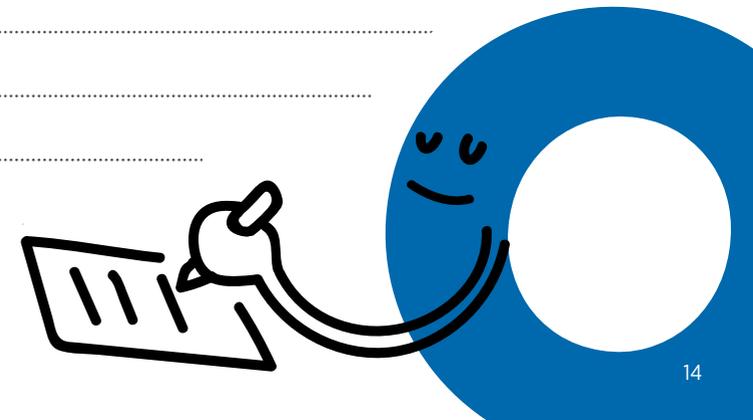
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**REMEMBER THAT EVERYONE IS DIFFERENT**

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

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. And your age, your general health and a whole load of other things can make a difference too. So bear in mind that if something has happened to someone else, that doesn't mean it'll happen to you.

**LOOK FOR BALANCE**

If you read one article or site 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...

**USE THE WEB AS A STARTING POINT**

Think of the information you find online as a way to start conversations with your parents, doctors and nurses – rather than as the end of the conversation. Ask questions about what you find out and discuss it with other people to see what they think. You might find it helps to take printed articles with you when you're meeting other people or going to appointments.



# NOTES

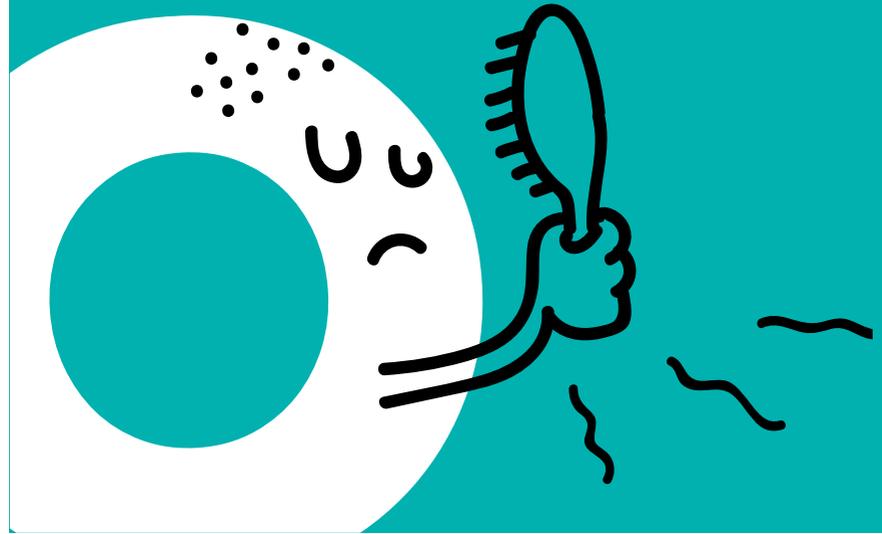
**We want you to scribble in the margins of this book whenever you feel the need. But, in case you need more space than that, we've also included blank pages like this at the end of every section.**

A series of horizontal dotted lines for writing notes.

# NOTES

A series of horizontal dotted lines for writing notes.

**MED  
STUFF**



# WHICH CANCER IS THAT?

**There are more than 200 types of cancer, all caused by cells in your body acting strangely.**

We describe some of the most common ones in young people over the next few pages, but if your cancer isn't mentioned or you want more detail, ask your doctors or nurses, or visit: [www.teenagecancertrust.org](http://www.teenagecancertrust.org)

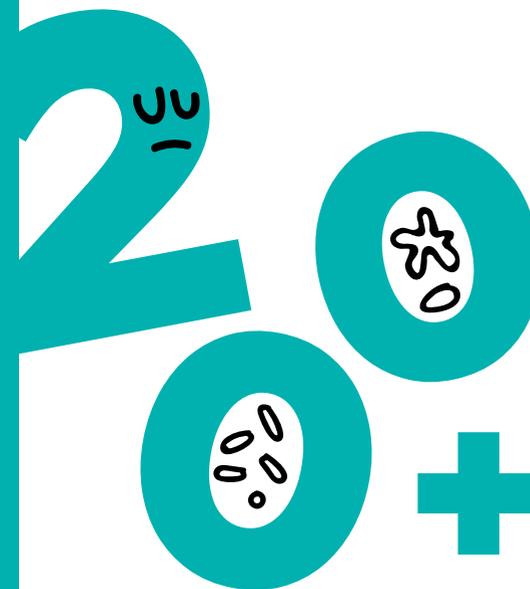
## **BONE CANCER**

### **The basics**

There are two main types of bone cancer in young people – Osteosarcoma and Ewing sarcoma. Both usually affect large bones. Osteosarcoma starts in the cells that make your bones grow, whereas Ewing sarcoma causes a tumour to grow in or around your bones.

### **Treatment**

Your doctors might recommend chemotherapy, radiotherapy or surgery – or a combination of these. Even if you need to have bone removed, it's often possible to replace it with a bone graft or metal implant. Sometimes doctors even take the affected bone out, kill all of the cancer cells using high dose radiotherapy and then put the bone back in! In some cases, amputation is necessary – but this happens less and less.



## BRAIN TUMOURS

### The basics

Brain tumours are classified as either benign or malignant. The benign ones tend to grow more slowly and are less likely to come back if they've been completely removed. The malignant ones tend to grow faster, sometimes spread and may come back after treatment.

### Treatment

Surgery, chemotherapy and radiotherapy are the main treatments. Surgery can remove all or part of a tumour if that's possible without damaging your brain. Radiotherapy and chemotherapy can be used if surgery isn't an option or to treat cells left behind after surgery.

## CERVICAL CANCER

### The basics

Cervical cancer is usually caused by the HPV virus. HPV is very common and often spreads during unprotected sex. A lot of types of the virus are harmless, but some can damage cells in the cervix and eventually cause cancer if they're not treated.

### Treatment

If cells are found that are abnormal but not cancerous, various – often painless – treatments are available. If cells are cancerous but found early, surgery and/or radiotherapy are often used. In more advanced cases, a combination of radiotherapy and chemotherapy is common, sometimes followed by surgery.

## GERM CELL TUMOURS

### The basics

Germ cells are the cells in your body that develop into organs. If germ cells begin developing abnormally they can form germ cell tumours. Many of these are benign, but some can become cancerous. Most testicular cancers, a few ovarian cancers and a small number of brain tumours are germ cell tumours.

### Treatment

Surgery is usually used to remove germ cell cancers, and this might be all the treatment you need. If your doctors think there is a risk of your cancer coming back, or if your cancer can't be completely removed, you might have chemotherapy and/or radiotherapy as well as surgery to kill off the cancer cells.

## LYMPHOMAS

### The basics

Lymphomas are types of blood cancer that start in the lymphatic system – a network of glands and tubes that runs through your body. There are two main types: Hodgkin lymphoma and non-Hodgkin lymphoma. Both are caused by white blood cells behaving strangely and causing tumours to form.

### Treatment

The treatment for Hodgkin lymphoma and non-Hodgkin lymphoma depends on your health and how advanced your cancer is, but both are often treated with chemotherapy, sometimes in combination with radiotherapy.

## LEUKAEMIA

### The basics

The most common types of leukaemia in young people are acute lymphoblastic leukaemia (ALL) and acute myeloid leukaemia (AML). Both involve abnormal white blood cells being released, which also affects the production of normal red blood cells, white blood cells and platelets.

### Treatment

Leukaemia treatment happens in stages. The first stage kills leukaemia cells and the second stage stops leukaemia coming back. Chemotherapy is usually the main treatment, and the whole process can last anything from four months to three years.

Some people need a bone marrow transplant to treat leukaemia. That involves being given very high dose chemotherapy or radiotherapy to kill all of the leukaemia cells. Your bone marrow (the stuff inside your bones that makes blood cells) is affected by this process, so it's replaced with healthy bone marrow taken from a donor.

## OVARIAN CANCER

### The basics

Ovarian cancer starts in the ovaries. The most common type is epithelial ovarian cancer, which affects the surface layer of the ovary. Germ cell tumours can also form in the ovaries (see the section on Germ cell cancer for more on these). Ovarian cancer can be hard to spot in the early stages, because the symptoms are often similar to period symptoms.

### Treatment

Surgery and chemotherapy are the main treatments. If ovarian cancer is diagnosed early, surgery might be all that's needed – often to remove the affected ovary and the connected fallopian tube. More advanced cancer might require more extensive surgery, and possibly chemotherapy too.

## SKIN CANCER

### The basics

There are two different categories of skin cancer – melanoma and non-melanoma. Melanoma starts in skin cells called melanocytes and usually affects moles. Non-melanoma cancers affect different skin cells. Both can be caused by exposure to the sun.

### Treatment

Melanoma treatment may only require the removal of a mole, but chemotherapy, radiotherapy, surgery or biological therapy (a drug treatment) might also be required.

Non-melanoma skin cancer is usually treated with surgery, although photodynamic therapy (when cells are killed by bright light), radiotherapy and chemotherapy are also used.



## SOFT TISSUE SARCOMAS

### The basics

Soft tissue describes parts of your body – like fat, muscle, blood vessels and nerves – that connect, support or surround other parts. Soft tissue sarcomas are cancers that affect these tissues and, because soft tissue is found all over your body, they can grow pretty much anywhere.

### Treatment

Surgery is the most common treatment. A surgeon removes the sarcoma and some healthy surrounding tissue to make sure all cancer cells are taken away. Radiotherapy and chemotherapy are used to treat sarcomas too, sometimes in combination with surgery.

## TESTICULAR CANCER

### The basics

Testicular cancer is unusual because, unlike most cancers, it tends to affect younger men. There are various types, but the most common one affects germ cells, which the body uses to help create sperm. The chances of making a full recovery from testicular cancer are good, but finding it earlier makes it easier to treat.

### Treatment

The first part of treatment is surgery to remove the testicle. You can choose to have a fake, prosthetic testicle fitted, so everything looks like it did before. If your cancer is more advanced, you might also need chemotherapy to kill off cancer cells and stop cancer returning.

## THYROID CANCER

### The basics

Several types of cancer start in the thyroid – a hormone-producing gland at the front of your neck, just above your collarbones. The most common type is called papillary carcinoma, which tends to affect younger people, especially women. Thyroid cancer can also be caused by having radiotherapy treatment to the neck as a child.

### Treatment

The first part of treatment is usually surgery, with all or part of your thyroid removed. Radiotherapy – and in particular a radioactive capsule or liquid called radioiodine – is also used to kill cancerous cells. And chemotherapy can be used to ease advanced cancers or if cancer returns after treatment.

**FOR MORE DETAILS  
ON YOUR CANCER**

**ASK YOUR  
CARE TEAM**

# TESTS, TESTS AND MORE TESTS

**Tests can become a regular part of your life when you have cancer, using various techniques to check how your body is responding to treatment.**

Some tests are quick and routine, others can be fairly uncomfortable, and how much you want to find out about them is up to you. Knowing what to expect can ease any worries you might have. But if you prefer not to know too much before having tests, now's the time to skip to the next section.

You can learn about some of the most common tests over the next few pages, but if you have questions or want to find out more, just let your doctors or nurses know.

## AUDIOGRAM

### What is it?

Some chemotherapy drugs can affect your hearing. If these drugs are recommended for you, you'll have an audiogram before and during treatment to check for any changes to your hearing. (An audiogram is actually the graph used to record the test results.)

### What's involved?

Doctors use various hearing tests to measure how your ears and nerves respond to sounds at different volumes and frequencies. All of the tests are painless.

## BIOPSY

### What is it?

During a biopsy, a small tissue sample is 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. A tissue sample is then taken for testing.

There are various ways of doing this. 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.

The cells are then examined by a pathologist (an expert in identifying changes in body tissues) 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 35.

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, all of which can be affected by cancer and cancer treatments
- **Haematocrit (Hct)** – Tested to check the volume of red blood cells in your blood
- **Haemoglobin (Hgb or Hb)** – Tested to check you're not anaemic or at risk of anaemia
- **Platelets** – Tested because chemotherapy can cause platelet levels to drop (platelets are the cells that stop bleeding)
- **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 (which you might also hear 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 – things like looking at chromosomes, identifying types of leukaemia or measuring very small amounts of leukaemia during treatment.

### 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 medicine wears off.

If you're not given a sedative, you'll be given a local anaesthetic via a needle. The anaesthetic might sting at first 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 up into a syringe. 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. A bandage is then applied to stop any bleeding.

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 are feeling a bit tender.

## BONE SCAN

### What is it?

Bone scans can show up unusual things in your bones much earlier than X-rays, so are 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?

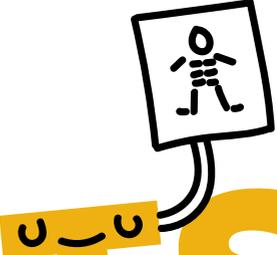
Before a bone scan, you're given an injection of a small, harmless amount of radioactive material. Your bones absorb this fluid, which shows up on a scan in areas where anything unusual is happening. This can include areas where there is a tumour or an infection.

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 a book or iPad to 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.



# AND SOME MORE TESTS



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.

## COMPUTERISED TOMOGRAPHY (CT OR CAT) SCAN

### What is it?

A CT or CAT scan (they're different names for the same thing) 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 a CT 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. The good thing about CT scans is that they're quick and painless. They

normally last between five and ten minutes, but you do need to lie very still to get a good scan. 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.

If you want someone with you in the room, 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). It can take a few days (or longer) to get your results.

## ELECTROCARDIOGRAM (ECG)

### What is it?

An ECG is used to check that your heart is working well if you're taking certain chemo drugs that can weaken the heart muscle.

### What's involved?

An ECG is 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.

## 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 to you 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. Alternatively, sometimes a short general anaesthetic is given instead.

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.

## MAGNETIC RESONANCE IMAGING (MRI) SCAN

### What is it?

An MRI scan 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.

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 30-90 minutes. You 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 is a liquid that helps the radiologist to see the different parts of your body more clearly. Contrast solutions can be drunk or given as an injection.

### **POSITRON EMISSION TOMOGRAPHY (PET) SCAN**

#### **What is it?**

A PET scan produces detailed 3D images of the inside of your body. It can show if lumps are cancerous, whether cancer has spread and if cancer treatment is working.

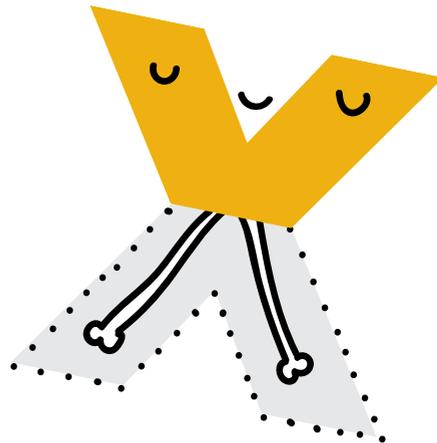
#### **What's involved?**

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.

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 the circular scanner. 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 is it?**

If you've ever broken a bone, you'll probably have had an X-ray. X-rays are a type of 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 – 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 who controls the X-ray machine will then put you in the right position. It takes a fraction of a second to take an X-ray, and then you can get dressed and head home. Your results will be sent to your doctors to discuss with you.

# TREATMENTS DECIPHERED

**Cancer is treated in lots of different ways – and getting your head around what could happen 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' uses drugs, called cytotoxics, to kill off the cells that cause cancer**

Chemotherapy works by attacking and destroying fast-dividing cells. That's good because it can kill cancer cells – which do divide fast (that's how cancer spreads in 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. (Turn to page 46 to read more about the side effects of chemo and other treatments.)

#### **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 prevent cancer returning. And it can be used as a medicine to help you feel better if your cancer is very advanced.

### What's involved?

Chemotherapy involves drug treatment. The drugs are often given in cycles – so you have drug treatment for a set period and then stop the treatment for a set period 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, depending on the type of cancer you have. And you might be given the drugs via an injection, via an IV infusion (see page 35 for more about infusions) or as tablets or medicine.

### How long does it take?

The length of your chemo treatment and the drugs that you take depend on the type of cancer you have. You might have daily, weekly or monthly treatment, and treatment can last for between a few months and several years.

### RADIOTHERAPY

#### Radiotherapy uses radiation to destroy cancer cells

Radiotherapy can be given to you externally or internally. In external radiotherapy, machines are used to target cancerous cells with special X-rays. Some people have protons instead of X-rays. Protons and X-rays are both just as good at killing cancer cells. In internal radiotherapy, radioactive liquids and implants are used inside your body to attack cancerous cells.

### When is it used?

Radiotherapy can be used on its own or in combination with chemotherapy.

It can be used before surgery to shrink a tumour so it's easier to remove, or after surgery to kill off any cancer cells that have survived. And it can be used to relieve cancer symptoms in more advanced cancers.

### What's involved?

#### • External treatment

During your appointments, you'll need to stay still for a few minutes while high-energy radiation is targeted at your cancer and at a small area of surrounding healthy cells – in case the cancer has spread. The machine that's used doesn't touch you, you won't feel any pain and you usually won't need to stay in hospital overnight.

#### • Internal treatment

Internal radiotherapy involves radioactive liquids and implants.

You might be given a liquid to drink, a tablet to swallow or an injection. Afterwards, you may need to stay in a hospital room by yourself for a few days while radiation levels drop.

Implants are things like wires and tubes, placed in your body to release radiation near cancer cells, then left in your body for between a few minutes and a few days – or sometimes for good. Don't worry: they sound much scarier written down than they actually are.

### How long does it take?

If you have external radiotherapy, you'll be given it in a number of individual treatments. These are called fractions.

People often have five treatments a week – one a day, Monday to Friday – with a chance to rest over the weekend and to let healthy cells recover. You might need treatment over the weekend too, though. In total, external radiotherapy usually lasts between one and seven weeks.

If you have internal treatment, your doctors will let you know how long a radioactive implant will be left in for, or how often you need to visit hospital. You might need to stay in hospital after internal treatment.

### 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. 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. 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.

### 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 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/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

Higher doses of chemo are more likely to kill cancer cells, but will also damage more of your bone marrow (the stuff inside your bones that makes blood

cells) and stem cells (the cells, made by your bone marrow, that develop into blood 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 – sometimes less, sometimes more. You might also have radiotherapy to kill any remaining cancer cells. Your bone marrow or stem cell transplant happens after that.

### Types of transplant

If you have an autologous transplant, that means the cells are taken from you, frozen and given back to you after high-dose treatment. Autologous transplants usually involve stem cells taken from blood.

If you have an allogeneic transplant, that means the cells are taken from someone else and given to you.

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 system will be weakened by the transplant, you'll stay in a single room in hospital for a few weeks – where there's less chance of picking up any bugs. You can't have many visitors and it can get pretty boring, but decorating your room with photos and bringing plenty of DVDs can help.

### STEROIDS

**You might be offered steroids (usually 'corticosteroids') alongside other treatment.**

Steroids might be used to treat the cancer itself. But they are sometimes 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.

### COMPLEMENTARY THERAPIES

**Complementary therapies are used alongside the conventional treatments described above.**

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

They're not intended to cure cancer, but that doesn't mean they won't help you feel better about yourself. 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 chemotherapy 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 know about them, and won't get angry or upset if you ask to talk about them.

# HANDY QUESTIONS



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

- Exactly which type of treatment is being recommended

- How long your treatment will last

- What the side effects might be, and how you can reduce them

- What the treatment is meant to achieve

- How effective your treatment is likely to be

- Whether any other treatments might work

# GETTING HOOKED UP

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



## HICKMAN LINES

A Hickman line involves a small tube being inserted into a big vein near your heart and then run under your skin so it comes out near your breastbone. (Don't worry – you'll have an anaesthetic while it's fitted.)

The other end of the tube splits into smaller tubes, which hang outside your body. These are used to give you drugs and fluids. The smaller tubes are called lumens, and are always covered with a sterile dressing.

It might all sound a bit scary, but it's actually a really clever piece of equipment – and definitely 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 bath or shower, and they might recommend you don't go swimming. They'll also show you how to change the sterile dressing.

Having a Hickman line usually becomes second nature pretty quickly. And if you do find yourself getting annoyed with it, try and think of all the needles you're avoiding.

## PORT/PORT-A-CATH

Also known as an implantable central line, 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 box, which is implanted under your skin (you'll be able to feel a small bump where the box is).

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.

Initially you can numb the skin above the box using anaesthetic cream before a Huber needle is inserted, 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.

### PICC LINE

A PICC line (it stands for Peripherally Inserted Central Catheter) is another type of central line. 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 don'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. Drugs and fluids are given to you through the PICC line in your arm.

### 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 drugs 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 an IV pole that's connected to the pump. Some pumps are designed so you can carry them around in a small bag.

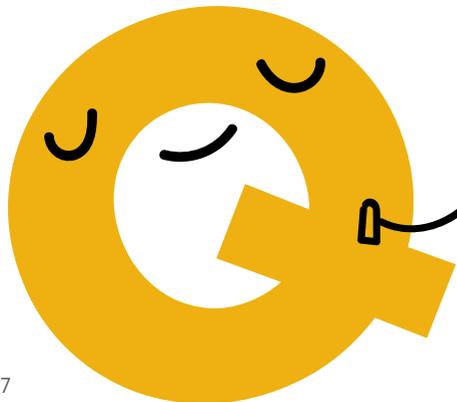
IV poles are on wheels so you can move around during your treatment. They beep quite a lot and can be annoying at first, but don't worry – you'll soon get used to it.

### 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 it's not exactly fun either. Don't be afraid to let your doctors and nurses know if you're not a fan of needles. Using an analgesic cream can help to numb the area, and reminding your care team to switch between your arms if you're having regular injections can help too.



# GIVE IT TO ME STRAIGHT: DOES IT HURT?

**It's probably one of the big questions on your mind. And the short answer, unfortunately, is that some of your treatments – or the side effects of those treatments – 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 hurting. No one will think any less of you, and painkillers can really help you to keep doing the things you enjoy. Everyone experiences pain differently, so try not to compare what you're feeling with other people. And don't be tempted to tough it out – it only makes things harder.

### CAUSES OF PAIN

Unfortunately, there are various 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.

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.

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 TREATMENT

## DEALING WITH PAIN

There are lots of different ways to relieve any pain you might have. The most important thing is to mention it to your doctors and nurses, who will talk you through potential options.

You might have read about people becoming addicted to painkillers. In reality, that's very, very rarely an issue. 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. End of story.

## 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.

But instead of lying awake at night worrying, 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.

For starters, 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
- Getting hypnotherapy if your worries become a big problem

Everyone involved in your treatment wants to make things as easy as possible for you. So if you need support, just ask for it. We've said it before and we'll say it again: you never have to face cancer alone.

**Top tip: In pain? Don't keep it to yourself. Your doctors and nurses can help – but only if you let them know.**

# WHO'S THE BOSS?

**Cancer can leave you feeling totally out of control – but this treatment is all about you, so never be afraid to make yourself heard.**

Who's the boss? You are. You might not always feel like it, 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.

But this is your treatment. It's you that everyone is talking about. So you're numero uno.

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.

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. Maybe you want to leave hospital for a couple of days to go on a school or college trip.

Whatever you're wondering, if you don't ask you don't get – so ask! Your care team will understand and be happy to chat through what's possible.

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. What matters is that the people around you know what's important to you.

And remember, you're the boss – and people listen to their bosses!

# MAKE YOURSELF HEARD



Of course, you might be happy for your mum, dad or carer to make all of the decisions about your treatment. That's fine – it's 100% your call.

But you might also find that you want to have your say but struggle to get your parents to listen to you. They're probably worried and want to do what seems best, but it can be pretty annoying at times.

If you find yourself in this situation, try to let them know how you feel (you can read more about this on page 104). If you are over 16, it's usually possible for you to make decisions about your treatment without your parents' input.

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

**YOU HAVE THE RIGHT TO BE INVOLVED IN DECISIONS ABOUT YOUR CARE AND TREATMENT – SO DON'T BE AFRAID TO SPEAK UP.**

## 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 safer and more effective than the ones that already exist – by testing them on people. They are a vital way of continuing to develop better treatments.

Clinical trials might look at:

- 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, ask as many questions as you need to, and weigh up the pros and cons before you decide if you want to be involved.

### IS IT SAFE?

Don't worry, clinical trials happen right at the end of a long, tightly controlled process. You won't be the guinea pig for some wild new treatment dreamed up yesterday and served from a witch's cauldron. And 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, which 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.

### IS IT WORTH IT?

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 and probably get even more attention than normal, which means changes to your health usually get picked up more quickly. And it's often the case that people on clinical trials see better results than similar patients not involved in a trial.

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

## IT'S COMPLETELY UP TO YOU WHETHER YOU WANT TO GET INVOLVED IN A CLINICAL TRIAL

## TAKE TIME TO WEIGH UP THE PROS & CONS

### WHAT'S INVOLVED?

Phase 3 trials usually involve hundreds of people in lots of different places. A computer randomly splits everyone into two groups, with half – the trial group – given the new treatment and half – the control group – given the best treatment that's already available. The results are compared to see which treatment is most effective.

Whichever group you're in, 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.

## MYTHBUSTER: CLINICAL TRIALS

### MYTH #1

**You'll be treated like a guinea pig.**

Definitely not. You get a very high level of care. No exceptions.

### MYTH #2

**You'll be given sugar pills.**

Dummy treatments like sugar pills (you might hear them called placebos) are very rarely used in cancer trials. You're either given the best available treatment or a new treatment that's being tested. You'll only be offered placebo treatment if that's the best way to see how effective a new treatment is. And if placebo treatments are involved in your trial, you'll be told about it before being asked if you want to take part.

### MYTH #3

**Trials only take place at big hospitals.**

Nope. Many trials now happen at smaller 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 does mean hitting the road.

### MYTH #4

**Once you've said yes, you're stuck.**

This one's not true either. If you change your mind at any point – including during treatment – you can leave the trial. Not a problem at all.

### MYTH #5

**You'll be kept in the dark.**

Noooo. 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.

### IS A CLINICAL TRIAL RIGHT FOR YOU?

Only you can decide if you want to get involved in a clinical trial. Our advice? Ask questions. Lots of questions. Write them down before appointments so you don't forget anything. Find out exactly what's involved. Talk it through with people close to you. And don't rush into a decision.

What you decide is 100% up to you. 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.

# MAKE SURE YOU ASK QUESTIONS

**DON'T RUSH INTO MAKING  
A DECISION!**

## SIDE EFFECTS - THE TRUTH

**OK, so you've read about the treatments you might have. That probably means you're wondering what they could actually do to you. Here's our no-nonsense guide to possible side effects.**

There's no point denying it. 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. Or, to put it another way, sometimes you may need to go through some tough times to get better.

The nature of any side effects depends on a lot of things, including the type of cancer you have and the type of treatment you're having. They can affect you in the shorter or longer term. And because everyone is different, it's not a great idea to compare yourself to other people.

It can be helpful, though, 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**

The bad news? Some of these can be pretty uncomfortable. The good news? They usually go away once your treatment is done.

### **FEELING SICK**

Some chemo drugs can leave you feeling pretty rough. Nausea usually hits a few hours after treatment – and can last for quite a while.

Let your doctors and nurses know if you do feel sick. There are drugs that can help, and if you take them quickly enough they might be able to prevent you from puking.

# EAT



As for general advice, these tips should come in handy:

- Avoid your favourite foods. At the risk of sharing too much information, they won't be your favourites for long if you eat them when you're not feeling great. Plus they'll taste even better once you're ready to eat them again
- Keep a sick bag handy
- Eat small, frequent meals and snacks (big meals can be hard to tackle, but hunger can make you feel worse)
- Chop up food into small pieces
- Eat your main meal whenever you feel best (even if that means a leftover roast dinner at 6am)
- Avoid foods that smell strong – and steer clear of people eating them too
- Choose drinks that will give you a boost – milk, juice etc...

- Take it easy after meals. Feet up and TV on
- Eat with other people to take your mind off your plate
- Get plenty of fresh air
- If you start to feel dodgy, take deeeeeeeep breaths. It can really help

## FEELING TIRED

Some cancer treatments – especially chemo – can leave you feeling totally wiped out. Even after your treatment is finished, you might feel like you're stuck in first gear. It can be frustrating, but try and be patient. Give yourself time to recover. Eat well. Sleep often. 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. And (while we know you might struggle to believe this if you're feeling exhausted right now), doing more often leaves you feeling able to do more. Honestly.

If you are 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. Start by turning to page 96 for some ideas for dealing with low moods.

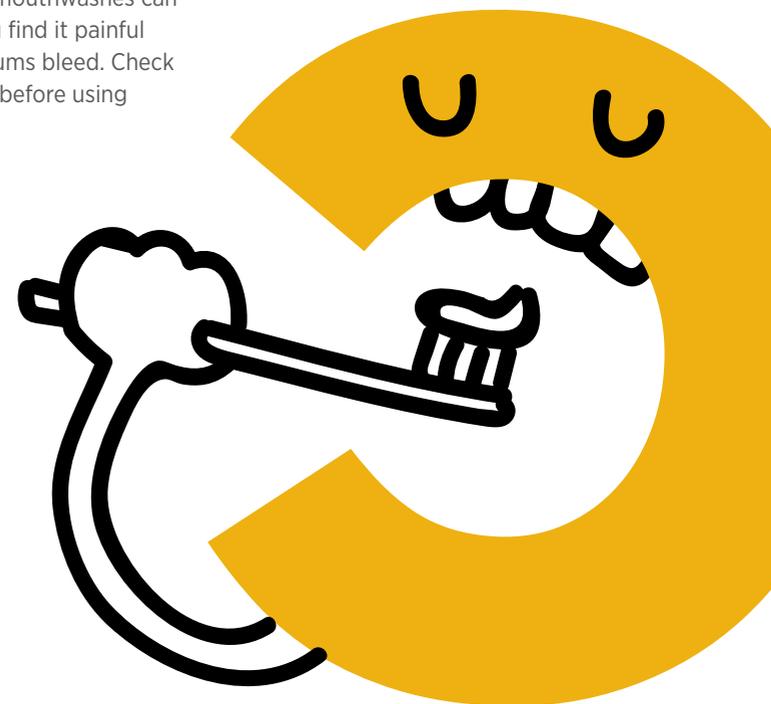
## MOUTH PROBLEMS

Chemo can be a real pain in the mouth. You might get mouth ulcers or have a sore mouth and/or throat during and after chemo. Food sometimes tastes bad too.

Sucking on red ice pops relieves pain (but only red ones – citric acid in yellow and orange ones might make your mouth worse). So does avoiding crunchy food and very hot or cold drinks. And you have the perfect excuse to get plenty of ice cream down you.

It's also 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.

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 find you lose your hair if you have chemotherapy. Radiotherapy can cause hair loss where you have treatment too. In both cases, it happens because the treatment kills fast-dividing cells, and cancer cells and hair cells both fit into that category.

(It doesn't happen to everyone though, so don't worry 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, go wild with the clippers or the hair dye before it does. Think bright pink. Think a zigzag mohican. Think braids. Think a bright pink zigzag mohican with braids. 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. If you know how to use photoshop, airbrushing your hair out of a photo can do the same thing
- Treat yourself to scarves, hats or whatever suits you best

- If you do lose your hair, try and learn to love your bald self. Show the world that bald is beautiful. If you're comfortable with it, other people will be too
- Contact support groups who can put you in touch with other young people who've lost their hair. It's a good way to vent, and you might pick up some good fashion ideas too
- Ask your nurse or youth support coordinator about the great projects out there that can provide wigs for you. The NHS and various charities can arrange this
- Try to remember that hair loss is only temporary – and once you're done with treatment, you can decide what style you fancy from now on

## EATING DURING TREATMENT

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

As we've already said, if you do find yourself feeling sick, let your doctors and nurses know. They might be able to give you drugs that will help. And 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...

These ideas might be useful if you don't fancy food:

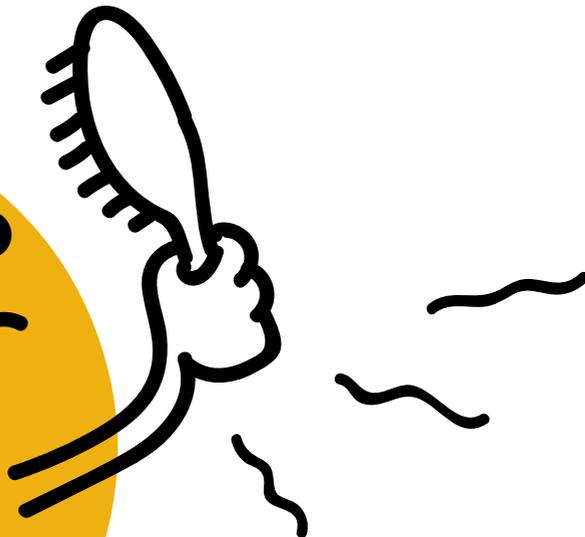
- Eat small, frequent meals, rather than a few big meals a day
- Chop up food small to make it easier to stomach

- Eat food that doesn't smell strong
- Eat with other people to take your mind off food
- Avoid your favourite foods after treatment – you can really put yourself off them
- Wait for a few hours when you can't face food. If you don't feel up to eating, just take a few hours then try again
- Keep a sick bag nearby, just in case

If you're losing weight, your medical team will suggest ideas that could help you put on a few pounds. You could try:

- Eating foods that have a lot of calories (surprise, surprise...). Ice cream, cheese, milkshakes, yoghurts and all of the other things you're usually told not to eat are ideal
- Drinking energy drinks
- Concentrating on getting plenty of protein-rich food – like beans, eggs, fish, meat and nuts

**DON'T WORRY**  
**WEIGHT**  
**LOSS** 😞 **OR**  
**GAIN** 😞  
**IS COMPLETELY**  
**NORMAL**



### 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.

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. Once it's done you can think about eating well and exercising to lose any weight you're worried about.

Try to focus on:

- Eating healthily, which will help you to avoid real 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. When you feel up to it, it can help simply to be up and about doing everyday things

- Wearing clothes you feel comfortable in. If you have put on weight, buying some new clothes can make you feel better about yourself (and make you smile once you lose the weight again)
- Talking about how you feel. Let people know if you're worried about your weight – keeping your feelings to yourself usually makes them worse

### CHEMO BRAIN

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

If you feel like this, keep yourself safe. No driving or taking up weightlifting. 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 is temporarily a bit on the sleepy side.

The symptoms tend to improve once you stop taking the medicine, but they can occasionally last for some time. If you're worried about the way you're feeling, talk to your care team.

# WHEN TO SEEK HELP?

### 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 rubbish during chemo treatment (even if you don't have a temperature), you must seek medical help as soon as possible. When you start your treatment, your doctors and nurses will let you know which hospital to go to and who to contact.

### OTHER SHORT-TERM EFFECTS

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

## LONG-TERM/LATE SIDE EFFECTS

You might hear about long-term side effects, late side effects or late effects. These are all phrases that are used to describe side effects that last longer than your treatment. To read more about these, turn to page 142.



# WHO'S THAT?

**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. So here's our advice.

Read this guide to who does what. Find out who's involved in your treatment. Ask them what they like to be called. Write their name(s) in the box next to their job description, and just use those names.



Who's that?	What's their name?
<b>Clinical nurse specialist (CNS)</b>	
<b>Consultant</b>	
<b>Dietician</b>	
<b>General Practitioner (GP)</b>	
<b>Palliative care team</b>	
<b>Physiotherapist and/or occupational therapist</b>	
<b>Psychologist and/or counsellor</b>	
<b>Social worker</b>	
<b>Surgeon</b>	
<b>Youth support coordinators</b>	
<b>Need to add anyone else?</b>	<b>What's their name?</b>

**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 'keyworker'.

**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.

**DIETICIAN**

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

**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.

**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.

**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 AND/OR OCCUPATIONAL THERAPIST**

Experts in helping with physical problems and movement. Sometimes cancer can affect movements like walking and bending, and physios and occupational therapists 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 who love 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 parents to working through any problems at school, college or work.

## **SPEECH AND LANGUAGE THERAPIST**

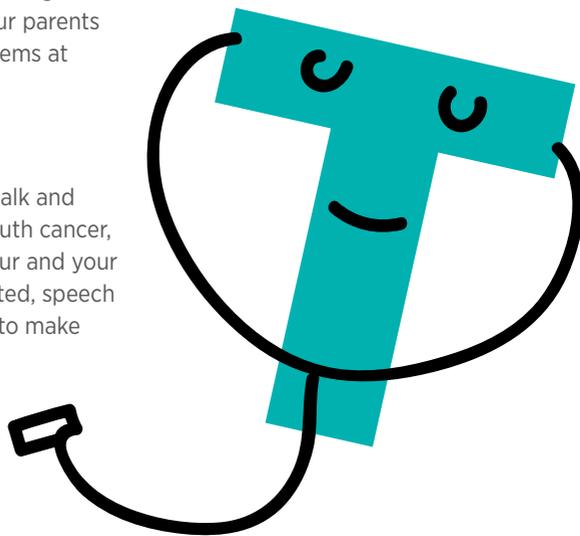
An expert who can help you talk and communicate. If you have mouth cancer, throat cancer or a brain tumour and your speech or swallowing is affected, speech therapists will help you learn to make yourself heard again.

## **SURGEON**

If you need surgery 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 op.

## **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

## Your insider's guide to life on a ward.

Up until now you might not have spent much time in hospitals, 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 or for longer stays.

What to expect depends a lot on where you are. You might be on a ward with other people your age, like one of our Teenage Cancer Trust units. You might be in a specialist cancer centre. Or you might be in a ward with older or younger people.

### **WHEN YOU ARRIVE**

Wherever you are, if you're staying overnight, you'll get asked a lot of questions – your address, your number, if you've got any allergies, how you're feeling, whether you're taking any medication and so on. The answers mean the staff can help you settle in and make sure you're comfortable.

You might get asked about things you'd rather your mum, dad or carer didn't know about – like your sexual history,

drug use or drinking. It's important to tell the truth to make sure you get the best treatment, and your team will keep everything you tell them confidential (unless you say something that puts you or other people at risk, in which case they need to pass it on).

You can also ask to talk to your doctors and nurses privately if you'd prefer. And if you're on a Teenage Cancer Trust unit your youth support coordinator can help you with any tricky conversations.

### **LIFE ON A SHARED WARD**

It can take a while to get used to staying in a shared ward, but people often say they get a lot from it. You and your family are guaranteed constant support. You're surrounded by people who are going through similar things – which is probably why lots of people end up forming life-long friendships in hospital. And if you've got questions about anything from taking medicines to coping with treatment, you're definitely in the right place.

There can be downsides, though, so it's worth trying to prepare for that as well. People nearby might not be doing too well. Privacy can be hard to come by. And while you'll have a curtain to pull around your bed, getting real me-time isn't always easy either.

If you're having a tough day, little things like beeping machines and other people's noisy visitors can seem pretty annoying. On days like that, take a walk if you can, reach for your headphones or just take a few deep breaths. It's surprising how filling your lungs nice and slowly can help frustration disappear.

If you're feeling OK, you won't need to spend all day in bed. You can get up and wander about, and lots of wards have places where you can relax and watch TV outside of your room. You'll usually be able to wear your normal clothes, and there might be a hospital shop or café you can walk to – as long as your doctors and nurses are happy for you to leave the ward.

Even if you don't feel like it, sometimes getting out of bed, spending time with other people or going for a walk can end up making you feel better. A change of scenery or some company can distract you and help break up the day, as well as helping you feel a sense of achievement.

And try not to compare yourself with anyone else. Everyone has a different experience of cancer, and everyone responds differently to treatment. If you've got questions about how your treatment is going or about life in hospital, chat to someone in your care team.

### STAYING IN A SINGLE ROOM

There might be times during your treatment when you need to stay in a single room. It can be a good chance to get a bit of peace and quiet, but if you get bored easily it's a good idea to fill up your phone or tablet with TV shows, films, songs and books beforehand.

If people ask if there's anything you need, why not suggest they pay for a few downloads? Or for times when you're struggling to concentrate, why not ask for wordsearches or sudokus? They'll both help to keep your mind active.

**One more tip:** if you're at risk of getting an infection because of your treatment, you might only be able to have a limited number of visitors in your room, and they might have to wear gloves and a gown to stop germs spreading – so keep your camera handy to get pictures of your guests in hospital gear...

### BOREDOM-BUSTING TIPS

Staying in hospital for a while can get pretty dull. But there's plenty you can do to show boredom who's boss...

- **Make the place your own.** Bring posters, pillows, photos, that teddy bear you've had since you were five: whatever makes you feel at home
- **Make a visitors book.** Get people to write in it every time they come: perfect bedtime reading, and good to look back on when you're out of hospital
- **Get your friends over.** Make sure you let people know if you want visitors. Then play cards. Take stupid photos. Chat about what they've been doing. Do whatever you'd normally do
- **Take photos.** And ask people to print them out and bring them in next time they visit
- **Chat to the staff.** They always have good stories. It's part of the job
- **Listen, watch, read, play.** Get friends to share music, DVDs, books, hand-held games consoles, magazines – whatever they've got! Now's the perfect time to get busy with box sets.
- **Go surfing.** You'll probably have Wi-Fi, so use your phone or tablet to instant message, check the web and stay in touch with people. And check the resources section on page 172 for websites you can use to connect with other young people with cancer
- **Listen to audiobooks.** These are great, particularly if you're tired. Put your headphones on, close your eyes and go wherever you fancy...
- **Get creative.** Letting out how you're feeling can really help, especially on tough days. Start a blog, draw pictures or write poems, a diary, a novel or whatever is on your mind
- **Learn something new.** Knitting. Crosswords. Sudoku. Rubik's cube. Sign language. Painting. Games on your mobile. There are plenty of ways to keep your hands (and mind) busy from the comfort of your bed
- **Keep a diary.** Writing down your thoughts can stop them going round and round your head. And keeping a diary can help you look out for things that make you smile or laugh, too
- **Chat to people.** You don't need to be sociable the whole time, but you never know who you might meet on a ward
- **Find out what's happening.** If there's a youth support coordinator or play specialist on your ward, chances are there will be plenty going on – from brunches to pamper days to circus skills workshops. And if there's something particular you'd like to try, they can probably help arrange that too
- **Make plans.** Have a think about what you want to do when you get out of hospital. It's never a bad idea to have things to look forward to
- **Get some fresh air.** Clear your head with a stroll around the hospital grounds (but make sure you check with your doctors and nurses that this is OK first)



# REMEMBER YOU'RE THE BOSS



We've mentioned this a few times now, but that's because it's important. With lots of doctors and nurses looking out for you, it can be tempting to simply sit back and do as you're told. But if you don't want to do that, you don't have to.

If something is bothering you, let your care team know. If you don't like the food, mention it. If you want to go to sleep later or get up later, don't keep it to yourself. It's often possible to get things changed.

## 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, try to 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 prefer to be seen by a male or female doctor, ask to see if this is possible. You can also take someone with you to appointments.

And if English isn't your first language, translation services will be available. It's really important you understand what the people on your care team tell you, so if you don't understand something, ask again until you do.

## 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.

After all, in hospital, you've never been far from expert care. Everywhere you look there are doctors and nurses and medical kit and all sorts of other things that make you feel safe.

Heading home – away from all of those things and your hospital routine – might leave you feeling slightly out on your own. If you feel that way, don't worry: it's totally normal to be a bit anxious when things change.

Remember, though, 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's phone number handy (or your keyworker's number)
- 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
- Have a plan, so everyone at home knows what to do if you're not well

## A WORD OF WARNING...

Once you head home after a hospital stay and start spending less time thinking about the physical side of things – treatments, tests, appointments and so on – 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 treated like everyone else. Head to page 99 to find out more about how coping strategies can help you deal with your feelings.

# WE'RE HERE IF YOU NEED US!



# TRANSITION

## What happens when it's time to move to adult services?

There might come a time when you need to move from services designed for children or young people to services designed for older adults. 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 to 18**, your treatment should 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 to 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 is always plenty of support available for you, whatever age you are.

### WHEN DOES TRANSITION HAPPEN?

There's no set date, and you definitely won't turn up for an appointment one day and suddenly be pointed to adult services. 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 be open about how you're feeling and try to talk through any concerns.

### PREPARING FOR TRANSITION

One of the best ways to get ready for adult services is to learn more about your cancer, your treatment and possible side effects. 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 shift as easy as possible
- Ask your parent/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 parent/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

- Learn about what it means to live healthily – from exercising and eating well to keeping clear of cigarettes, drugs and alcohol. (You can read more about that over the next few pages.)

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.

### DEALING WITH YOUR PARENT/CARER

It's worth bearing in mind that this can be a tricky time for parents and 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 is hard, and it can take time for parents 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 your parents and carers on page 104.



### CHOOSING WHERE TO GO

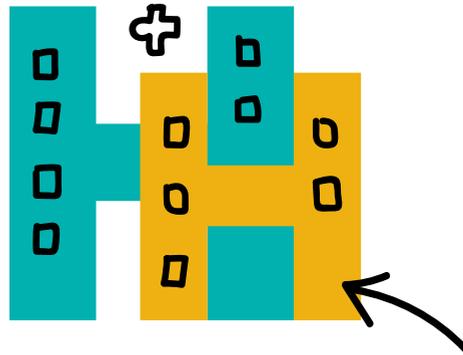
You might be able to choose between different hospitals, clinics and other services. If that's the case, your nurses and doctors will chat to you about what's available at each of them. It's a good idea to go for a visit too – to get a feel for the places and see whether they seem right for you.

### 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 – start learning and taking control before the transition and 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 can always invite your friends over. Even if you feel a bit lost at first, pretty soon your new surroundings will feel totally familiar. It can help to think about other transitions you've been through – like how quickly you settled into secondary school after leaving primary school.



### HANDY QUESTIONS

- 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?

#### Top tips:

**Learning more about your cancer can make the transition to adult services a lot easier. Just make sure any info you read is reliable – head to page 11 for more about that.**

# STAYING HEALTHY

**Weird one, right? You're living with cancer and we're talking about staying healthy? Well, it might seem odd, but looking after yourself can make a real difference to how you feel.**

### EATING WELL

When it comes to food and cancer, the theory is pretty simple. A healthy, varied diet is important, because it gives your body the energy it needs to fight cancer.

In practice though, it's not always that easy. Sometimes you just need to eat what you fancy. Some treatments might make you feel sick, so you end up losing weight because you can't face eating. Others – like steroids – might make you put on weight, so you end up feeling self-conscious and not wanting to eat.

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)

But worrying won't make food easier to stomach. So eat what you can when you can. And turn to page 50 for some ideas that might help.



## BEING ACTIVE

There might be times when exercise is the last thing on your mind, so don't push it. If you're feeling wiped out during treatment, your body is asking to recover. It's important to listen.

But on the days you do feel better, being active can give your body and mind a boost. You don't need to run a marathon or end up covered in sweat. Instead, set yourself small, achievable targets – especially if you're not in the mood for exercise – 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.

We're talking:

- A walk around the park
- A few squats or stretches
- Going swimming with friends (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 is never the same as curling up in your own bed.

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 DVD. Listen to music. Do whatever makes you feel calm – and try not to stress about anything that's on your mind
- **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 an energy drink, coffee or 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



- **Give up easily** - It's not advice you hear very often but, when it comes to sleeping, it makes sense. 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, surgeon-style

- Avoid certain foods – ask your doctors and nurses for a full list
- Make sure your food is always washed and cooked properly
- Avoid spending time with people who are ill
- 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 35 onwards)

**Top Tip: 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 straight with your doctors and nurses if you smoke, drink alcohol or take drugs.**

Don't worry – we're not here to tell you that drugs, cigarettes and alcohol are bad for you. That's not exactly a secret. But it is important you know that all of those things can have an impact on your cancer treatment. And by not drinking, smoking or getting high now, you can give your body the best chance of dealing with cancer.

## **WHY DRUGS AND CANCER DON'T MIX**

Cancer and cancer treatments mess with your body. They can hit your energy levels and make you more likely to get infections. Drugs and alcohol only

make matters worse – just think how you felt if you've ever had a hangover or a comedown and you'll know what we mean.

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
- Mess with your head, 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.

Long story short: if you've used legal or illegal drugs – from alcohol and cigarettes to weed, coke, ecstasy, ketamine or whatever – don't pretend you haven't. It's better if the people looking after you know, and you can talk to your medical team in private, without your parents 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. Hopefully you'll agree it's worth another go now. But before trying, it's best to discuss this with your care team.

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.

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

# LET'S TALK ABOUT SEX

**That's right. It's time to cover the stuff you're probably interested in but not all that happy talking about.**

Having cancer doesn't stop you being interested in sex. Sure, there might be times when you're not feeling sexy in the slightest. And there might be times when you're sick or exhausted and sex is the last thing on your mind.

But on the days when you're feeling OK, you might find that sex creeps into your mind. It's only natural. And the good news is that, unless your doctor tells you otherwise, you're fine to have sex. (Remember that the legal age to have sex in the UK is 16 for you and your partner, though.)

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.

**CHEMO = CONDOM**

## 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 a pack of condoms handy – and use them for at least a couple of weeks after treatment. They'll prevent pregnancies and stop you picking up anything nasty, too.

IT'S COMMON TO LOSE INTEREST IN

SEX

## 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. Whether you're single or in a relationship, you might find your confidence takes a hit, so 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 start to feel like having sex again. But if you're still not as interested in sex as you were a while after treatment, it can be helpful to talk to a psychologist or counsellor.

## Top tip: Try and talk to your partner.

If you're in a relationship and lose interest in sex, try and talk to your partner to help them understand what's going on.

Reassure them that they've not done anything wrong. Let them know what you're going through. Listen to what they're thinking.

You might be feeling pretty unsexy but that doesn't mean they've stopped finding you attractive, so try not to push them away. And remember there's plenty you can do to enjoy each other's company without having sex.

## WHAT'S GOING ON DOWN THERE?

Cancer and cancer treatment can cause various changes that affect sex...

### FOR THE BOYS

#### **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 balls, 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 – whether it's ways to manage stress, Viagra or vacuum pumps.

#### **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 stop having sex.

#### **You might not come when you have an orgasm.**

This happens if you have your prostate gland removed. It's called a dry orgasm and it's nothing to be worried about. Some people say that it doesn't change the way an orgasm feels; others think it can make things feel a bit less intense.

### FOR THE GIRLS

#### **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 on your breasts, 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 uterus, ovaries and vulva might change the way you feel about sex too, or might make it more difficult to have sex. If you're worried about any of these things, try and let your doctors and nurses know.

# FERTILITY

## Kids? Me? When you're young and diagnosed with cancer, you need to think about loads of things you probably haven't thought about before.

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

#### **Cancer treatments can sometimes affect your fertility by:**

- Messing up your sperm production
- Messing up 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. Your doctor will be happy to let you know more about this.

### THE DETAILS: WOMEN

#### **If you've started having your periods, cancer treatment can sometimes affect your fertility by:**

- Messing up 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 make you have an 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. Your doctor will be happy to let you know more about this.

### 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.

### GETTING PREGNANT

It's not a good idea to try to have a baby during cancer treatment, as the treatment could harm your baby. It can happen, though, so if you do have sex during treatment, make sure you play it safe. You can chat to your doctor about the best type of contraception for you (and doctors 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 for a baby after treatment, so check with your doctor or clinical nurse specialist if you're thinking about starting a family.

### FERTILITY TESTING

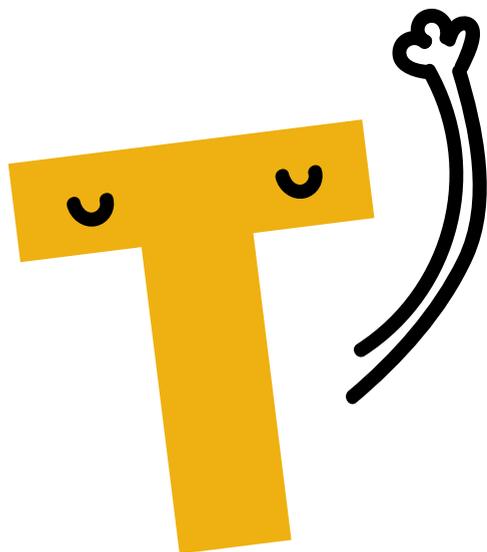
After cancer treatment, you can be tested to check your fertility levels. It's worth thinking carefully about this and maybe chatting to someone close to you about how you would deal with bad news. You might prefer not to be tested, or to wait.

And remember that infertility caused by treatment can be temporary – so your first test result isn't necessarily a final result.

### QUESTIONS TO ASK

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

- Whether treatment will affect your fertility
- Whether it will affect you permanently or temporarily
- Whether it's possible for you to store eggs or sperm
- Whether the treatment could affect your periods
- What contraception will be best for you during treatment
- What fertility treatments might be possible after treatment
- How long after treatment you should wait before trying to get pregnant
- Whether any other treatments might work



# WHEN TO WORRY

**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, act fast.**

A lot of us aren't great when it comes to calling the doctor. We ignore things. We make excuses. We say we'll call but then it gets late and we're tired and we're busy and we'll-definitely-do-it-tomorrow-honestly.

If that sounds like you, it's time for a change. During your treatment, 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 but think you might have some of these – it's time to get on the phone. Delaying will make things worse.







# LET'S TALK ABOUT FEELINGS...

**So you know that phrase  
'emotional rollercoaster'?  
That could have been invented  
to describe what it's like to  
have cancer.**

You might experience all kinds of emotions. 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, positively, no-doubt-about-it normal.

#### **OPENING UP**

It can be tricky to let other people know what you're feeling, especially if you're the kind of person who likes to keep things to yourself. You might prefer to ignore your emotions and hope they'll go away.

Unfortunately, that's not how it works. Keeping feelings bottled up usually makes 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. And sometimes just putting a name to what you're feeling makes a difference.



# TRY NOT TO BOTTLE IT ALL UP

You might be...

- **Shocked** - Even if you suspected something was wrong, hearing a doctor mention cancer for the first time probably sent your head spinning.

Shock can do strange things to you. You might have felt like you were watching the conversation happen from a distance. 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 tough you are – and no matter how old you are – cancer can be scary. If you're worried about anything, from treatments to what could change in your life, it often helps to try and find reliable

information about what you're going through. See page 11 for more advice.

You might find out you've actually been worrying for no reason – and just admitting you're afraid can feel like a massive weight off your chest too.

- **Uncertain** - Not knowing what's going to happen is one of the toughest things about cancer. You want to know everything is going to be OK and you want to plan for the future, but instead you're stuck in an endless waiting game.

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 – rather than the things you can't.

And try to remember that cancer treatments are improving all the time too.

- **Angry** - So here's the thing: cancer isn't fair. You know that. We know that. And here's another thing: it's totally natural to feel seriously angry because of that. Most people ask WHY ME? – and the fact that it's not your fault probably won't make you feel any better.

You might constantly feel a bit annoyed, or the tiniest things might send you into a rage. You might snap at your doctors and nurses or at the people closest to you – and then feel guilty and more angry at yourself. They're all understandable ways to act, but it is important to try and find things that calm you down, instead of bottling it up. See page 97 for a few ideas that might help.

- **Sad** - There are lots of reasons you might feel sad when you have cancer. Changes to your body, health, lifestyle and relationships can all bring you down.

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 should come and go. If it feels constant or you lose all hope for the future, this could be symptoms of depression. Depression can be treated, so it's important to ask for support. See page 91 for more information about this.

- **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** - Weird one, this. It doesn't make any sense – because you've not done anything to cause cancer – but since when did feelings make sense? The truth is that people feel guilt for all sorts of reasons after a cancer diagnosis. You might blame yourself for getting ill or feel like you've made life harder for your family. It's easy to get caught up in thoughts like that, but they don't help, so try to remember this really 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.

IT'S OK TO HAVE A

# BAD DAY

- **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.

It can help to think about what you're happy to tell people – and to tell yourself that people usually ask questions either because they're genuinely interested or because they're feeling embarrassed themselves.

- **Jealous** - It can be tough seeing your brothers, sisters 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 places – and that you'll be there whenever you feel well enough.
- **Lonely** - Being surrounded by people doesn't always stop you feeling lonely, and there might be times when you feel like no one really gets what you're going through. You might find people treat you differently or get distant. You might have to stay in hospital and miss out on school, college or work. Or you might feel like you're growing up more quickly than your friends. All of these things can make it seem like you're on your own.

If loneliness is a problem for you, 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. Visit [www.teenagecancertrust.org/usefulcontacts](http://www.teenagecancertrust.org/usefulcontacts) to find out how to connect with young people near you. And remember that you can always speak to a member of your care team too.

- **Withdrawn** - There might be times when you just want to head to your bedroom, close the door and be left by yourself. That's OK, but if you find you're shutting yourself off most of the time and never feeling like showing your face, you might be becoming depressed. Turn to page 96 for more advice.

### STAYING POSITIVE

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, don't worry if you feel miserable sometimes. It's natural to have good days and bad days, and feeling negative won't affect how your treatment works or make your cancer worse.

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 whole lot better.

# COPING STRATEGIES UNCOVERED

## Feeling stressed? Not been a good day? You need a coping strategy...

A coping strategy is basically anything you do to make yourself feel less stressed. Ever taken a few deep breaths to calm yourself down before an exam? That's a coping strategy. Ever taken a friend with you when you're nervous about going somewhere? That's a coping strategy.

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 on page 102.

Everyone is different, but it can help to:

- **Learn about cancer** - Some people feel better knowing everything they can. But have a think: do you like to know exactly what to expect or find out as you go along?
- **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
- **Be the boss** - 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
- **Choose your friends wisely** - Now's not a good time to hang out with people who make you feel stressed or embarrassed
- **Do the things you used to do** - It's easy to forget about seeing friends or watching films or playing sport 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

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

- **Get creative** - Write a blog, buy some paints, take a few 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 giggle just makes you feel better, so hang out with people who know how to tell a joke, 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.)
- **Have a makeover** - Pampering yourself on the outside can make you feel better on the inside
- **Try something new** - Learn an instrument. Figure out how to do sudoku. 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?
- **Get your eight hours** - Sleeping well is a big part of feeling well and dealing with your emotions. Turn to page 66 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 do 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: You don't have to stop living life because you have cancer.**

## WHAT'S YOUR COPING STRATEGY?



# 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 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 a holiday
- Your confidence and self-esteem take a hit

### IS THIS GRIEF I'M FEELING?

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.

You might start to feel more positive pretty quickly or it might take time. You might have good days and bad days. You might feel you're getting over one thing and then feel down about something else.

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.

There is a lot of professional support available. Our Teenage Cancer Trust 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.

And 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 [www.samaritans.org](http://www.samaritans.org)

**Top tip: Ignore people who tell you to 'get over it', 'move on' or 'cheer up'. Deal with grief in your own way and your own time.**



# IS THAT REALLY ME?

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

Worrying about your appearance doesn't make you vain or self-obsessed. It just makes you human. The media bombards us with images of what 'beauty' is. Often, they're using airbrushed images which are impossible to match – so it's not surprising 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

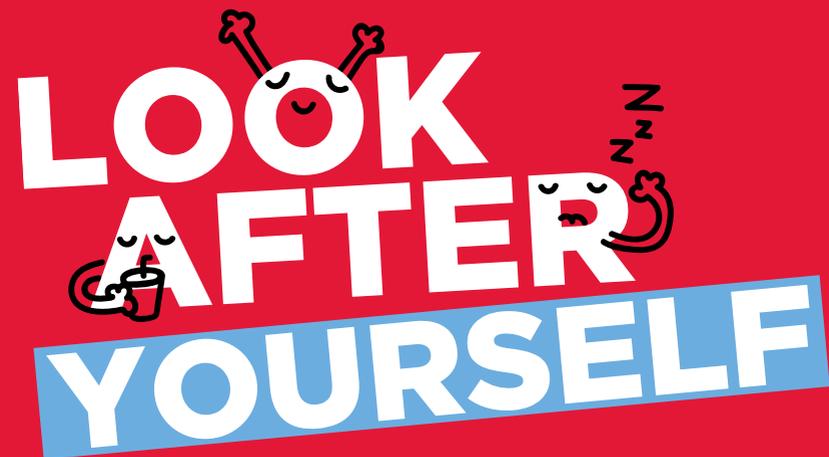
It might sound strange, but evidence shows that the way somebody feels about their appearance doesn't have much to do with how they look. One person with a tiny scar can feel devastated. Another person with a more obvious change might not feel self-conscious at all.

What matters is how you feel about it and how you approach it. Which is where psychologists, youth support workers and your care team can be useful (as well as your friends and family). 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 is 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 you skin, or an amputation.
- It is OK to mourn the loss of how you looked before – it is a loss after all so why shouldn't you feel some grief.

# LOOK AFTER YOURSELF



- Do anything you can think of to help yourself feel more confident. For example don't stop going out but if you feel anxious in case someone stares at you, take a friend with you. Or think about how you want to reply if people ask about your appearance. Sometimes if you see someone staring at you, it's only out of curiosity – they might just be wondering where your trousers are from, or they might be going through treatment themselves. Often the best response is to smile at them and turn an awkward moment into a pleasant one.
- Don't lose sight of your strengths and the things you like about your appearance – really maximise these.
- Keep in mind that a lot of appearance changes are 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.

## DEALING WITH LOSING SOMEONE

**Sometimes cancer treatment isn't successful. And if you build close relationships during your treatment with other young people who then pass away, 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 though. Right now that might sound stupid, but things will get easier.

It might help to remember that there's no right or wrong when it comes to grief (or to how you respond to cancer, for that matter). 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 totally 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 GRIEF

It's important to remember this isn't your fault. Nothing you could have done would have changed this. Cancer sucks. You can't blame yourself.

If you feel up to it, try and open up about your grief. You can talk to people close to you, or there are lots of professionals out there who can help. You can talk to your doctors and nurses. You can talk to 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 02 888 40) and offers advice at [www.childbereavementuk.org](http://www.childbereavementuk.org)
- **Childline** offers guidance and support all day, every day at 0800 1111 and at [www.childline.org.uk](http://www.childline.org.uk)
- **Cruse Bereavement Care** operates [www.hopeagain.org.uk](http://www.hopeagain.org.uk) especially for young people who are dealing with grief, with message boards so you can share your experiences

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. It's not weird or morbid: it's a way of remembering why you enjoyed their company
- **Laugh** - It's OK, you know. You'll probably feel guilty at first, but you're not offending anyone by cracking a smile
- **Ask for help** - If you need it, there is 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.



# IF IT ALL SEEMS TOO MUCH

## Dealing with the emotional side of cancer isn't easy, and sometimes you might need support if you're feeling low.

A lot of us struggle to admit when we're having a hard time. Instead of confiding in someone or opening up about our feelings, we pretend we're alright and keep on keeping on.

But there's no reason to feel embarrassed if you're feeling down. No one is happy all of the time, and your mental health is just like your physical health: sometimes you might feel good, other times you might need help.

It can be tempting to keep quiet to avoid upsetting the people close to you, but your family and friends will want you to be honest and to focus on your health, not on how they might react.

So if you are finding things tough, try to tell someone – and if it seems hard, try to work on it (we've included a few tips

on speaking about tricky issues on page 118). Pretending you're OK when you're not is exhausting, and opening up can actually help you feel a whole lot better.

### 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 this stuff, 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 will:

- Listen to you
- Be there when you need them
- Keep things private if you want them to be

- Be honest
- Not judge you
- Not try and solve everything
- Not tell you they know what you're feeling

You could try:

- **Your parents/carers** - You might decide they're the best people to help you deal with your feelings. Just try to be clear when you need their support and when you'd rather be by yourself
- **Your brothers or sisters** - If you've got them, you might feel most comfortable chatting to brothers and sisters – and they might help your parents see what you're going through, too
- **Other relatives** - It can help to talk to aunts, uncles, cousins or grandparents – people who probably aren't living with you but will have plenty of love and support to give you
- **Your doctors and nurses** - They're not only there to talk about physical problems – your care team can also help with the emotional stuff
- **Friends** - Sitting down and talking through your fears and frustrations with friends can help you deal with your emotions – and help you feel more like your old self, too
- **Partners** - Boyfriends and girlfriends can give you the perfect 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, don't be afraid to contact them to ask for a chat – teachers tend to be pretty good listeners

- **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. Turn to page 178 for useful contacts
- **Online support** - It's easy to find 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 tread carefully (visit [www.thinkuknow.co.uk](http://www.thinkuknow.co.uk) for tips on internet safety, and see page 16 of this book for more about reliable info)



## ANXIETY - AND PANIC ATTACKS

It would be strange to go through cancer and not feel at all anxious, so anxiety is to be expected. If the anxiety is really intense, it might show itself as a panic attack.

There are lots of tips to help manage anxiety, but if you are having panic attacks tell somebody in your care team because a psychologist can really help you conquer them.

Panic attacks are really scary but the good news is that they respond incredibly effectively to some basic techniques.

### Breathe... and other tips

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

- Learn an effective breathing technique, like the one described opposite - people often think they have tried breathing exercises and they don't work but it usually turns out they've not been doing the technique quite right
- 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 and if your body feels relaxed, it's hard to feel anxious inside.

- 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

### Panic attacks

When it comes to panic attacks, there's good news and bad news. Yes, panic attacks are one of the most awful things someone can experience, but they are also one of the easiest things to treat with talking therapy.

Panic attacks can happen at any time – when you're waiting for treatment or in the middle of the night or when you're walking down the street. They are often triggered by a particular thought or image or smell, but sometimes they feel as if they just come out of nowhere.



## What's happening?

You might have heard of 'fight or flight' – nature's way of helping if you are in physical danger (for example, if you were faced with a hungry saber-toothed tiger). Fear fills your body with adrenaline, and blood rushes to the muscles you need to fight or run away.

It's all pretty useful if you come face to face with a tiger (not likely). Not so helpful when the anxiety is there because of cancer. You can't spring into physical action by running away or fighting so the adrenaline just stays in your body with no way of being released.

That's what causes the pounding heart, feeling faint, shaky and sick. And as some muscles fill with blood, others, like the digestive muscles get less blood to them – which can also make people feel sick or have diarrhoea.

Sometimes you might breathe more quickly and not get enough oxygen which makes things feel even worse (if your lips have ever tingled that's a sure sign to slow down your breathing).

So what can you do?

### If you're having a panic attack

The aim is to get rid of the adrenaline your body has filled with. How? Change the levels of carbon dioxide in your blood. And the way to do that is to breath out for two seconds longer than you breath in. You need to do this for at least five deep breaths and you need to time it because it has to be precise! It doesn't matter how many seconds you inhale for as long as you exhale for two seconds longer. Timing this will also distract your mind from the images or thoughts that are fuelling the anxiety.

## FEELING LOW?

### Knowing the signs of 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, try to speak to someone about it.

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. Drugs are sometimes used too.

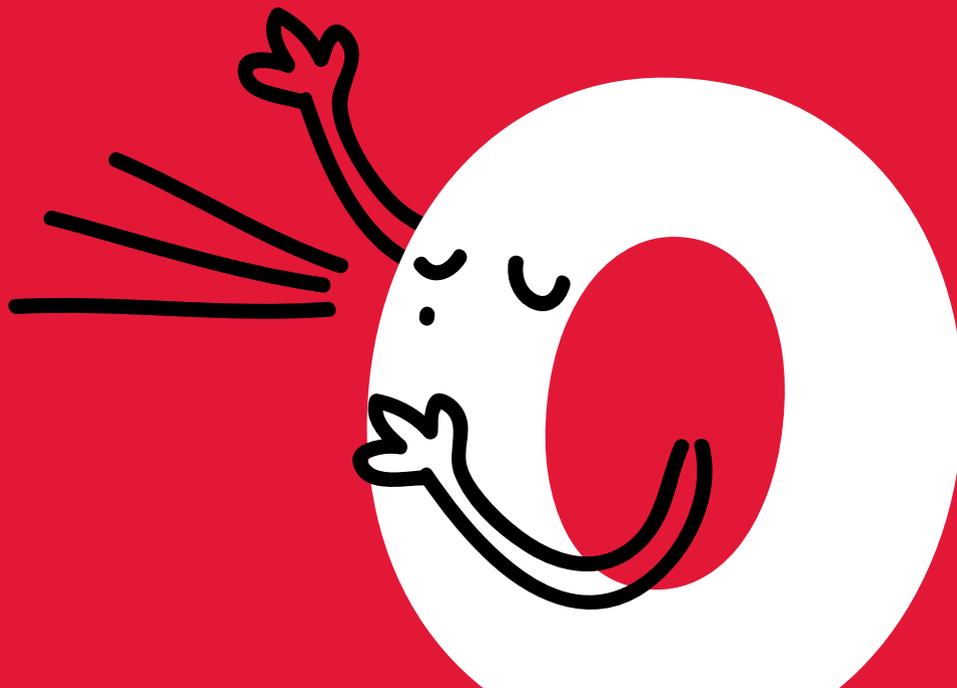
There are also various things you can do to help yourself. If you feel up to it,

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 the 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.

But the first step is mentioning how you're feeling to someone else. So try to start there and talk to the people close to you to figure out what's most likely to help.

**Remember:** You're not alone. Definitely not. Your friends, family and care team are there for you.

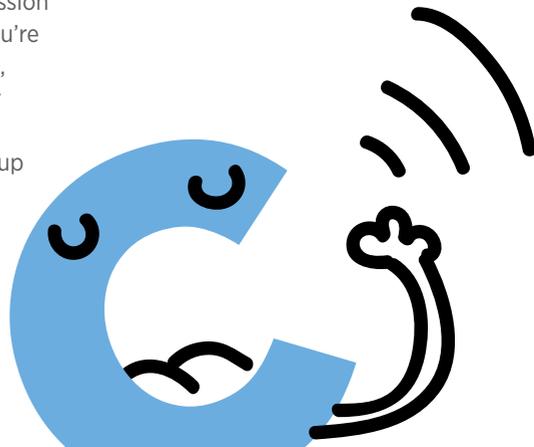


## FEELING ANGRY?

It's not unusual to feel seriously fed up when you have cancer. But there are unhelpful ways of dealing with anger – like taking it out on other people, distancing yourself from family and friends, hurting yourself, taking drugs and drinking. And then there are more helpful ways to deal with it. For instance...

- **Taking some deep breaths** - Concentrate on nothing but your breathing for at least five breaths. The key trick here is to exhale for two seconds longer than you inhale. This changes the carbon dioxide levels in your blood, creating a calming effect. Make sure you time this accurately or it won't work. Timing your breaths can also help because it distracts you from whatever is making you angry
- **Shouting** - As loud as you can. And then shouting even louder. Screaming at the top of your lungs can be an amazing release, so find somewhere private and let rip
- **Punching your pillow** - It's a good way to get aggression out – and a much better idea than punching a wall (less painful too...)
- **Exercising** - It works for depression and can work for anger too. If you're feeling physically OK, a jog, walk, swim or bike ride can really clear your mind and help use up some of that angry energy that's built up inside you

- **Writing down what you're feeling** - It's not a test and no one else has to read it – so don't edit, just vent
- **Turning up your music** - Metal. Mozart. Musicals. Whatever makes you feel better
- **Having a good cry** - All of these ideas basically come down to releasing what's inside. So if you feel like crying, don't try and sniff back those tears – let it all out
- **Talking to people** - You're probably getting used to us recommending this one by now, and that's because it works. Being honest about your emotions can help your anger fade away
- **Learning self-help techniques** - Cognitive Behaviour Therapy (normally called CBT) might be a bit of a mouthful, but it can actually really help you to deal with difficult emotions like anger. Try [www.getselfhelp.co.uk](http://www.getselfhelp.co.uk) as a good starting place to find out more



# 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. Our advice? It's the same as it's been throughout this book: try and be honest about what you're thinking and 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.

### NEW TO ALL THIS?

If you've not been particularly interested in religion before, it can feel pretty weird to start wondering about gods and faiths, but it's definitely not unusual. In fact it's pretty 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 this stuff.

#### **ITS 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.

You might find it useful to chat to them about their faith and what it means to them, too.

This can be a difficult time to get your head around. It's certainly completely unfair that you've got cancer. And thinking through things like religion and spirituality might just help you get through it a bit more easily.

**IT'S OK TO  
TALK ABOUT  
SPIRITUALITY**

**NO**  **ONE**  
**WILL** **JUDGE**  
**YOU** 

# **NOT A SAINT? THAT'S JUST FINE**

**There are lots of things written about people who are 'touched by cancer' and come out the other side grateful for the experience and having discovered the meaning of life. If you don't feel remotely like that, don't worry – and don't even think about feeling guilty.**

Sure, lots of young people say cancer made them look at things differently, appreciate things more and find strength they didn't know they had. It's not unusual to want to change things after cancer treatment, whether that means little things like calling your friends more often or taking life less seriously, or bigger challenges like running a marathon or jumping out of a plane.

But while lots of people do feel inspired by what they've been through, lots of young people also say cancer didn't change how they feel about life at all – and that's absolutely fine.

So if you feel like you've somehow failed because cancer hasn't made you see the world in a new way, it's time for a reality check, courtesy of our 100% accurate bullet list of how it's OK to feel during and after treatment...



# NOTES

A bit more space for whatever you want to write.

A series of horizontal dotted lines for writing notes.

**LIFE  
STUFF**



# DEALING WITH RELATIONSHIPS

**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, so they end up acting weird – when you'd really like them just to be normal.**

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.

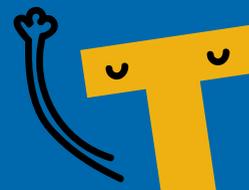
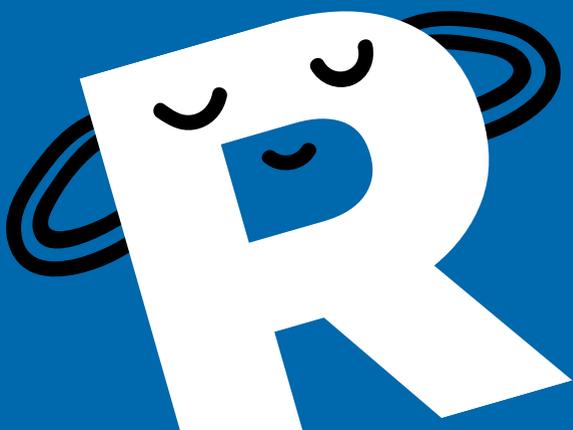
## LET'S START WITH PARENTS AND CARERS

Cancer can put any relationship to the test, and a cancer diagnosis can feel just as overwhelming for your parents/carers as it does for you. This list isn't here to freak you out – that's the last thing we want to do. But it might help you think about what your parents are dealing with in case they start acting differently.

They might be feeling:

- Shocked, scared and angry
- Worried about you, and about your brothers or sisters
- 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.



# KEEP

# FRIENDS & FAMILY CLOSE

## 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 parent/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 parent/carer for emotional support or for practical things like driving to appointments or cooking you 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 parent/carer to help out financially too, which can be difficult if you're used to having your own cash 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 parents/carers are fussing or nagging or treating you like a kid.

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. Chances are they won't know what you need from them otherwise...

## TAKING CONTROL

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

Your parents or carers 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 need to be involved too – and learning about your cancer and your treatment can help you feel more confident about having your say. (And if there are limits to what you want to know – like the details of a procedure – just let people know before they start explaining things.)

If you do feel like you're not being listened to, try to talk to your parents calmly about what you'd like from them. You might discuss:

- 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've always enjoyed
- How you'll stay in touch and tell your family what's happening – maybe you want to know they're always a phone call away, rather than 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. So 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.

## THE EMOTIONAL STUFF

Sometimes you might not want to tell your parent/carer if you're feeling scared, depressed, stressed or just in need of a hug. Maybe you're worried 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 you're from a family that doesn't do conversations about emotions, you might find it helps to write in one of the cards at the back of this book and leave it somewhere where your parents or carers will find it. They'll understand how you feel – without you needing to squirm and try and find the right words on the spot.

And 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 parents/carers and your brothers and sisters 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.

Turn to Page 178 for cancer support organisations.

## 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.



# BROTHERS AND SISTERS

**Fight like cat and dog? Get on like a house on fire? A bit of both? Whatever your relationship with your siblings is usually like, you might find that cancer makes things a little different.**

If you have brothers and sisters, 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.

But a cancer diagnosis can affect your relationship with siblings too, in lots of different ways.

It might bring you closer as you deal with this together. Your brothers and sisters can be a handy link with 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 need to move back home, for example, that can be tricky. As you're trying to get your head around being

back in your old room, they'll be going through the same thing (especially if that room had become their room and they've now been kicked out of it...)

You might find your brothers and sisters suddenly get really overprotective – so you end up with three (or four or five) parents/carers, instead of one or two. Or they might go quiet: staying silent and not mentioning your cancer at all. Either way, it can be pretty weird.

And if you're in hospital for a while, that 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 hanging out.

## WHY ARE THINGS CHANGING?

It's always strange if relationships you've taken for granted start to change. But it's worth trying to think about what your siblings are going through and, if things are changing, to try and figure out why.

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.

You might find your brothers and sisters are:

- **Scared** – No matter how tough they pretend to be, they'll be worried about you – especially if they feel like your parents aren't telling them everything or if they don't quite understand what's going on
- **Angry** – They might feel left out or annoyed because they have to do more chores or because all of the attention is on you (and they might be angry at themselves for feeling like that)
- **Jealous** – It probably sounds weird to you, but you're getting a lot of attention – and they may not be. It can seem unfair if you're getting presents or not having to do so much around the house, while your brothers and sisters have to pick up the slack

- **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 parents spend 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 this is their fault** – Sometimes brothers and sisters think they might have 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 seem pretty complicated. But 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

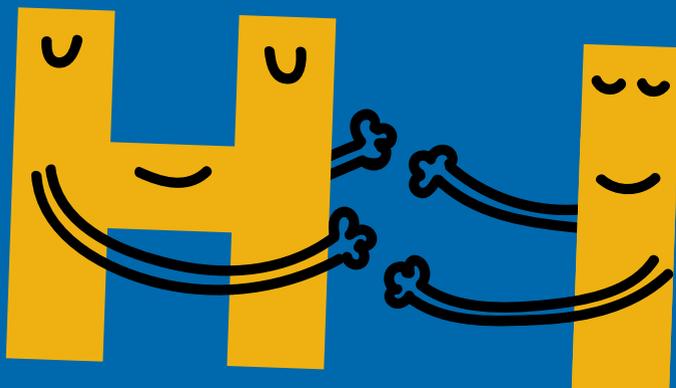
**Your friends might be amazing during your cancer treatment – saying and doing all the right things, generally being awesome. But cancer can put pressure on any relationship, and sometimes even the closest friendships get messed up.**

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 straight 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 because people feel awkward. Your friends don't know what to say. Maybe you've gone a bit quiet on social media for a while – maybe they have. They worry about saying or doing the wrong thing. And before you know it you're not seeing each other as much as you used to.



## TIPS TO STAY IN TOUCH

You might need to take the lead to help your friends deal with what they're going through. That can feel pretty frustrating – it's not like you haven't already got plenty on your plate – but they might not have been around someone with cancer before, and they're probably stressing about how to act.

**Top tip: Try and imagine how your friends might be feeling. If they're acting differently, it's probably because they care about you but aren't sure what to do.**

Often all it needs is for you to be straight with people and let them know they don't need to walk on eggshells.

It can help to try and see things from their perspective. (And if one of your friends has ever lost someone they loved or if their parents separated, think about how you felt – probably pretty awkward.) You might find that your friends are asking themselves a whole lot 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 shut up about it?
- Should I talk about other things or will that make me seem selfish?

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

## TALKING

# WILL REALLY HELP CLEAR THE AIR

An illustration of a yellow mobile phone with a black cord. A speech bubble is coming from the phone, containing the word 'HELP'. The phone is positioned to the right of the word 'WILL' in the main title.

You could:

- Ask people to keep calling, texting and inviting you out
- 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 just thinking cancer, cancer, cancer.

So let them know if you're happy to hear the usual gossip and day-to-day stuff (otherwise they might think it's too trivial to bother you with).

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

## THE TEENAGE CANCER TRUST EDUCATION & AWARENESS TEAM

You can arrange for our education experts to visit your school and speak to your friends. It's a great way for people to learn more about cancer and to ask questions they might be worried about asking you. Search for 'education' at [www.teenagecancertrust.org](http://www.teenagecancertrust.org) to find out more about arranging a visit.

### IT'S WORTH REMEMBERING...

There might be times when your friends annoy you, especially if you're feeling crabby or crappy 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 more robust than you are inside
- **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 not being very friendly. They might even be jealous of the attention you're getting. Or your perspective on life might change, so you struggle to relate to people like you used to.

If this happens to you, 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 years or got chatting to them on the bus this morning.



# BOYFRIENDS AND GIRLFRIENDS

## Dealing with boyfriends and girlfriends can be a minefield at the best of times. Throw cancer into the mix and things often get even more complicated.

If you're in a relationship, going through cancer treatment can bring you together, helping you realise just how much you mean to each other. But it can also push you apart, as you 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 worry that your partner didn't sign up to

this. 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.

### 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** - We wanted to start with this one because it does happen and because the rest of the list can seem pretty negative. But 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** - This is the total opposite of getting distant. 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 fancy you any more. And if your fertility is affected by your treatment, that can weigh on your mind too

**BEING HONEST ABOUT HOW YOU FEEL IS KEY**

- **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

**Top tip: Whatever happens in your relationship, remember that it's not your fault that you got cancer.**

#### **HONESTY = 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. It's a pretty good medicine. (Crying can be pretty effective, too, if that's how you feel.)

#### **TIME TO MOVE ON?**

There's never an easy time to end a relationship, but having cancer doesn't mean you should stay with someone who isn't right for you. And it doesn't mean someone should stay with you when they don't want to, either. If you were having doubts about your relationship before your diagnosis, be honest. Even if you and your partner now feel you 'should' stay together because of what's happened, that might not really be the best thing for either of you.

#### **MEETING NEW PEOPLE**

Getting diagnosed with cancer doesn't mean you suddenly stop being interested in relationships. Sure, there might be times when you're feeling too tired to even think about it, but there might also be times when you fancy meeting someone new. It can be great for your self-confidence and help your life to feel a bit more normal.

But how do you go about it? It's not something most people find easy at the best of times, and now you might have added worries about how your body has changed or how tired you sometimes feel.

**MEETING NEW PEOPLE IS EASIER THAN YOU THINK**

Well, here's the thing. There are plenty of people out there who will like you for who you are, and who will see you as who you really are – not as someone who has cancer.

Not only that, but the internet has made it a lot easier to meet those people. Of course, you can still do things like get your friends to set you up, or join a sports club, or hang around in the supermarket hoping that Mr or Mrs Right is doing the weekly shop. But if that doesn't work for you, we have two words: dating sites.

Try not to let the fear of rejection stop you from dating. Even if you're not feeling great about yourself, that doesn't mean other people won't find plenty to like in you.

Of course, you might meet people you're not keen on, but that's just the way it goes. The point is that if you do want to meet new people, there's no reason you won't end up meeting someone great.

## INTERNET DATING: STAYING SAFE

The web is a great place to meet people, but it's also really important you stay safe and remember that people aren't always who they seem. It's a good idea to:

- **Be anonymous** – Choose a username that doesn't include your full name and don't include your email address, home address, phone number, workplace or school in your public profile
- **Trust your instincts** – If something doesn't seem right, or if someone asks for money or says things you're not comfortable with, walk away
- **Go slowly** – Once you've shared anything online, you can't get it back. So take care and take your time when you talk about yourself. You don't need to share your life story straightaway
- **Do your own research** – If you've met someone you like but want to check them out, a quick search of Google, Twitter and Facebook can usually show you if they're who they say they are
- **Be smart when you meet someone** – Meet in public during the day, tell your friends where you're going to be, arrange to contact someone afterwards and leave at any time if you feel uncomfortable

One more thing: think very carefully before you start sexting. It's illegal, first of all, and it can also put you in a really vulnerable position. Once you've shared private images, you can't get them back and have no control over them.

So protect yourself and, if you've been sent explicit images by someone you're in touch with and feel uncomfortable,

download Childline's Zipit app. It helps you get flirting back under control and has plenty of handy tips and comebacks for when people share too much.

Finally, for a lot more useful info about staying safe online, head to [www.thinkuknow.co.uk/14\\_plus](http://www.thinkuknow.co.uk/14_plus)

## WHAT TO TELL A NEW PARTNER

It's up to you when you decide to tell someone new that you have cancer. You might want to wait until things seem to be getting serious, or you might want to put your cards on the table 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.

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 120 for a little more advice on telling people about your cancer diagnosis.

# TELLING YOUR KIDS

**If you've got children, you'll need 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 want to learn, and they also don't have the same fear of the word cancer that adults do. If you explain things in a simple way, they'll get it. And if you're open and honest with them, chances are they'll be open and honest with you.

## 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, it's possible to make the conversation less painful. You might find it helps to:

- **Explain things step-by-step**, so that your kids can come to terms with your diagnosis and treatment gradually
- **Be honest**, they'll figure 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 cancer isn't contagious

- **Tell them you love them**, because there aren't many things that provide more comfort than that
- **Ask them to repeat what you've said** - so you can check they've understood it

There are books you can use to explain what's happening, so ask your youth support coordinator if you'd like to use one of those. And there might be play specialists at your hospital who work with children and can help with the conversation too.

#### 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 IS TOUGH

## OK, so all through this book we've been encouraging you to open up about your feelings. But what if you struggle with that?

You might already have seen videos online or looked at leaflets that feature families sat together after a cancer diagnosis, with everyone calmly discussing their feelings like it's the most natural thing in the world. The trouble is, real life often isn't like that.

Lots of people like to keep themselves 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 usually makes 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 (see page 80 for more about this)

- Being scared that you will 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
- Remember how we suggested that you plan what you want to say before you talk to doctors, and maybe write it down? That can be a good idea when you're talking to friends and family too. (You could even write a letter instead of talking, so people have time to process your news and think about their response.)

- It can help to start by explaining what you'd like to talk about and if there's anything you'd rather avoid
- There might be silences and people might get upset. That's OK, so try not to let it freak you out. Take a few breaths, have a cup of tea 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. Most of the time, 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.

We've included some cards at the end of this book that might come in handy. They're designed to make it easy for you to let people know what's on your mind. All you need to do is leave them where people will find them or drop them in the post.

Or you could always:

- Send an email, letter, text or instant message
- 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
- 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, 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.



# **'YOU'VE GOT WHAT?!' CHOOSING WHO TO TELL**

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

After you're diagnosed with cancer, it's normal to start asking yourself questions about your relationships. Questions like, 'How will people react if they find out?', 'Do I want that person to know?' and 'Am I really 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 for everyone you're wondering about telling.

#### **YOU MIGHT DECIDE TO TALK TO PEOPLE BECAUSE...**

- Keeping cancer to yourself can be stressful and exhausting, whereas being honest can be a big relief
- Telling your teachers or boss can make it easier to get extra support at school, work, college or uni, like having time off for appointments, changing your work hours or avoiding things like heavy lifting or using machinery

- 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 you might decide not to talk to people because:**

- You're worried about getting a weird 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, like your testicles or breasts
- For as long as possible, you want to keep school, work, college or uni 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 (though it is 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 125)

**HOW TO TELL PEOPLE**

This one is up to you too. 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 at once or keep your explanation short.

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

- **How much information are you happy to share?** You could write this down beforehand
- **What do you want to say?** It can help to practise on your own first
- **How do you feel about people passing the news on?** Let them know if you don't want it to go any further (but 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 so stay silent. Either way, it can help to let people know what 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.

We've said it before and we'll say it again: **You're... The... Boss.**

# SCHOOL AND STUDYING

## What happens with school, college 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 or uni to help your recovery. This can sound like a great idea at first, but can quickly feel quite weird. There's only so much daytime TV a person can take.

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 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 tutors about what is possible for you to do, but try to avoid taking too much on and stressing yourself out.

**LETTING PEOPLE KNOW**

Your school, college 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. 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, too. But all of these things can take time to get sorted. Cancer charities can often help with information for teachers, lecturers and friends.

**LEARNING AT HOSPITAL OR HOME**

If you're in compulsory education (which means you're 16 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 these facilities have education departments that employ teachers.

And if you're 16 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 or uni can help life seem more normal – even if you're simply emailing tutors or meeting up with friends.**

### **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 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 parents or a friend to go with you - or 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. It can help you avoid having to answer the same questions a thousand times.

We've developed a wide range of lesson plans, quizzes and games your teacher can use to help people learn about cancer.

Visit [www.teenagecancertrust.org](http://www.teenagecancertrust.org) and search 'education'.

And you can arrange for a member of the Teenage Cancer Trust education team to visit your school and talk about what cancer is and how treatment works. They'll be able to answer any questions people might have about cancer, too. You can find out more and book a session by visiting [www.teenagecancertrust.org](http://www.teenagecancertrust.org) and searching for 'education sessions'.

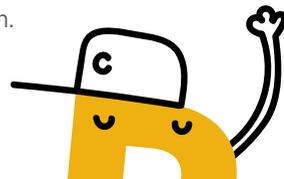
### **YOUR FIRST DAY BACK**

Like a lot of things, your first day back usually seems a lot worse in your head than it turns out to be. Sure, you might find that some people stare at you or seem a bit awkward, 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, try not to react. As well as being idiots, they're probably just nervous or confused about cancer. And if it carries on, let someone know – dealing with bullies isn't something you need to deal with on your own.



### **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 will get easier as time passes.

And remember to let people know if you're going to miss classes because of appointments. You could:

- Ask a friend to take notes for you
- 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's not a blag and 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.



### **WHO TO TALK TO**

If you've got concerns 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, which might sound like a scary option but really isn't – these are people who are trained to listen and help you deal with problems
- Your parents, who can talk to 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

### **USEFUL CONTACTS**

For more support and advice about anything to do with school, you can get in touch with:

- Our experts, by emailing [support4you@teenagecancertrust.org](mailto:support4you@teenagecancertrust.org)
- CLIC Sargent – [www.clicsargent.org.uk](http://www.clicsargent.org.uk)
- Macmillan – [www.macmillan.org.uk](http://www.macmillan.org.uk)

# ALL ABOUT WORK

## 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. And for ideas about how to tell your boss and colleagues about your diagnosis, turn to page 121.

### **Don't rush into anything!**

If you're reading this section because you've had a cancer diagnosis and are thinking of quitting your job – don't do anything rash! Take some time, speak to people close to you and work out whether that's really what you want to do.

### **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 that's 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 boss, 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.

**Top tip: Thinking of going back to work (or school)? You can always contact Teenage Cancer Trust for more support and advice. Email [support4you@teenagecancertrust.org](mailto:support4you@teenagecancertrust.org) and we'll get right back to you.**

### **TIPS FOR GOING BACK**

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 boss 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 boss 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 boss might be obliged to make reasonable adjustments to make things easier for you
- **Go easy on yourself** - It takes time to recover from cancer and cancer 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. You might want to talk to everyone together, or you could speak to a few people and ask them to let others know.

We've also included some cards at the end of this book that might come in handy. They're there for any times when you don't feel like talking but don't want people to feel ignored.

### **Keep your eyes open!**

Most bosses and companies are brilliant at adapting to make your life easier – but some aren't. So 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: we've included their details in the Useful contacts section on page 178.

### Looking for work

Searching for a new job is tricky 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, or 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 – false answers have a habit of coming back to haunt you in the future.

And remember that, while you might not think of yourself as disabled, the Equality Act and the Discrimination Act consider everyone with cancer to be disabled.

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 'positive about disabled people' symbol on job ads, too. If you meet the

basic conditions for these jobs, you'll definitely be asked in for an interview.

#### 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](http://myplusstudentsclub.com)**

#### Changing career

A lot of people decide to try something different after going through cancer treatment. It can change your perspective and make you feel like the path you were on isn't right for you anymore. If you're feeling like that, make sure you take time to think about your options.

This could be the start of something brilliant, but there's no rush. Take time to think about what you really want to do. Chat to your friends and family. And then start shaping your future – exactly how you want it to be.

# GETTING AWAY FROM IT ALL

## 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.

Let's start with the good news: this section isn't here to tell you that there's no way you can go on holiday before, after or even during cancer treatment. Definitely not. A change of scene can do wonders for you and your family.

What is important, though, is that you chat 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.

So don't rush off anywhere just yet, but don't throw away those holiday brochures either. 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 that trip to hike the Inca Trail in Peru. 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.

**REMEMBER  
TO LISTEN TO  
YOUR BODY**

# TALK TO **YOUR** DOCTORS, THEY'LL HELP **YOU MAKE A** PLAN



## **CHECK OUT INSURANCE**

Getting travel insurance can be more difficult when you have cancer and can take longer to arrange. That's because 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. Turn to page 178 for useful contacts.

## **ASK ABOUT VACCINATIONS**

To travel to some countries you need to get vaccinations before you leave (as if you've not had enough injections already...) 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.

## **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 flights or trains are 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 drugs 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 [www.gov.uk](http://www.gov.uk)). It's also a good idea to get a letter from your doctor listing all the drugs that you're taking. And make sure you carry any drugs, syringes and medical pumps in your hand luggage so you can get to them easily.

## **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. So 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

## **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 AN EHIC CARD**

If you're travelling anywhere in the EU, or to Norway, Lichtenstein, Iceland or Switzerland, apply for a European Health Insurance (EHIC) card online. Having one of these means you can get healthcare for free or at a reduced cost in those countries. And don't get duped into paying for one – lots of websites charge for these cards, but you can get one for free at [www.ehic.org.uk](http://www.ehic.org.uk)

## **PROTECT YOURSELF IN THE SUN**

Some cancer treatments can make your skin more sensitive to sunburn – and it's good advice anyway. So cover up, pop on a hat and slap on sunscreen that's Factor 30 or higher and remember to re-apply regularly.

## **ENJOY YOURSELF**

We know it can seem like a lot of faff to get all of these things sorted, but once you're there, make the most of it. So from the moment you arrive, it's time to relaaaaaaxxxx...



# LEGAL STUFF, MONEY STUFF

**We're not lawyers and we're not financial advisers, but we do know where you can get answers if you've got the law or money on your mind.**

There are a whole lot of legal and money issues that can come up during cancer treatment. Maybe you think your boss could be discriminating against you. Maybe you want to know more about benefits or about any support that exists for your parents. Maybe you'd like to find out about help with travel costs.

Issues like this can seem like a real pain 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 parents 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 parents 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 – we've listed a few in the useful organisations section (page 133) - but they can only help if you talk to them.

## **DEALING WITH DISCRIMINATION**

You have important 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 (who 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 boss, teachers, landlord or whoever about how you're feeling. If that doesn't sort

the problem, speak to your social worker or youth support coordinator, or contact Citizens Advice Bureau (see over).

## **TRAVEL INSURANCE**

Our travel section on page 128 lists a few things to think about if you want to get away from it all for a while – and one of those things is travel insurance. It can be tricky to get insurance during or after cancer treatment, but it is possible. So read our travel tips on page 128 and then turn to page 178 for useful contacts who might be able to help.

## **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 millions stashed away in a secret bank account – a Will is simply a way to explain what you want to happen after your death.

**GET THE  
RIGHT  
ADVICE**

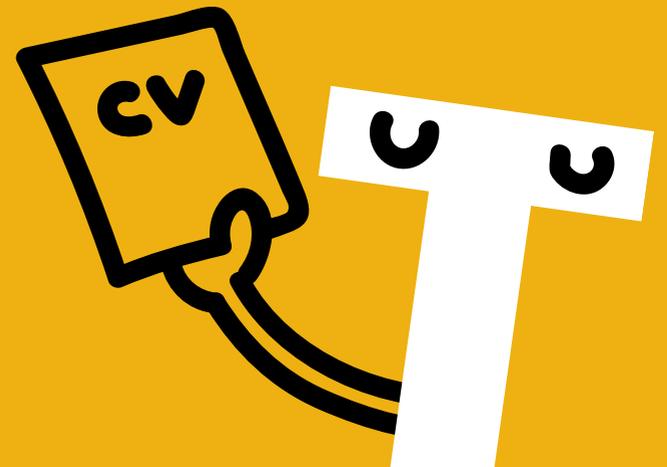




# NOTES

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# BEYOND CANCER



# GETTING BACK TO 'NORMAL'

**So you've heard the word you've wanted to hear for so long – 'remission'. Congratulations, that's amazing news. But what happens now?**

When you're living with cancer and getting treated for cancer, you tend to spend a lot of time thinking about cancer – and about doctors and nurses and hospitals and tests and more tests and side effects and everything else that goes with a cancer diagnosis.

But finally the day arrives when you don't have to think about those things anymore, and everything can feel a bit weird and even slightly scary. What do you think about now?

If the world seems strange at the moment, don't worry. There's nothing ordinary about going back to your ordinary life after cancer treatment. And no matter how much you've been looking forward to it, it takes time to adjust to your new normal.

## **WHAT IS 'NORMAL' NOW?**

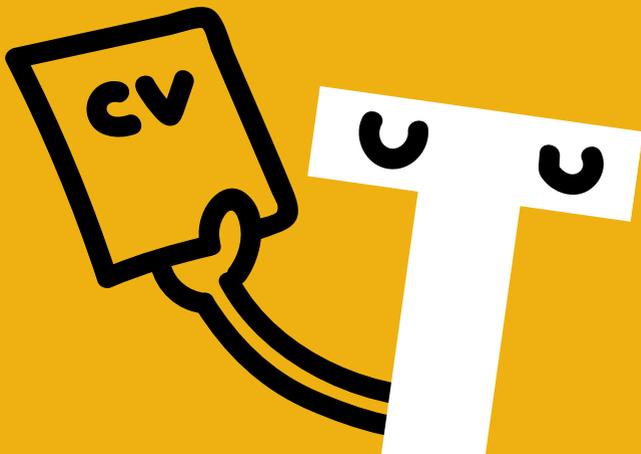
You and the people close to you have come through a massive challenge. But getting over cancer doesn't happen when you get rid of the disease.

In fact, it can be hard to work out what normal is now. That can be exciting – because you can begin again however you want – but it can be confusing too.

So give yourself time and don't rush to make choices. It might help to think about redefining your life now, rather than rebuilding it.

## **REDEFINING YOUR PLANS**

Now can be a good time to look into different options. 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 used to have. This can be hard to adjust to, but don't rush to plot out a new direction. The time will come when you feel ready to think about different opportunities
- Maybe you're thinking about aiming towards a totally new career. You might want to work in healthcare after seeing the amazing work your care team does during your cancer treatment. (or maybe you never want to set foot in a hospital again). 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.)

### LOOKING FOR MEANING

Cancer is a life-changer, so it's not unusual to think about the impact it's 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

# NOW'S THE TIME TO THINK ABOUT YOUR SHORT & LONG-TERM GOALS

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 you in touch with people your age who have been through cancer. Remember that everyone's experience is different, though (and remember that not everything you read online is true – turn to page 16 for more on that)

### 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 hit your confidence and self-esteem)

- You might feel like your relationships with the people close to you have changed
- You might feel more mature and stronger
- 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, but try to remember that it won't last. Doing the things you used to do – like going to school or work or just hanging out with friends – can help people get used to having you around again. And meeting new people can be a good idea too, if you feel up to it.

It can also be difficult getting used to not being the centre of attention anymore. That's also natural. 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.

### WILL CANCER COME BACK?

That's usually one of the first questions people ask when they find out their cancer is in remission, and it can be a difficult one to cope with.

Some people even struggle to make plans or to enjoy life fully because they're worried cancer might come back.

The truth is, it's not an easy one to answer. You might find your doctors and nurses are reluctant to say that your cancer is 'cured' because cancers can come back in the same place or somewhere different. This is usually because treatment didn't destroy all of the cancer cells in your body.

The good news is that, for most cancers, the more time passes, the less likely it is that cancer will come back. But if you are worried, don't try and hide your fears. Everyone has bad days, so try to accept your feelings and work through them.

People like clinical psychologists and counsellors aren't just there for you during treatment; it can really help to talk to them afterwards, too. They're able to suggest ways of managing any anxieties you have, which can be especially handy if your worries about cancer coming back are getting in the way of you living your life.

There's no doubt that living with uncertainty can be tough, but it does usually get easier. And while you'll never completely forget having cancer, it's likely you will think about it less and less as time goes by.

**Teenage Cancer Trust organises regular events that bring young people together and tackle the topics that are important. To find out about upcoming events email [support4you@teenagecancertrust.org](mailto:support4you@teenagecancertrust.org)**

# RELATIONSHIPS AFTER CANCER

**You know that phrase ‘getting back to normal’? Life often isn’t like that. You go through things that change you, and going back to how life was before doesn’t seem right or realistic.**

You might find that’s how you feel after your cancer treatment. The people close to you might feel the same way. And, as a result, your relationships might start to change.

## **FAMILY**

During your treatment, you and your family will have adjusted to your new reality. You might have needed more support than you’re used to.

Your mum and dad might have given you more attention than your brothers and sisters. Your brothers and sisters might have needed to do more around the house. And so on and so on.

Now your treatment is over, figuring out how things are going to be from now on can be complicated. It can leave you feeling like you’re dancing around each other as you try and get your independence back and everyone tries to readjust.

**LISTEN  
TO THE  
PEOPLE AROUND  
YOU**



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 (that’s a good idea as you work through all of your relationships). You’ll figure 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 sometimes it’s not that straightforward. Maybe you feel you’ve missed out on things or can’t relate to your friends like you used to. Maybe you 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, so you find 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 what you care about and what kind of people you want to hang out with. Just give yourself a bit of space and time.

## **BOYFRIENDS AND GIRLFRIENDS**

The section on page 112 gives a lot of advice on changes that might happen to relationships during cancer treatment, but what about afterwards?

Even if you’ve been with someone 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.

You should know each other pretty well by now, so talk about anything that feels strange. It might be that neither of you have really spent much time thinking about what’s going to happen. Even if you’ve talked about the future before, the situation can seem different when that future 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:

- Anything new you want to do in the future
- Anything you’re confused about or want help with
- 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.

### MEETING SOMEONE NEW

Trying to start a new relationship is often daunting. If cancer has affected the way you look or given your confidence or self-esteem a knock, it can seem even harder.

But people will still feel attracted to you after you've had cancer. And while you never know when you might bump into Mr or Mrs Right, if you do want to meet someone new, it might help to:

- Join local groups or clubs, especially if you've not hung out with many new people lately
- Join an online dating service (but go to page 115 first to find out more about keeping yourself safe)
- Talk to other people who've had cancer about how they met people after treatment



- Focus on anything positive that's come out of your treatment – maybe you feel stronger or you appreciate people more
- Talk to friends, family or a professional – like a psychologist or a counsellor – if you've got body issues that are weighing on your mind

If your treatment has affected your fertility, you might be worried about telling people about that. But there's no rush. If you meet someone and the time feels right, explain the situation and talk through what it means – and remember that you can always talk to your doctors about fertility treatments too.

### 'GETTING OVER IT'

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' are about as useful as an inflatable dartboard, but that doesn't mean you won't hear them.

If you feel like people are pushing you, try to explain that even though your treatment might be over, you still need to deal with what's happened – in your own way.

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, a doctor or nurse, your youth support coordinator or a clinical psychologist or counsellor. Asking for help doesn't mean you've done anything wrong. The time after treatment can be one of the most challenging to get used to.

# LATE SIDE 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 seriously frustrating and pretty 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/late side 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 side 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 side effects!

### WHAT'S GOING ON?

Late side effects come about because some cancer treatments, including surgery, radiation therapy, bone marrow transplants and some types of chemo, can do damage to healthy cells as well as cancerous ones. And this can cause problems that take months or sometimes years to appear.

### WHAT ARE WE TALKING ABOUT?

Potential late side 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 side effects and lets you know what to look out for. (If you're not given one of these, ask about it.) You'll have regular check-ups, too, to increase the chances of picking things up early.

### WHAT CAN YOU DO?

Late side effects can be really hard to deal with and make you feel like you'll never be free of cancer. But to help identify and deal with them as early as possible, it's important to:

- Talk to your doctor or nurse about whether you're likely to have late side 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 (and if you haven't got a care plan, go and ask your doctors and nurses about it!) This can help doctors you meet in the future who weren't involved in your cancer treatment
- Look after yourself – a healthy lifestyle (eating well, exercising, not smoking and so on) can reduce the impact of late side effects

If you do experience late side effects, it might help to go back to our tips for coping with difficult emotions on page 80. All of that advice still stands.

**TELL YOUR DOCTORS ABOUT ANY PROBLEMS**



# 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. Getting that news can be devastating – a real 'why me?' moment.**

It's one of the hardest truths about cancer: there is a chance that 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%.

### WHY DOES CANCER COME BACK?

There are several reasons that it can happen – but it's never because of anything you've done.

Sometimes cancer treatment doesn't get rid of all of the cancer cells, and the ones that were left behind form a new tumour – either in the same place as your

original cancer or somewhere nearby. Sometimes cells have spread to another part of your body and form a tumour there. Sometimes cancer treatments increase the risk of getting cancer again in the future. And sometimes cancer cells mutate and become resistant to treatment.

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.

### DEALING WITH FEAR

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. 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 YOUR CANCER COMES BACK

Hearing a doctor tell you that your cancer is 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. We're talking:

- **Shock** - Which is only natural, especially if you've been feeling well and like you've moved on
- **Anger** - That's only natural, too. 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 be well

Facing up to feelings like this again can be really difficult. But you do now have one thing you didn't have before: experience.

That experience won't stop you from having bad days or from wishing this wasn't happening to you again. But it can help you to focus on one thing: you got through cancer treatment before, and you can do it again.

**REMEMBER**  
**YOU'VE**  
**GOT THROUGH**  
**THIS**  
**ONCE**

# WHEN TREATMENT IS UNLIKELY TO CURE CANCER

**Sometimes cancer treatment doesn't work. We'd love that not to be true. No doubt you would too. But sometimes doctors do have to let people know 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. 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.

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.



## DEALING WITH YOUR EMOTIONS

If you're told your treatment isn't likely to work, you might become silent or feel like you're not able to listen or focus anymore. You might start crying and feel like you'll never stop. You might feel completely numb. Or you might feel calm and detached – that happens too.

Especially in the first few days, people often experience a whole range of different emotions. Some 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.  
  
One other point worth making, though: 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 92.

- **Sadness** - You probably don't need us to tell you that you might feel really upset. That's not exactly a surprise. You might find you feel too low to share your feelings with others, so 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 catching buses and going shopping and doing other, 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. 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 annoyed. 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. If you think that could help you, the charities listed on page 178 might help you make contact.
- **Guilt** - You might be worried that you are 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 a whole lot 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 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 tough, 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, talk to people you know won't make things harder 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 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 a range of drugs, 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 to read, but some people do say they're gradually able to 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.

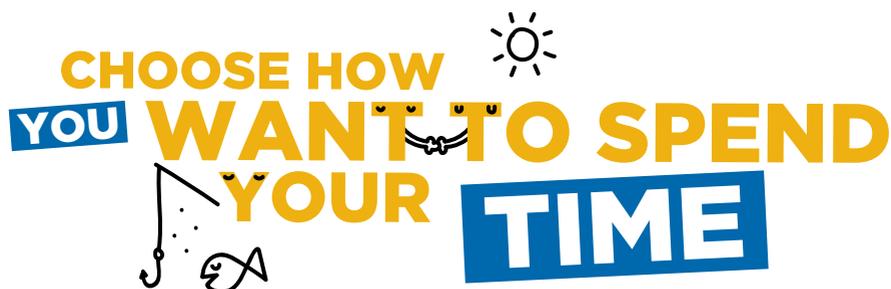
Your doctors and nurses might want to talk to you about advance care planning, to help you decide how you would like

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 parents 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.**



# LET IT ALL SINK IN

**We've covered a lot of ground in this book, so here's a quick recap of a few main points we've kept coming back to.**

Getting diagnosed with cancer can make your head spin, just when you need to take in a whole lot of new information. We hope this book has cleared up a lot of things for you, but in case you're still feeling a bit dazed and confused, here are a few things that we think are definitely worth remembering.

### **YOU'RE NOT ALONE**

No way. There is a huge amount of support available to you, as you'll find out in the coming months. There are all sorts of people you can talk to – from family and friends to social workers and clinical psychologists. And there are lots of young people who have – or have had – cancer, too. Getting in touch with them online or through support groups can really help if you're feeling isolated. The charities listed on page 178 might help you connect.

### **YOU'RE THE BOSS**

It can be easy to feel that you should just sit back and do as you're told throughout your treatment. But if you're worried or unhappy about something, or if you'd like to try or do something new, don't be afraid to speak up. It's your treatment, and your care team are there to listen.

### **ASK QUESTIONS**

Keep asking them. Ask some more. And then ask some more. If you want to know about anything at all, ask until you get an answer that makes sense. We guarantee your doctors and nurses won't be offended.

### **BEING HONEST HELPS**

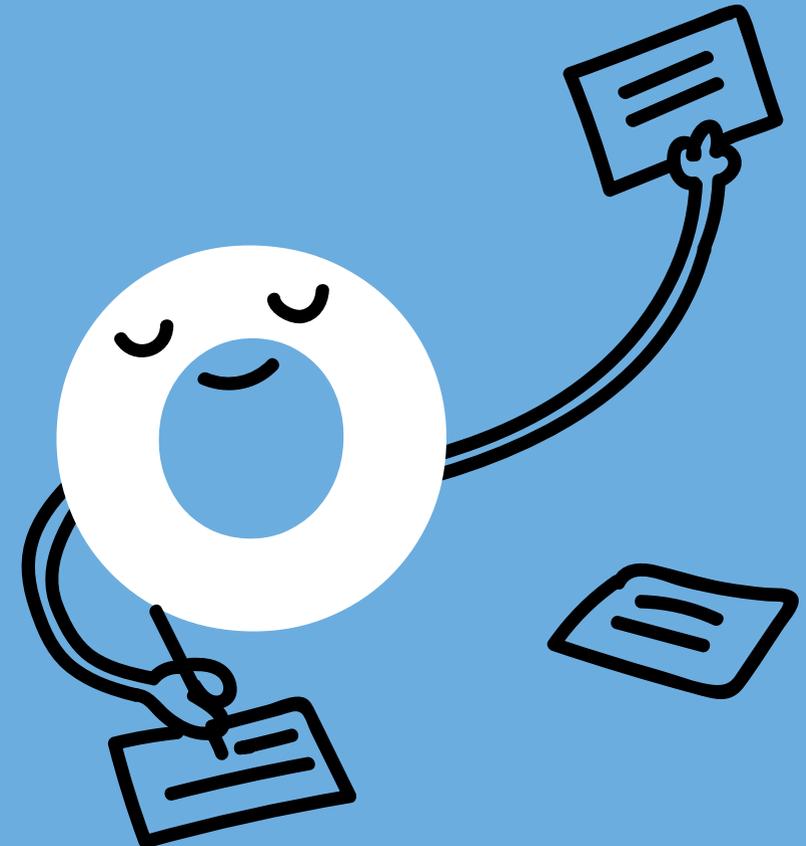
We've mentioned this one a lot. That doesn't mean it's easy, but it does mean it can make you feel a whole lot better. Cancer can do strange things to your emotions, friendships and relationships. So – when you feel ready – try and be open about what you're going through.



# NOTES

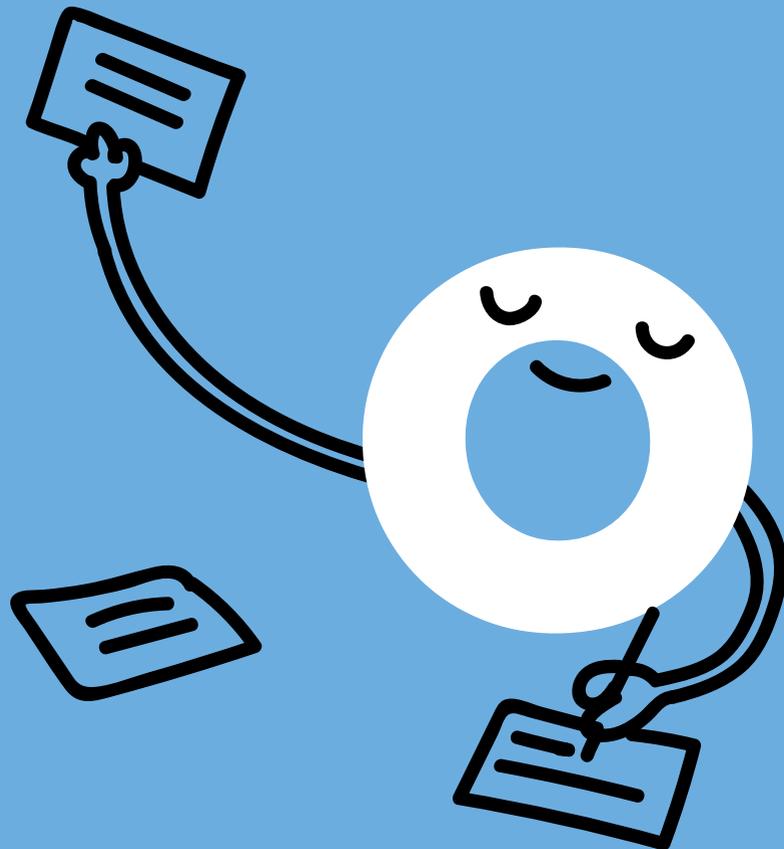
A series of horizontal dotted lines for writing notes.

# HANDY STUFF



# GLOSSARY (OR WHAT THE... DOES THAT MEAN?)

**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.**



And if you hear anything you're not sure about that isn't on this list, we'd love you to email us at: [information@teenagecancertrust.org](mailto:information@teenagecancertrust.org) so we can add it to the glossary on our website.

- **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

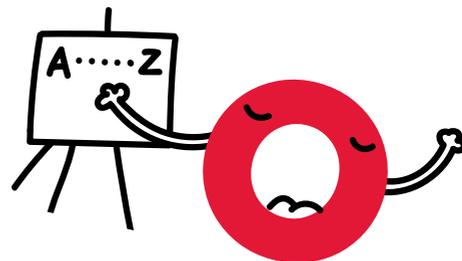
- **Benign** – The medical term for a growth in your body that isn't cancerous
- **Biopsy** – A procedure involving a small amount of tissue being taken from your body so cells can be studied under a microscope. Biopsies are usually done using an anaesthetic
- **Blood count** – The number of different 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
- **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, but what you really need to know is that 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
- **Diagnosis** – The identification of a disease
- **Donor** – A person who gives blood, body tissue or organs to be used by another person
- **External radiation** – A type of radiation (radiotherapy) treatment. It's 'external' because radiation is given from a machine outside of your body
- **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
- **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
- **HPV** – Humanpapilloma virus. 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
- **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
- **Intravenous (IV)** – Drugs, blood and other fluids that are given to you directly into a vein
- **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

**CHECK**  
**IF YOU'RE**  
**NOT SURE**



- **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
- **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
- **Oedema** – Swelling caused by a build-up of fluid in your body
- **Oncologist** – A doctor who specialises in treating cancer
- **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
- **Play specialists** - Experts in helping children to play in ways that help them cope, deal with anxieties, make friends and keep developing during cancer treatment. Play specialists usually work on paediatric wards
- **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
- **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
- **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
- **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
- **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
- **White blood cells** – The cells in your blood that help to fight infection

# DON'T FEEL LIKE TALKING? THESE CARDS CAN HELP

**At times during your treatment, you'll probably feel like being by yourself and not speaking to anyone.**

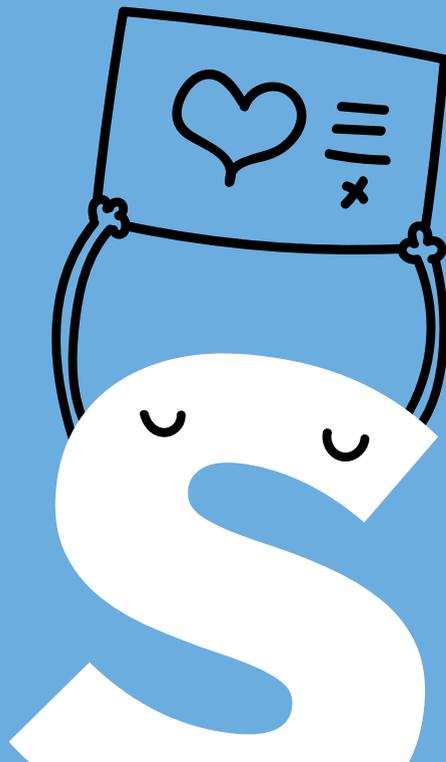
There might be times when you want people to do things for you but you struggle to ask for help.

Sometimes you might find that friends and family aren't sure what to do or say.

And maybe there are things you want to say but don't feel ready to talk about.

For all of those times, and for when you just want to say thank you, we've created these cards. Some are for particular people, others are more general. You can tear them out and put them in the post or wherever people will find them. And you can print them out from our website if you need more (search 'Don't feel like talking cards').

**Sometimes writing can be a lot easier than talking - but just as powerful.**

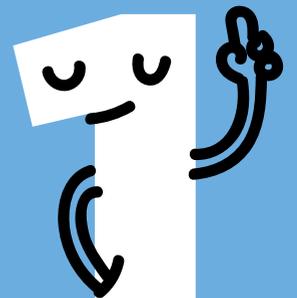


It's difficult to know what to say when people ask how they can help. But, if you think of things you need, try writing them on these cards. Then the next time someone asks what they can do, hand one of the cards over and talk it through.

Having friends around you can really help during cancer treatment. So these cards might be useful if you want to tell your mates you appreciate them and let them know what's going on.

IT'S  
**GREAT**  
TO HAVE  
**YOU**  
AROUND

THERE'S  
THIS  
**ONE**  
THING



**It means a lot to me to have you as a friend. I know things can be difficult at the moment and you might be worried about doing or saying the wrong thing, but I'd love you to...**

- Call me, email me, text me and message me. It's always good to hear from you, even if I don't feel up to replying straightaway
- Keep inviting me to things. I might not always make it, but I'll come whenever I can
- Come and hang out with me at hospital
- Come and spend time with me at home
- Send me things to make me laugh - like jokes, DVDs, photos and videos
- Talk about the stuff we've always talked about
- Let me know what's going on in your life
- Be honest about how you're feeling, and feel free to ask questions when you have them (I just might not want to answer them all)

**FROM** \_\_\_\_\_

**If you get a chance to do this one thing for me, it would make a real difference. I don't want to hassle you, but if you're able to help I'd really appreciate it.**

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**FROM** \_\_\_\_\_

Tired of explaining which cancer you have or what treatment you're having? Then these cards might come in handy.



Got something you'd like to say to your parents but don't fancy talking or can't find the words? No problem. Just reach for one of these cards.



**It gets pretty exhausting talking about cancer all the time.  
But I want you to know what's going on, so here are the basics...**

- I have... \_\_\_\_\_
- Which means that... \_\_\_\_\_
- The treatment I'm having is... \_\_\_\_\_
- Most of the time I feel... \_\_\_\_\_
- I'd prefer not to talk about... \_\_\_\_\_
- What I'd love you to do for me is... \_\_\_\_\_

**FROM** \_\_\_\_\_

**Sometimes I try and say something but can't find the right words or  
end up getting upset. So I want to give you this card to make sure you  
know how I'm feeling.**

- I know this is really tough for you and I wish you weren't so worried
- I really appreciate the help you give me
- I'm sorry I got angry at you
- Thanks for letting me do some things on my own.  
I know that's not easy for you
- Please try and remember I'll ask for help if I need it.  
I know you're there for me
- Thanks for being my taxi and my chef
- Don't forget to take some time for yourself. It's important
- Remember we can still do the stuff we've always done.  
I don't want everything to be about cancer

**LOVE** \_\_\_\_\_

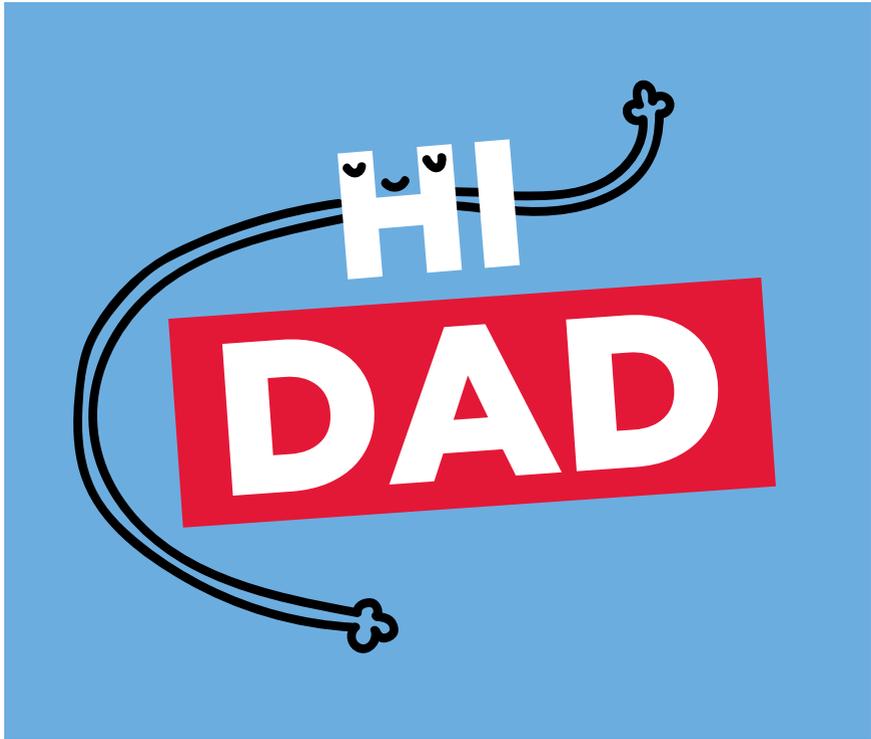
Got something you'd like to say to your parents but don't fancy talking or  
can't find the words? No problem. Just reach for one of these cards.

HI  
MUM



Got something you'd like to say to your parents but don't fancy talking or  
can't find the words? No problem. Just reach for one of these cards.

HI  
DAD



Sometimes I try and say something but can't find the right words or end up getting upset. So I want to give you this card to make sure you know how I'm feeling.

- I know this is really tough for you and I wish you weren't so worried
- I really appreciate the help you give me
- I'm sorry I got angry at you
- Thanks for letting me do some things on my own  
I know that's not easy for you
- Please try and remember I'll ask for help if I need it.  
I know you're there for me
- Thanks for being my taxi and my chef
- Don't forget to take some time for yourself. It's important
- Remember we can still do the stuff we've always done.  
I don't want everything to be about cancer

**LOVE** \_\_\_\_\_

**There might be times when you want to let people know that you're not feeling great, or that you need to be by yourself, or that you've got something on your mind. These cards are for those times.**

Leave them on your table if you're in hospital or somewhere people won't miss them if you're at home. And once you've used them once, tuck them into the back of the book so you can use them again.

Sometimes I try and say something but can't find the right words or end up getting upset. So I want to give you this card to make sure you know how I'm feeling.

- I know this is really tough for you and I wish you weren't so worried
- I really appreciate the help you give me
- I'm sorry I got angry at you
- Thanks for letting me do some things on my own.  
I know that's not easy for you
- Please try and remember I'll ask for help if I need it.  
I know you're there for me
- Thanks for being my taxi and my chef
- Don't forget to take some time for yourself. It's important
- Remember we can still do the stuff we've always done.  
I don't want everything to be about cancer

**LOVE** \_\_\_\_\_

**I'M NOT  
UP FOR  
TALKING  
RIGHT NOW**



KEEP YOUR  
**CARDS**  
HANDY

A simple line drawing of a hand holding a rectangular card with three horizontal lines representing text. A curved line extends from the bottom of the card, ending in a small smiley face.

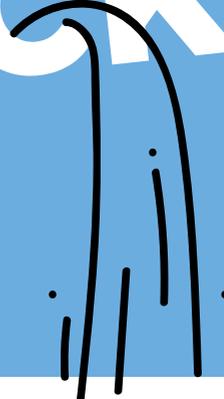
KEEP YOUR  
**CARDS**  
HANDY

A simple line drawing of a hand holding a rectangular card with three horizontal lines representing text. A curved line extends from the bottom of the card, ending in a small smiley face.

**I'M** FEELING  
TIRED

A cartoon character with a round body, a small head, and a large, drooping mouth. It has three 'Z's above its head, indicating it is tired or sleeping.

**I'M** FEELING  
SICK

A cartoon character with a round body, a small head, and a large, drooping mouth. It has a long, curved line extending from its mouth, representing a vomit stream.

**KEEP YOUR  
CARDS  
HANDY**

A stylized illustration of a hand holding a card. The hand is simple, with a thumb and index finger gripping the card. The card is white with three horizontal lines representing text. A curved line connects the hand to the word 'HANDY' in the text below.

**KEEP YOUR  
CARDS  
HANDY**

A stylized illustration of a hand holding a card. The hand is simple, with a thumb and index finger gripping the card. The card is white with three horizontal lines representing text. A curved line connects the hand to the word 'HANDY' in the text below.

I'D  
**LIKE**   
TO TALK TO A  
**DOCTOR** OR  
**NURSE**

Over the next few pages,  
we've included a range  
of cards you might want  
to give to friends, family  
or people on your care  
team, whenever the time  
feels right.

KEEP YOUR  
**CARDS**  
HANDY



I WANTED  
TO WRITE  
TO TELL YOU  
WHAT'S ON MY  
**MIND**



**THANK**  
**YOU**  
IT REALLY MEANS  
A LOT TO HAVE **YOU**  
**AROUND**



I hope you don't mind me writing it down, but it can be hard to explain it lots of times.

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**LOVE** \_\_\_\_\_

I hope you don't mind me writing it down, but it can be hard to explain it lots of times.

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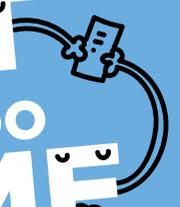
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**LOVE** \_\_\_\_\_

I'D  
**LOVE IT**  
IF YOU COULD DO  
THIS FOR ME



**I DON'T FEEL LIKE  
TALKING RIGHT NOW,  
BUT IT'S IMPORTANT  
TO ME THAT YOU KNOW**

**THIS**



If you get a chance to do this one thing for me, it would make a real difference. I don't want to hassle you, but if you're able to help I'd really appreciate it.

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**FROM** \_\_\_\_\_

I hope you don't mind me writing it down, but it can be hard to explain it lots of times.

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**LOVE** \_\_\_\_\_

HERE'S THE  
**EDITED**  
VERSION OF  
WHAT'S HAPPENING  
TO ME



HERE'S THE  
**EDITED**  
VERSION OF  
WHAT'S HAPPENING  
TO ME



I hope you don't mind me writing it down, but it can be hard to explain it lots of times.

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**LOVE**

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I hope you don't mind me writing it down, but it can be hard to explain it lots of times.

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**LOVE**

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# 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.**

For starters, we'd recommend:

- Teenage Cancer Trust (obviously...)  
**[www.teenagecancertrust.org](http://www.teenagecancertrust.org)**
- Cancer Research UK  
**[www.cancerresearchuk.org](http://www.cancerresearchuk.org)**
- Citizens Advice  
**[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)**
- CLIC Sargent  
**[www.clicsargent.org.uk](http://www.clicsargent.org.uk)**
- Government website  
**[www.gov.uk](http://www.gov.uk)**
- Macmillan Cancer Support  
**[www.macmillan.org.uk](http://www.macmillan.org.uk)**
- NHS choices  
**[www.nhs.uk](http://www.nhs.uk)**
- CEOP (for advice on staying safe online)  
**[www.thinkuknow.co.uk/14\\_plus](http://www.thinkuknow.co.uk/14_plus)**

And we'd also recommend heading to our website, where you'll find contact details for a whole host of organisations that can help with issues like fertility, drugs, smoking, alcohol, money, insurance and your rights. Simply head to **[www.teenagecancertrust.org/usefulcontacts](http://www.teenagecancertrust.org/usefulcontacts)**

If you have any queries, or would like to know more about the support Teenage Cancer Trust can offer young people, please contact **[support4you@teenagecancertrust.org](mailto:support4you@teenagecancertrust.org)**



# HOW WE PRODUCE OUR CANCER INFORMATION

Young people with cancer were involved in every stage of creating this book. They helped us choose the writer. They told us what they wanted to read. And they checked out what was written and suggested changes too.

Why do we work like this? Because we don't just care about producing accurate information. We care about producing accurate information that's as useful as possible for young people. And to make sure that happens, young people have to be at the heart of the process.

Accuracy is vital too, of course. So we started by only using trusted sources, and we then got everything reviewed by specialist doctors, consultants, nurses, psychologists and youth workers. 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.

## THE INFORMATION STANDARD

Teenage Cancer Trust is a certified member of The Information Standard, ensuring we're writing to strict quality control guidelines and providing information you can trust.

This means we have undergone a rigorous assessment to check that all of the information we produce is clear, accurate, balanced, evidence-based and up-to-date. To find out more about The Information Standard, visit: [www.england.nhs.uk/tis](http://www.england.nhs.uk/tis)



## WANT TO GET IN TOUCH?

If you're a young person who has cancer and would like to help develop our materials, we'd love to hear from you. Please email:

[information@teenagecancertrust.org](mailto:information@teenagecancertrust.org)

To find out more about the evidence sources we use, please email:

[references@teenagecancertrust.org](mailto:references@teenagecancertrust.org)

This book was first printed in June 2015, and reviewed and then reprinted in August 2018. It's due to be reviewed again in 2021, but if you spot anything you're not sure about, or have any queries, comments, ideas or concerns, please do email: [information@teenagecancertrust.org](mailto:information@teenagecancertrust.org)

# ACKNOWLEDGEMENTS

## Thank you to every single person who helped develop this book. We really hope we haven't missed anyone...

Thank you to our team of experts, Teenage Cancer Trust employees and all of the fantastic young people and support staff who gave such valuable input, especially those who attended workshops at the Royal Albert Hall and from our Teenage Cancer Trust units in Cardiff, Glasgow, Sutton and Birmingham, for all their help.

- **Dr Louise Soanes**  
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- **Vicky Britton**  
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**If you have any queries, or would like to know more about the support Teenage Cancer Trust can offer young people, please contact [support4you@teenagecancertrust.org](mailto:support4you@teenagecancertrust.org)**

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- Cancer Research UK – [www.cancerresearchuk.org](http://www.cancerresearchuk.org)
- CLIC Sargent – [www.clicsargent.org.uk](http://www.clicsargent.org.uk)
- Macmillan Cancer Support – [www.macmillan.org.uk](http://www.macmillan.org.uk)
- NHS Choices – [www.nhs.uk](http://www.nhs.uk)
- National Institute for Health and Care Excellence (NICE) – [www.nice.org.uk](http://www.nice.org.uk)



# IN CASE YOU'RE WONDERING ABOUT US...

## We're Teenage Cancer Trust, and we're here for young people with cancer.

We believe every young person should get the best possible care and support from the moment the word cancer is first mentioned.

So we develop specialist cancer units. We fund nurses and youth support coordinators. We bring young people together to share their experiences and gain support from each other. We fund training courses to help health professionals understand how cancer affects young people.

And we publish information about cancer. The sort of information you'll find in this book. Honest answers. Sound advice. Just like it says in the title.

To find out more about our work – and about how you can help us to keep doing what we do, head to [teenagecancertrust.org](http://teenagecancertrust.org). Our website includes personal stories from young people.

Would your school and friends benefit from knowing more about cancer and what it's like to be a young person with cancer? Search for 'Mates Matter' on our website.



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