



# What happens when you are diagnosed with cancer

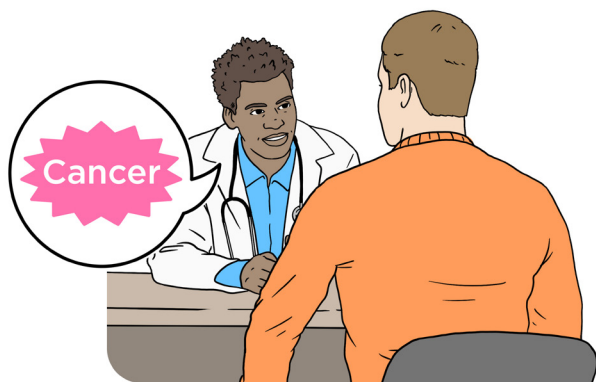
**easy read**



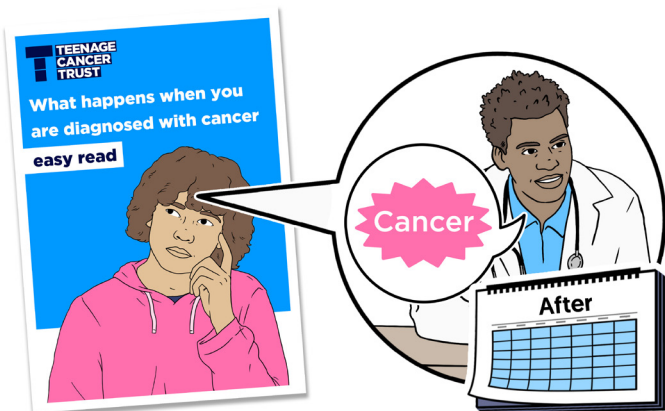
# What is this booklet about?



This booklet is for all young people aged 13 to 24 who have got a cancer **diagnosis** or who are having cancer treatment.



When a doctor tells you that you have cancer, this is called being **diagnosed**.



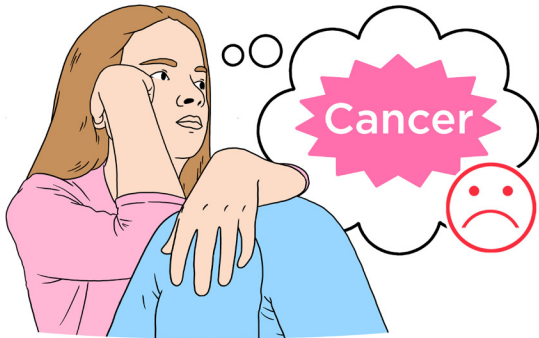
This booklet is about what happens next after you have been diagnosed with cancer.



You will find out about the different people in your care team who will be looking after you.



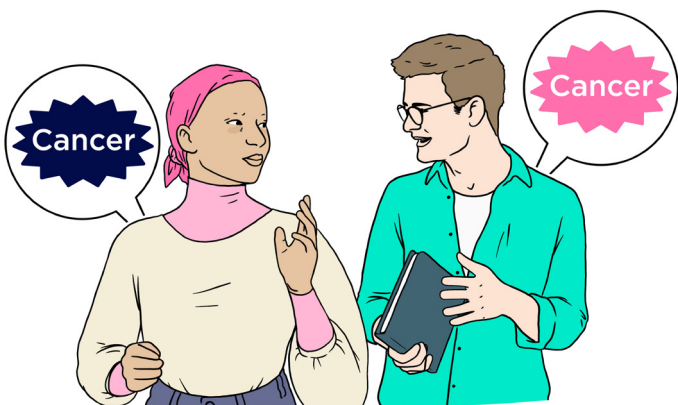
And you will learn about what to expect from staying in hospital.



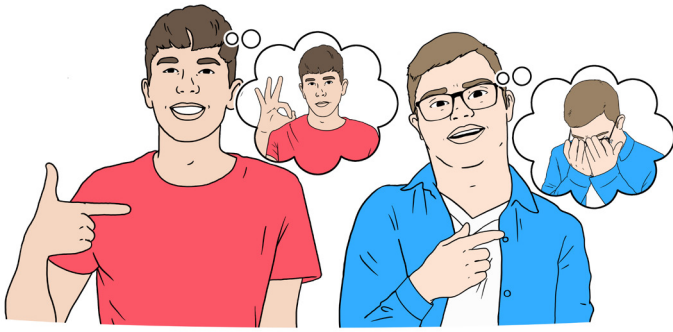
Finding out you have cancer can be a scary time.



During your experience of cancer you might meet other young people having a similar experience to you.

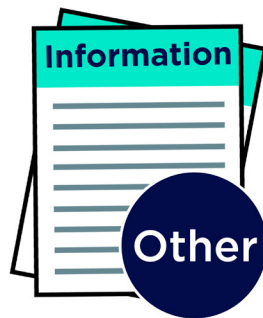


You might also meet young people who are having a very different experience to you.

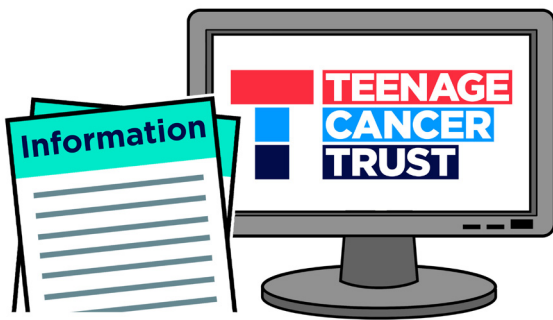


Every young person's experience of cancer is different and that is OK.

## Where can I find more information?

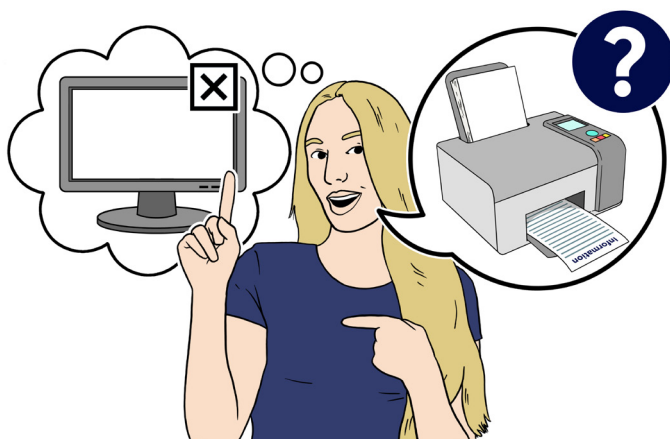


This booklet is just a starting point when it comes to information about your cancer diagnosis and what to expect. This means there is more information you can find.



There is lots more information and support available on our website:

[teenagecancertrust.org](https://teenagecancertrust.org)



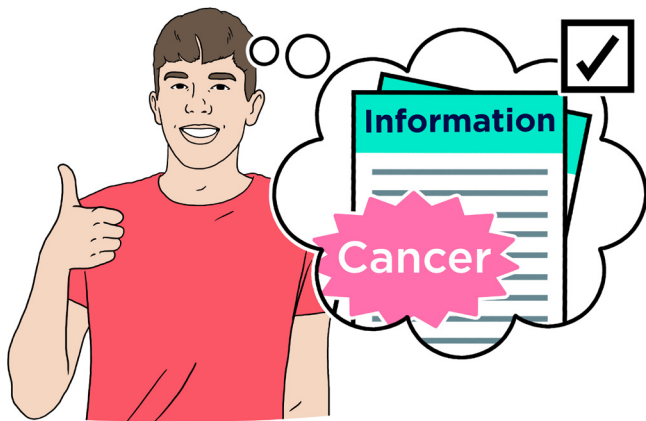
If you are not able to access information online you can ask your **care team** for printed information from Teenage Cancer Trust or other charities.



Your **care team** are the doctors and nurses who take care of you and help with your cancer treatment.



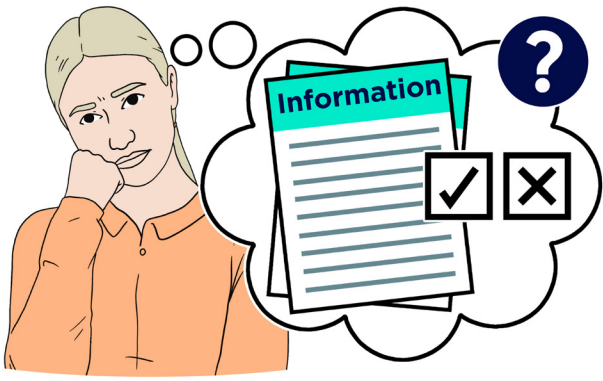
If you are finding it difficult to understand any of the information you read about your cancer diagnosis or treatment, you can ask your care team to explain it to you.



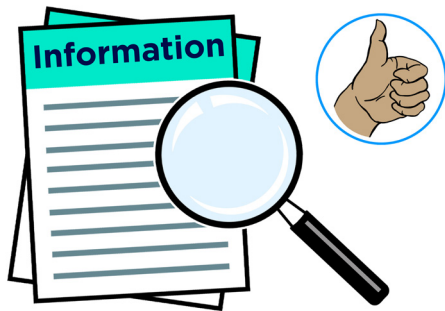
It is important you understand what to expect from your diagnosis and treatment. This could be things like what kind of treatment you may have and who will support you.



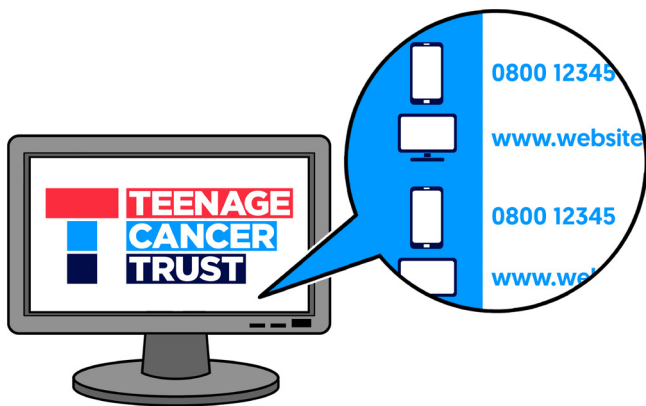
It is your choice how much information you want to know about your diagnosis and treatment.



Sometimes it is hard to know what information you can trust. You may worry that something you have read may not be true.



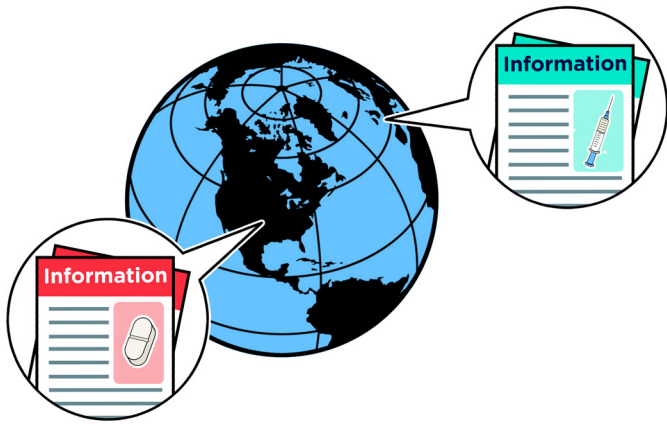
Here are some tips to help you know what information to trust:



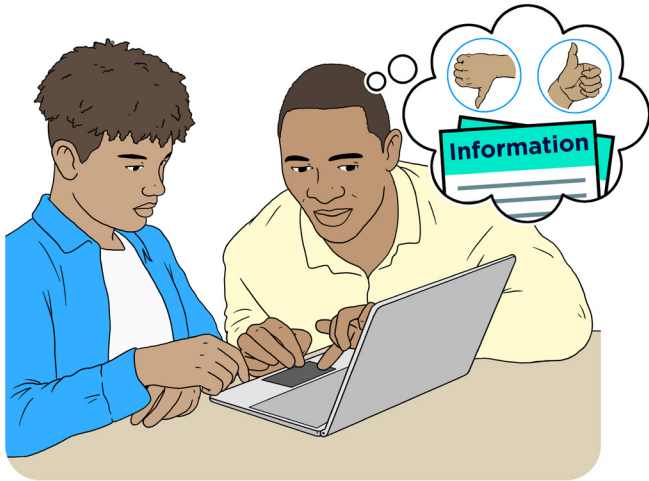
■ We have a list of useful contacts on our website which tells you about other organisations who might be able to help you.



■ Try to read information from organisations that are in the UK.



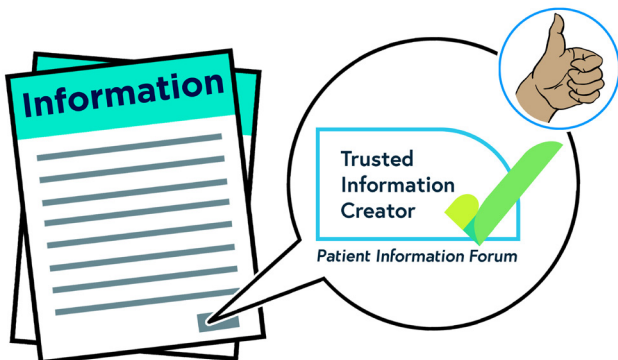
Types of treatment and medical care can be very different across the world and information from different countries might not be right for someone in the UK.



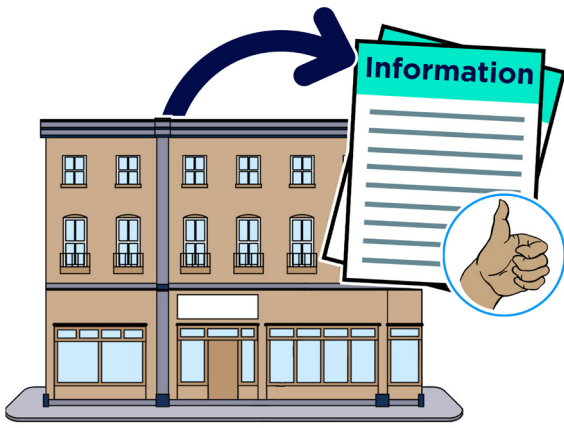
- ■ Ask someone you trust to help you look for information. They can also help you decide if the information is right for you, or not.



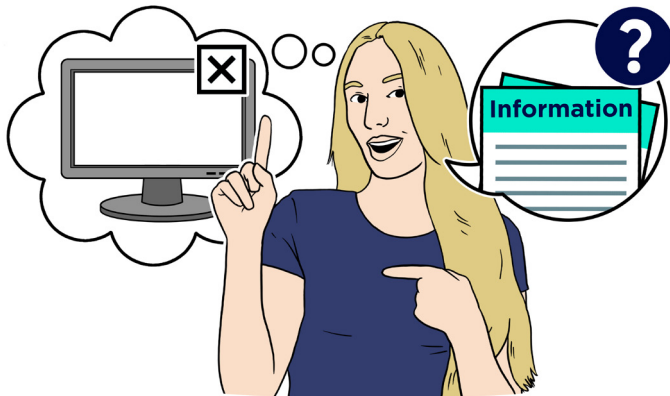
You might want to ask your care team, your carer, or someone else you trust.



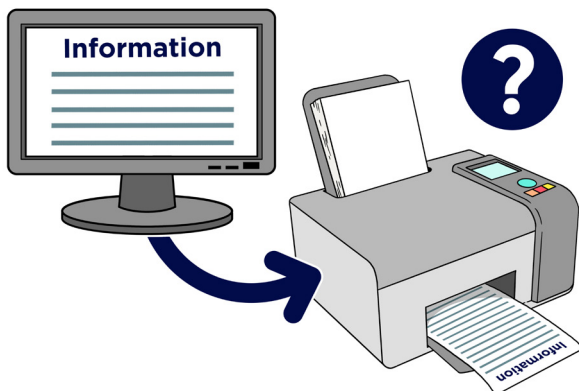
- ■ You can trust information that has the **Patient Information Forum** (PIF) logo, sometimes called the PIF tick.



The **Patient Information Forum** (PIF) is an organisation that supports other organisations that provide health information you can trust.

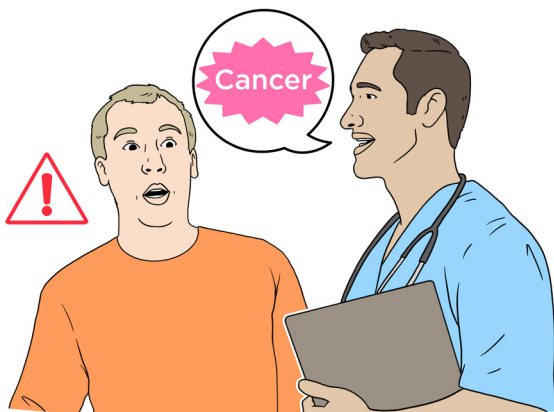


If you do not want to look on the internet for information, you can ask your care team for other printed information booklets about cancer.



You can also ask them to print out information from a web page for you.

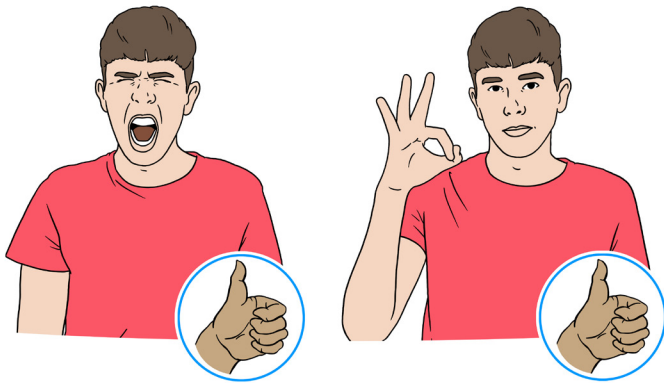
## Being diagnosed with cancer



Being told you have cancer can feel like your whole world has turned upside down. Everyone reacts differently, and there is no right or wrong way to react.



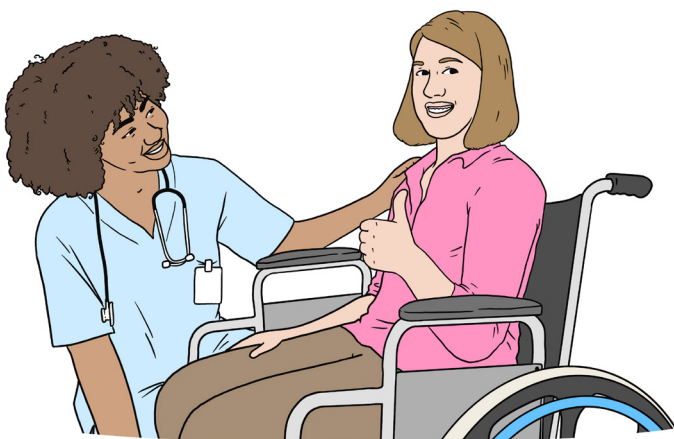
You might be feeling angry, shocked, scared, guilty, or **numb**, this is when you do not feel anything.



You might be feeling one, all, or none of these emotions. However you are feeling right now is OK.



It is important to know it is not your fault and you are not alone.



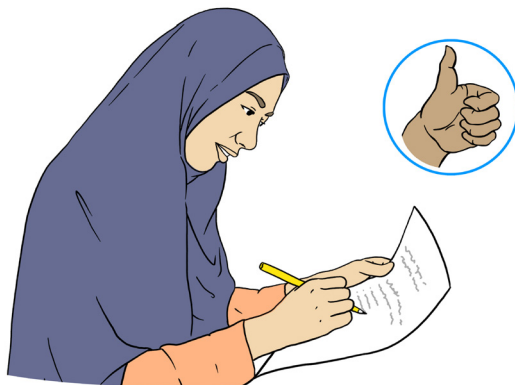
There is lots of support available and you will meet plenty of people whose job it is to help you through your experience of cancer diagnosis and treatment.



It can be hard to take in a lot of complicated information in one go. Do not feel embarrassed or worry about asking too many questions.



Your care team will answer any questions you have. It is important to make sure you understand what is happening.



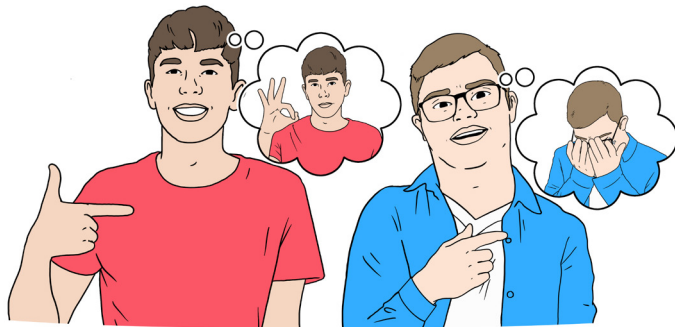
Making notes can help you remember things you have been told.



You can also ask if it is OK to use your phone to record what is said.

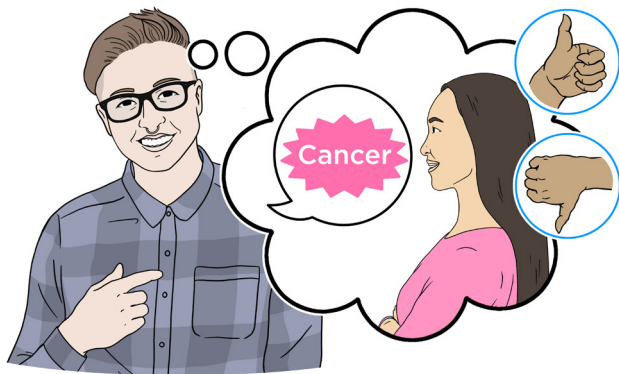


You might meet other young people who are having a similar experience of cancer to you, or they may be having a different experience.

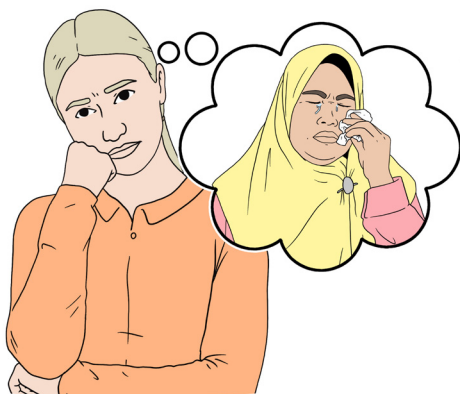


Remember, everyone's experience of cancer and treatment is different, and some people may feel differently than you do.

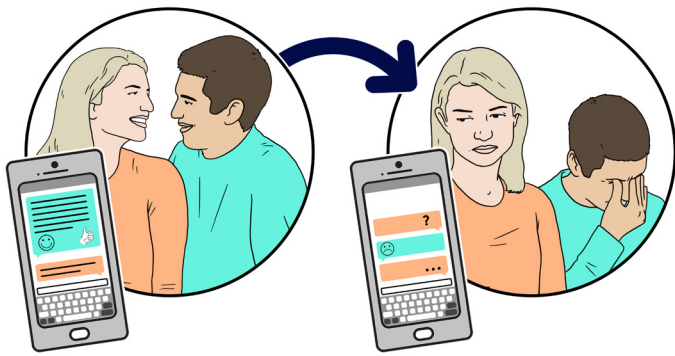
## Talking about cancer



How you talk about your cancer diagnosis and who you tell is completely up to you. It is your experience and your choice.



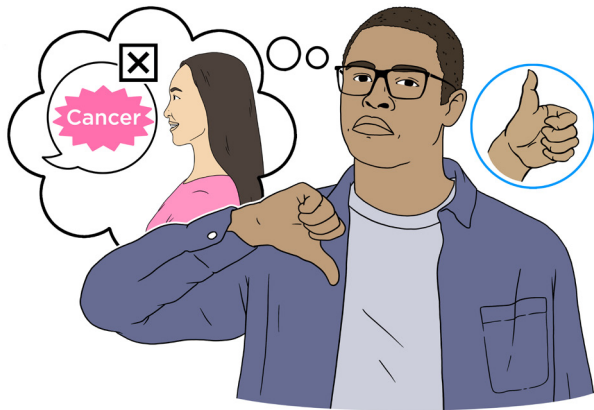
You might be worried about how people will react when you tell them about your diagnosis.



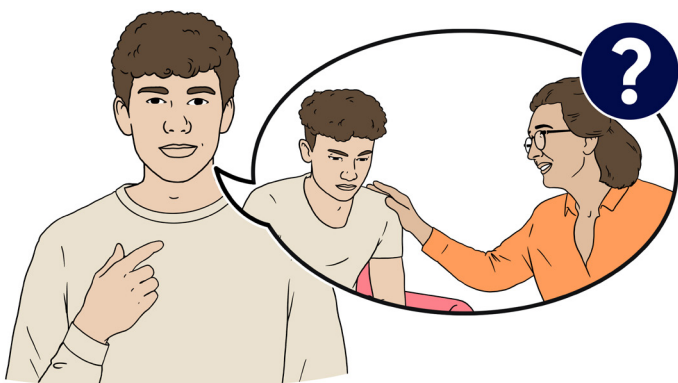
You might feel scared that your relationships, or the way people treat you, will change.



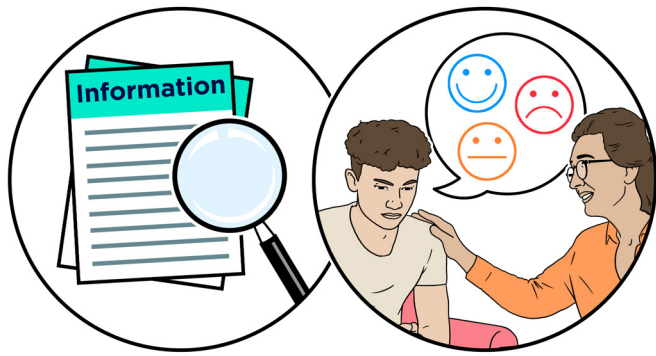
It can be helpful to tell your friends and family about how you are feeling and how they can help you.



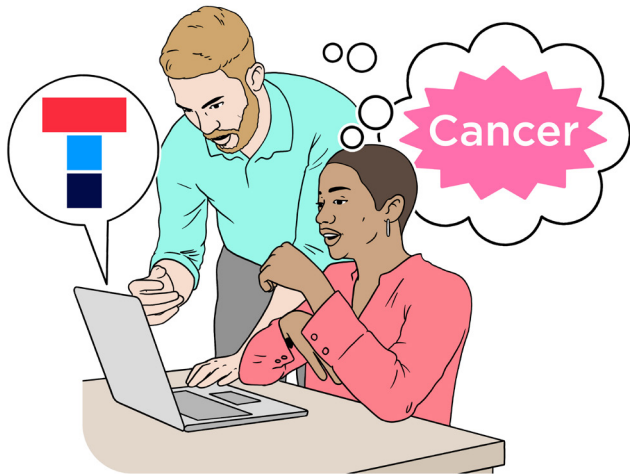
But you are in control of what you tell people about your cancer and your treatment. If you do not want to share something then you do not have to.



If there is a person or people that you would like more support from, it might help to let them know how you feel.



You could suggest some examples of how they can support you if they want to. This could be things like helping you find information, or talking to you about your feelings.



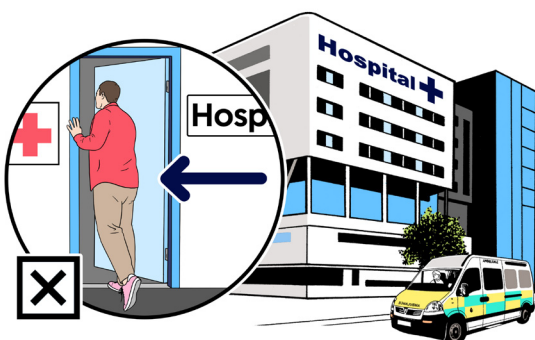
If your family or friends want to learn more about cancer they can check our website.

[teenagecancertrust.org/information](https://teenagecancertrust.org/information)

## What to expect from staying in hospital



You might not have spent a night in hospital before.

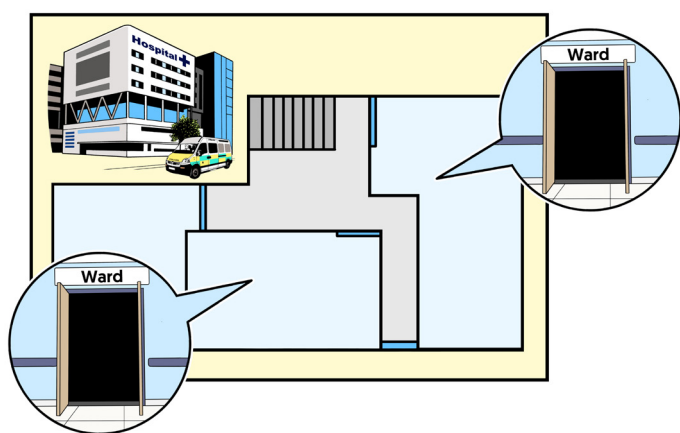


Or you might not have even been inside a hospital before you were diagnosed with cancer.

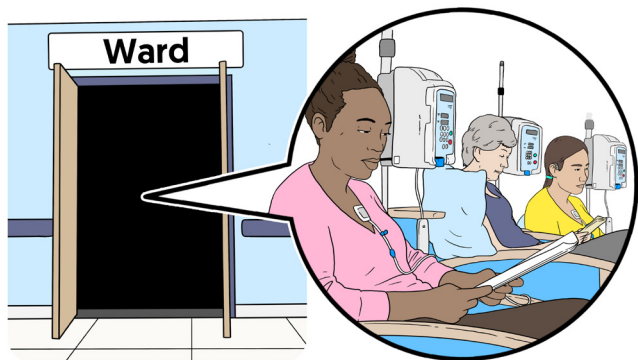


Hospitals can be big and busy places with a lot of people and sounds, so it can help to know what to expect before you have to spend time in hospital.

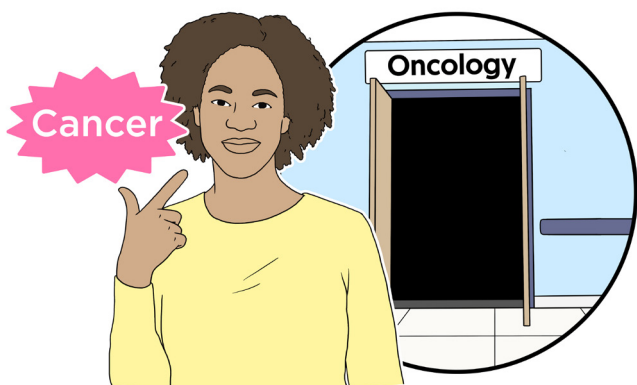
## How do hospitals work?



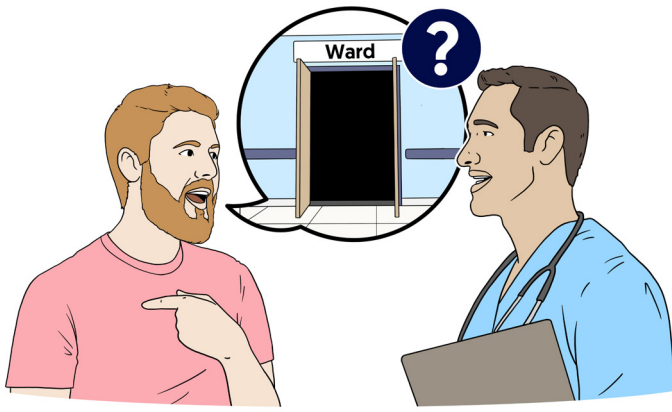
Hospitals are split up into different sections, called **wards**.



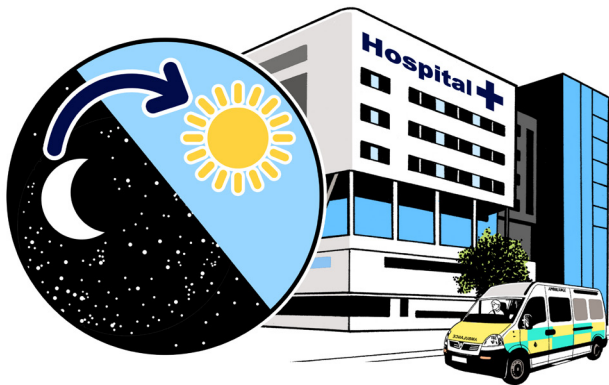
**Wards** are different areas of the hospital where people with the same or similar conditions are treated.



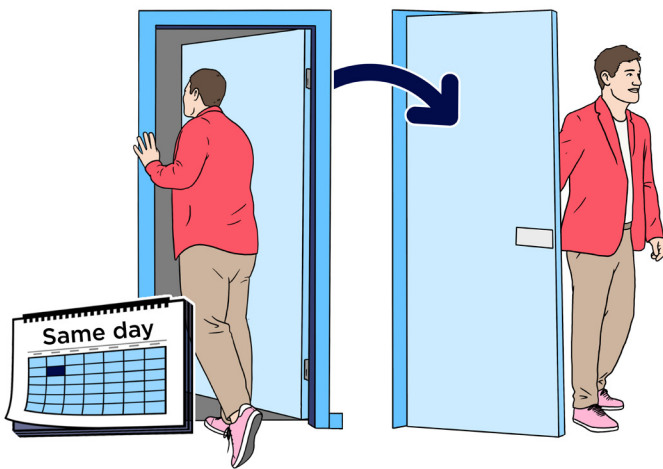
Cancer patients are usually treated on an **oncology** ward. **Oncology** is the area of medicine that diagnoses, treats and studies all types of cancer.



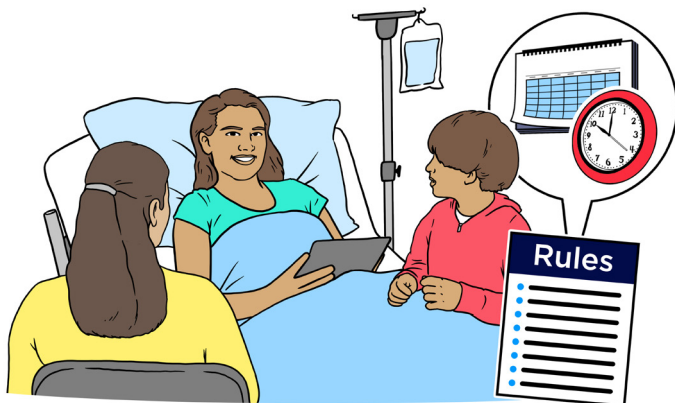
You might be on a different type of ward. You can always ask your care team if you are not sure why you are in the ward you are.



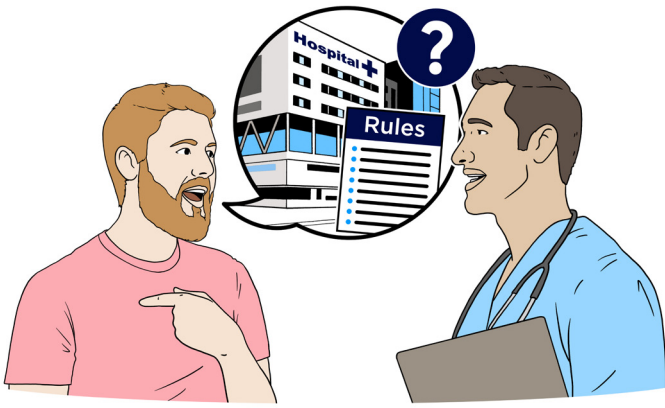
If you are staying in hospital over night, you are called an **inpatient**.



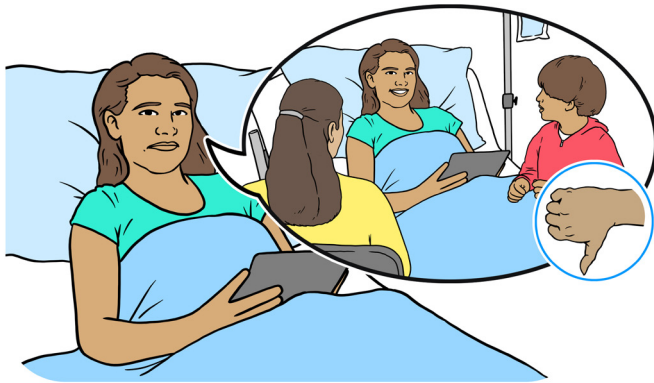
If you are only going in to hospital for an appointment, or for part of the day and then going home, you are called an **outpatient** or a **day patient**.



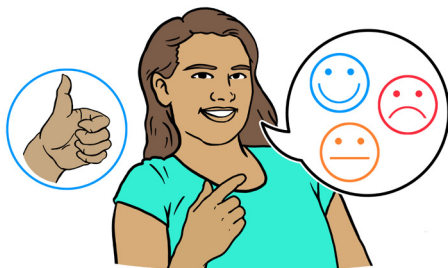
Each hospital will have different rules about when people can visit you.



Ask your care team to let you know what the rules are in your hospital.



It is OK to say you do not want visitors, or that you are not feeling well enough for visitors.



It is always better to be honest about how you are feeling and your friends and family will hopefully understand.

## Top tips from young people about staying in hospital



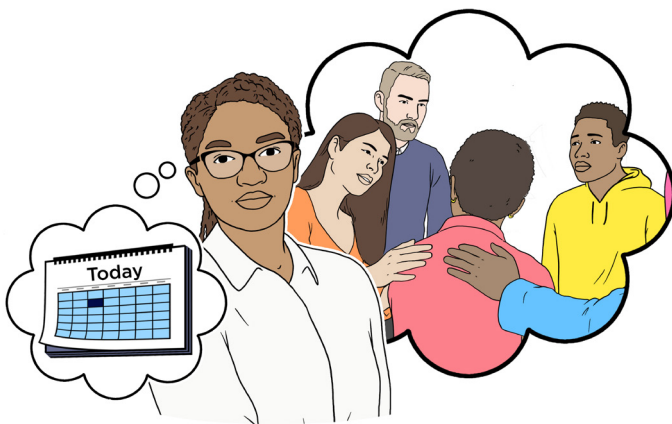
Hearing from other young people who have been through similar experiences with cancer diagnosis and treatment can be really helpful.



So we asked them for their top tips about staying in hospital. Their top tips are:



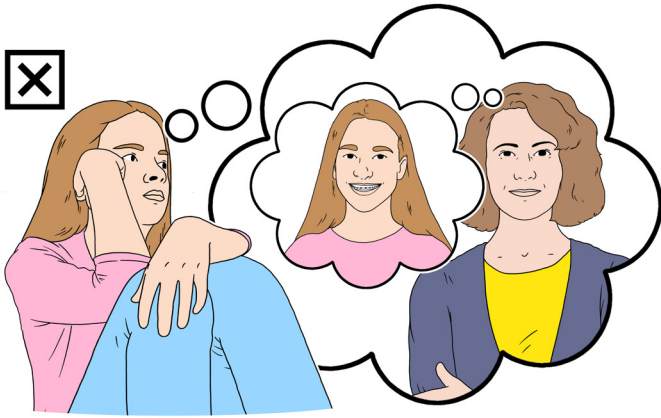
■ ■ Do not be afraid to ask questions



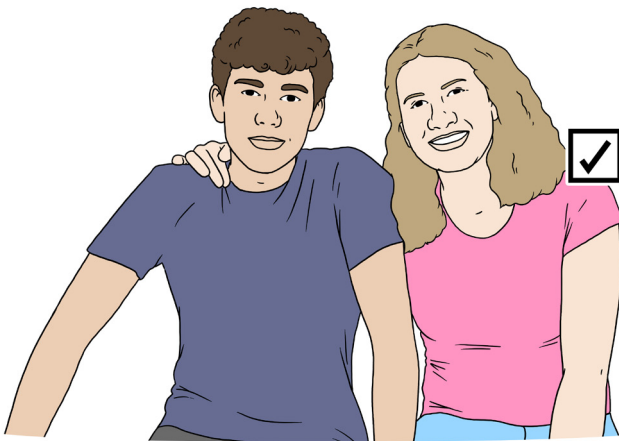
■ ■ Take each day as it comes and know that you are not alone



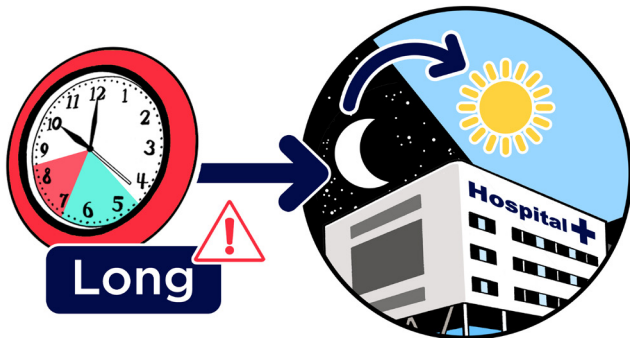
■ ■ Talk to people! Your care team are all there to help you and they can really help cheer you up when you need it



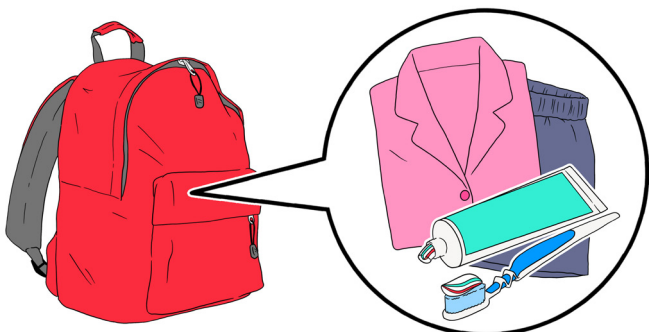
■ ■ Do what is best for you, try not to worry about what other people think



■ ■ If possible, have somebody you love and feel comforted by with you when you can



■ ■ Day patient sessions can go on longer than expected sometimes so you might need to stay the night.



■ ■ Bring a bag with you to appointments that has things you need to stay overnight

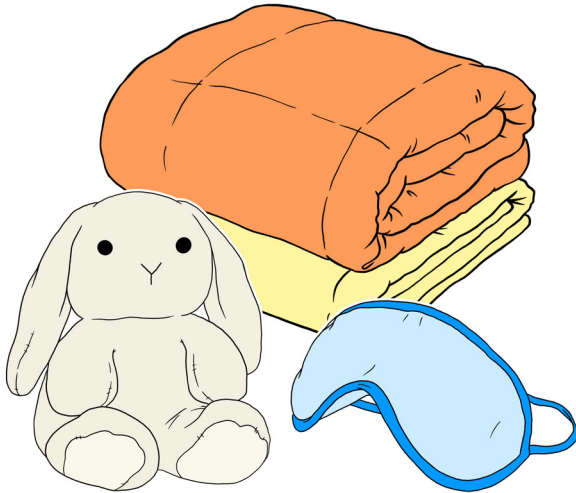


We also asked young people:  
“what were the most useful things  
you took with you to hospital?”

These are their answers:

### Comfy things

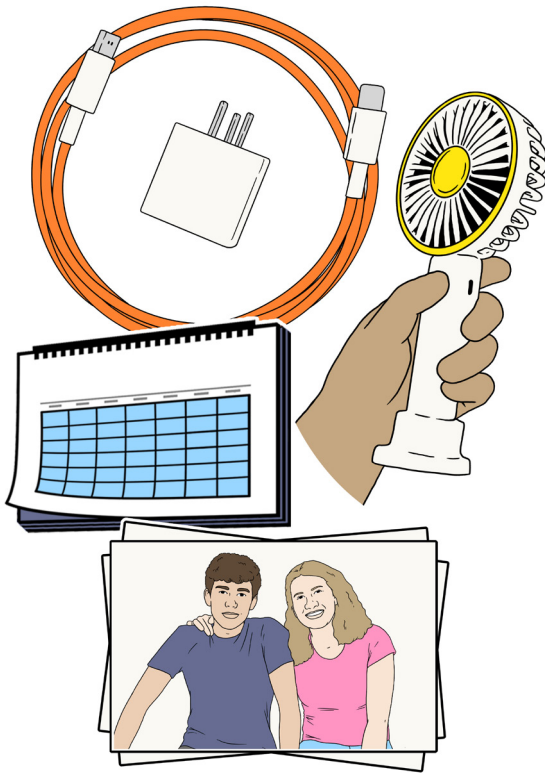
- Duvet, pillow and/or blanket from home
- Sleep mask – this might help you sleep during the day
- Soft toy



### Clothes

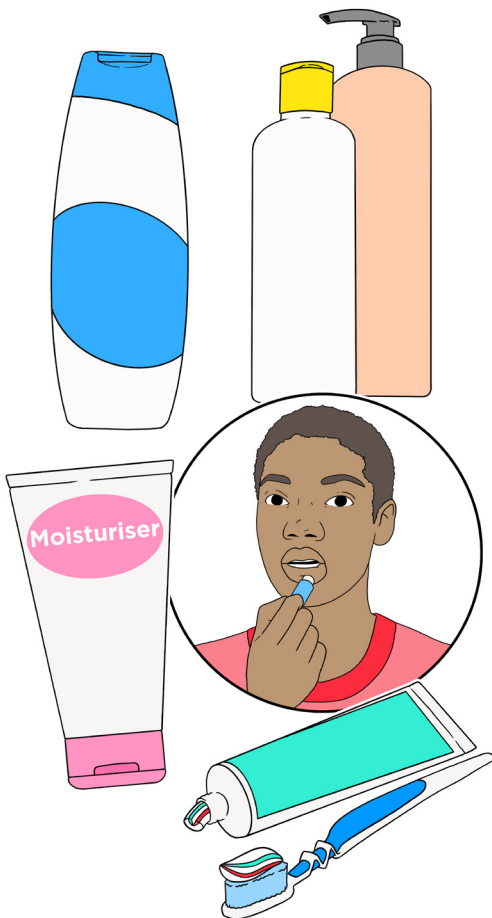
- A few sets of pyjamas – it is good to have warmer and cooler options
- Dressing gown and slippers or sliders for if you want to go for a walk inside
- Comfy clothes and shoes for when you want to go for a walk outside – something like a tracksuit and trainers





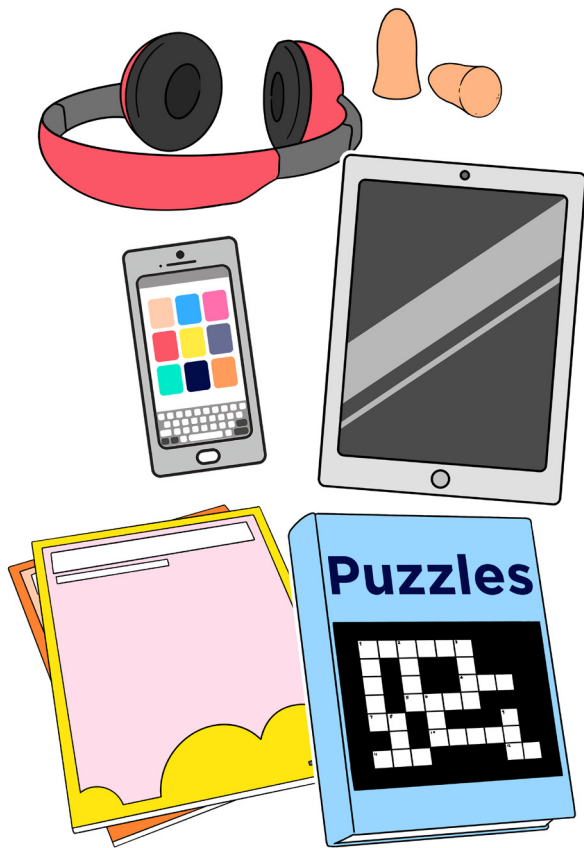
## Useful things

- Extra long phone charging cable – plugs might be far away from your bed
- Calendar – you can lose track of time when you are sleeping a lot
- Photos – these might be of your friends and family or pets
- Mini fan – in case you get too warm



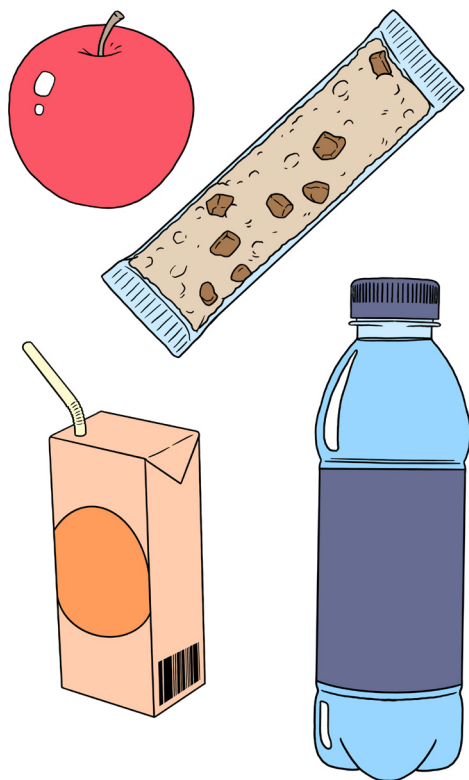
## Self care

- Soft toothbrush or a child's toothbrush – cancer treatment like **chemotherapy** can make your mouth very sensitive
- Wash products that are gentle on your skin – do not bring your favourites, you might not enjoy them when you finish treatment!
- Moisturiser and lip balm – chemotherapy can make your skin very dry



## Things to do

- Headphones or earphones - to listen to music or watch TV
- Earplugs - to block out noise
- Something you can watch films or TV shows on
- Books and magazines
- Things to distract you - like puzzles, a book of crosswords or a colouring book



## Food and drink

- Snacks and drinks - this can be especially useful if you have a special diet or have food allergies that might mean what you can eat is limited
- Big water bottle so you do not have to fill up too often

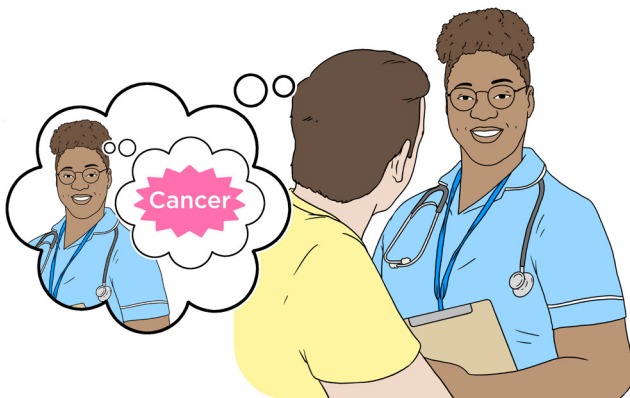
# Who will I meet?



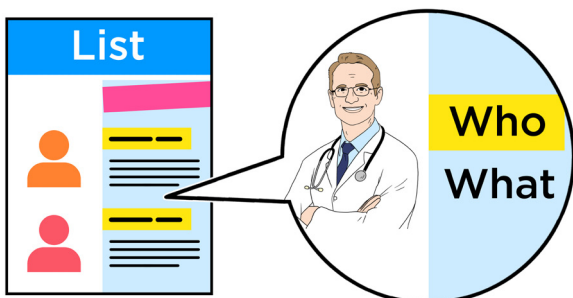
You will be treated by a team of experts who specialise in different areas of cancer. All of these people have important jobs in looking after you.



You will probably meet a lot of people and it can be hard to remember what they all do.

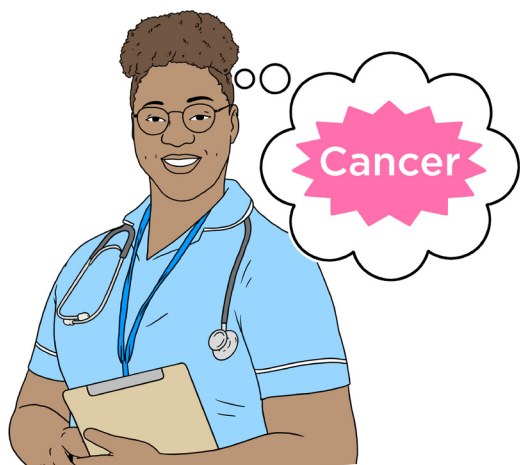


You will not meet them all in one go but it can be helpful to have an idea of who each person is when you do.



We have made a list of different experts who might help look after you. It will tell you their job title and a little bit about what they do.

List of experts who might help you:

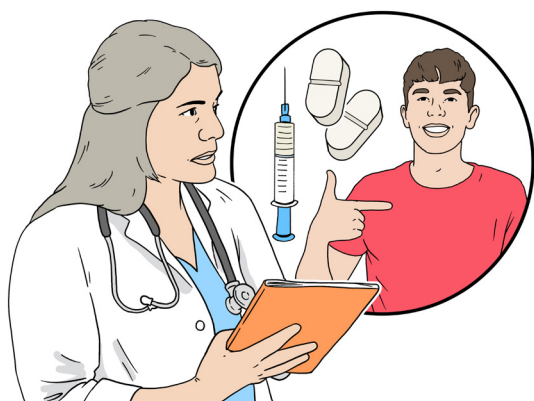


## Clinical Nurse Specialist (CNS)

An expert nurse who focuses on cancer treatment.

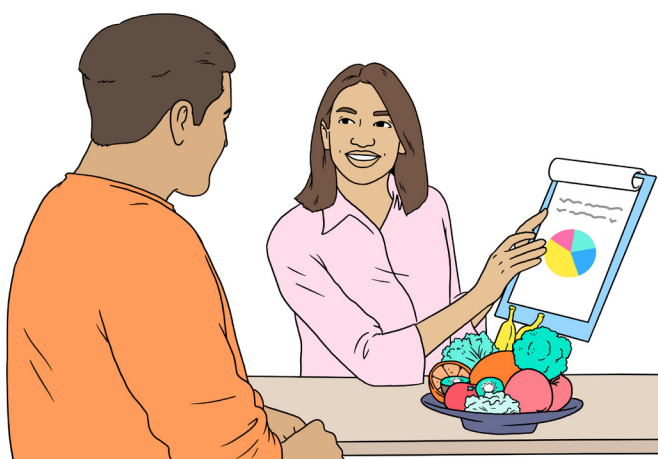


They can give you advice and practical support, and they will be there for you if you need someone to talk to. They might also be called your **keyworker**.



## Consultant

A **specialist** doctor. **Specialist** means they are experts in particular areas of medicine. The consultants are in charge of your overall treatment.



## Dietitian

An expert who can look at your diet and help you plan what to eat.

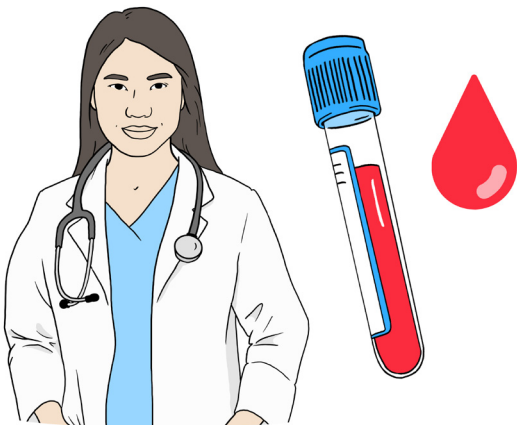


## General Practitioner (GP)

Your GP is your family doctor.



You might stay in contact with your GP throughout your treatment, as they can help you make decisions about things like where you want to be treated.



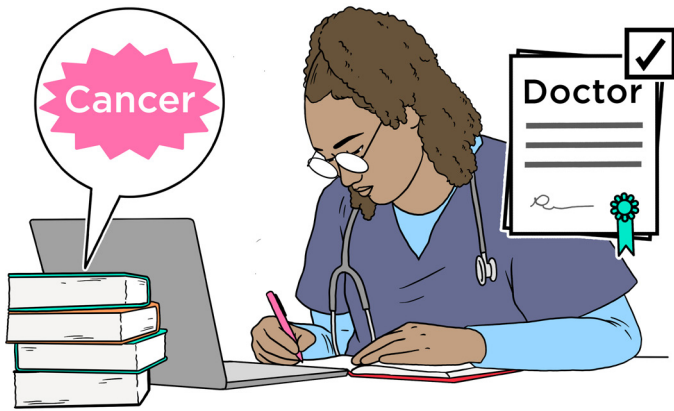
## Haematologist

A doctor who specialises in blood cancer and other blood problems.



## Healthcare assistant

A healthcare worker who supports nursing staff with checking on patients and helping with treatment.



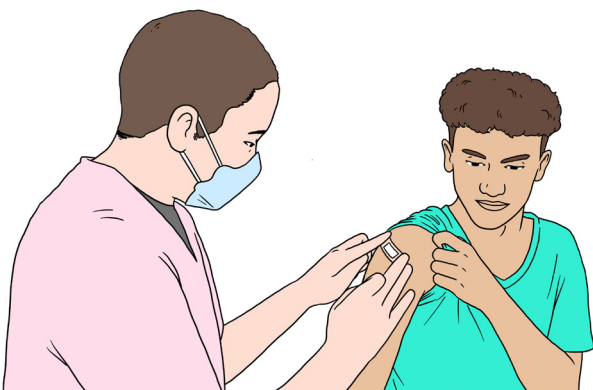
## Junior doctor

Qualified doctors who have a medical degree and are training to become an expert in an area of medicine, like cancer.



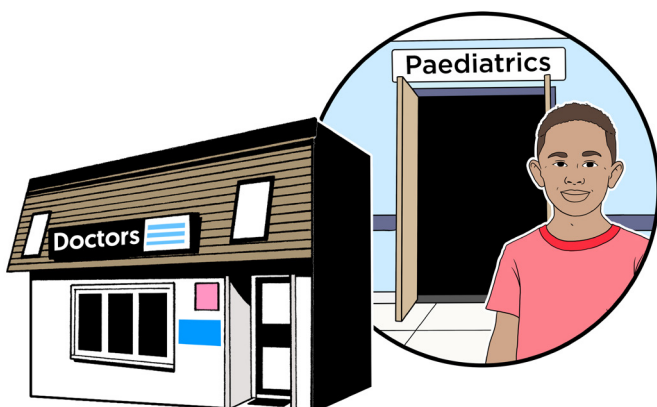
## Multi-Disciplinary Team (MDT)

The group of health professionals who work together to diagnose, treat and care for young people.



## Nurse

Nurses give direct patient care and can work in many different places.



They might work in particular areas like a GP practice, or **paediatrics**, this means treatment and care for children.

## Occupational therapist

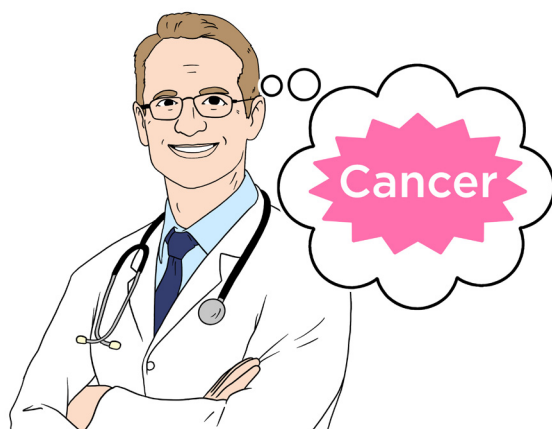
Cancer can affect your ability to take part in life as you normally would. An occupational therapist can help you to do what you want and need to do, to feel like yourself.

Occupational therapists work with you through your experience of cancer, and help you to improve your ability to do everyday tasks or activities.

They can help you make plans, set goals, and talk about any problems you are having.

## Oncologist

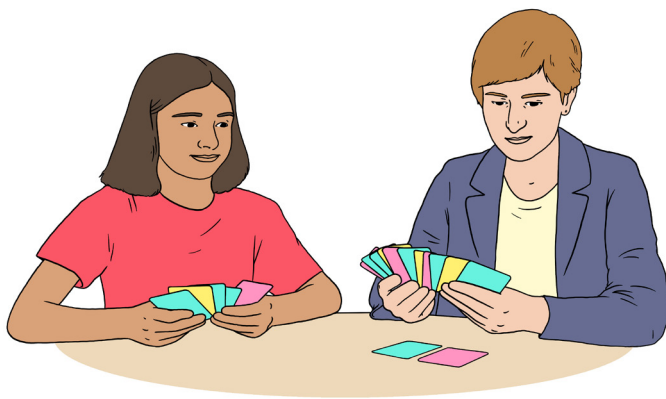
A doctor who specialises in treating cancer.





## Palliative care team

This is a team of healthcare workers who help you with your cancer symptoms and help you manage any pain.

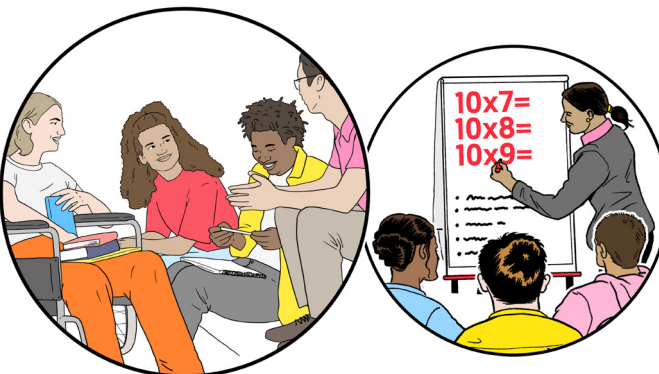


## Play specialist

Play specialists usually work on children's wards. They are experts in helping children and young people play in ways that help them deal with **anxiety**.



**Anxiety** means lots of feelings of worry and being scared.

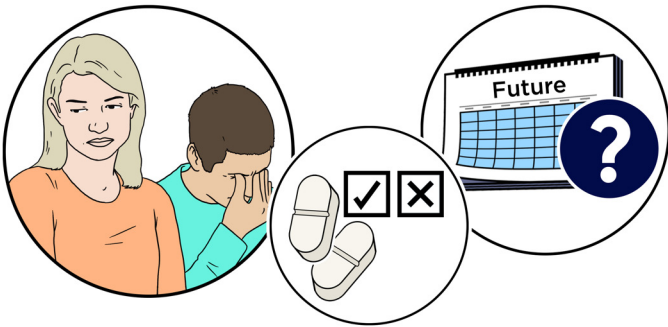


Play specialists help young people to make friends, and keep growing and learning during cancer treatment.

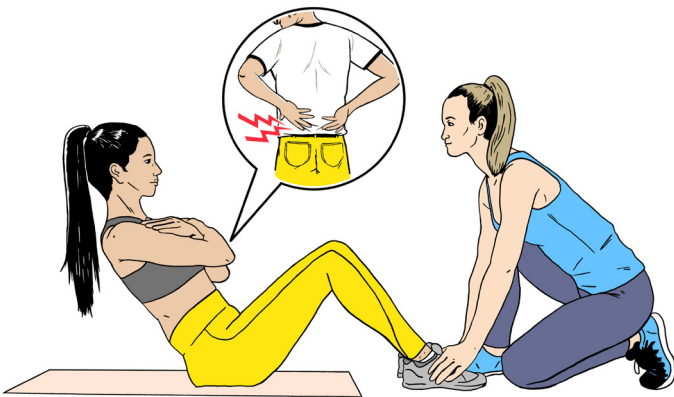


## Psychologist and/or counsellor

A trained professional who can help you deal with difficult feelings. You can talk to them about how you are feeling.

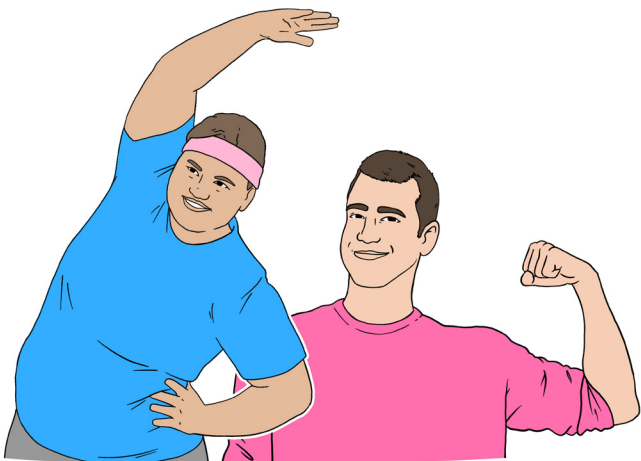


They can also help you with problems in relationships, decisions about your treatment and worries about the future.



## Physiotherapist (physio)

Experts in helping with **physical** problems that may be caused by cancer and its treatment. **Physical** means your body and how it moves.



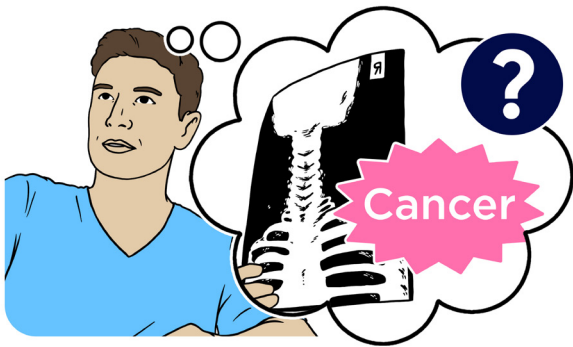
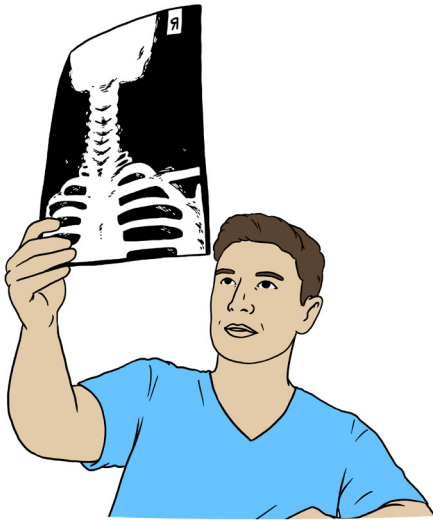
Physiotherapists can help you get back movement and strength in your body if you have lost some because of cancer or your treatment.



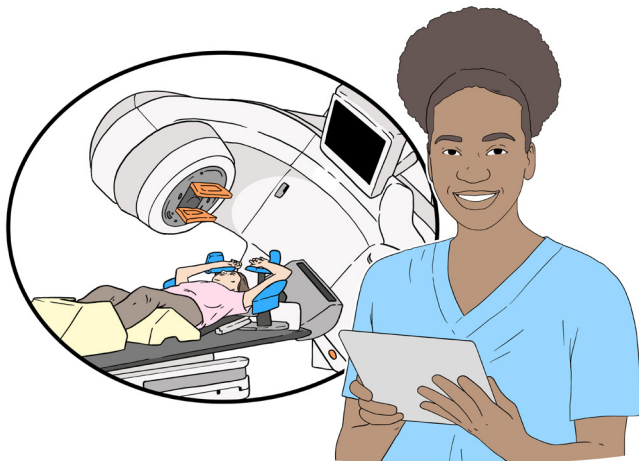
They can also support you to stay active and keep doing your everyday activities.

## Radiologist

An expert at reading scans, radiologists will look over and read any X-rays or scans you have.

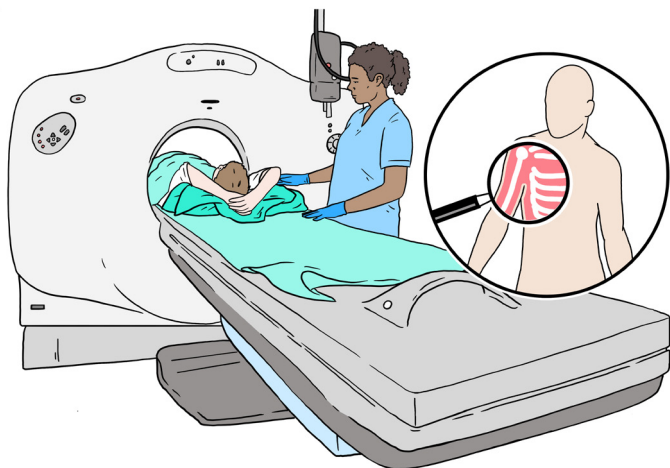


They check the X-rays or scans for signs of cancer and to see how your treatment is going.



## Radiotherapist and radiographer

Experts who give a cancer treatment called **radiotherapy**.



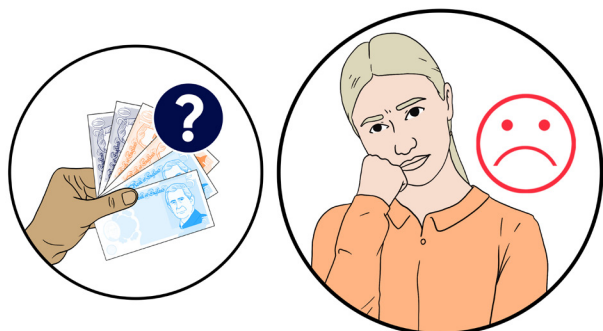
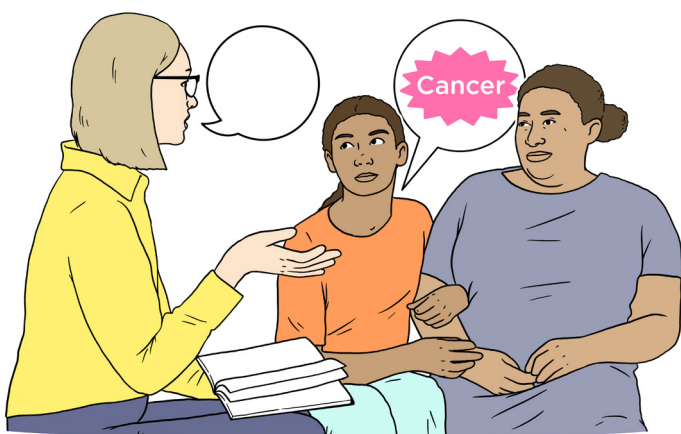
They also control the machines used for X-rays, **CT scans** and **MRI scans**. These are all ways of taking pictures of inside your body.

## Social worker

Social workers can support you and your family with changes to your life during and after cancer treatment.

They can help with **practical** problems like how you will pay for things you need, and **emotional** problems like if you are feeling worried.

They can also help you deal with any problems at school, college or work.





## Speech and language therapist

An expert who can help you talk and communicate.

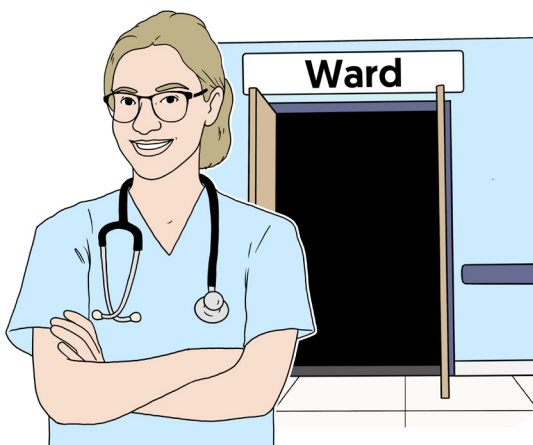


## Surgeon

A doctor that does **surgery**, this is when a doctor removes, replaces or fixes something inside your body. This can also be called an **operation**.



If you need an operation to treat your cancer, a specialist cancer surgeon will be in charge of the operation.



## Ward nurse

This is a nurse that works in a ward.



They carry out day to day care and can give treatment that you are having, like giving injections and taking blood samples.

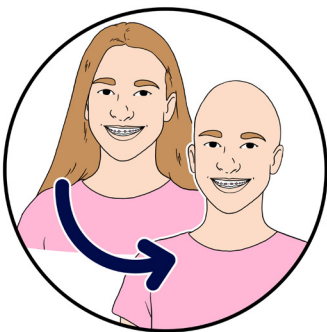
## Youth Support Coordinator



Youth Support Coordinators are people who are there to give emotional support and help you relax in hospital. You might hear them being called a YSC.

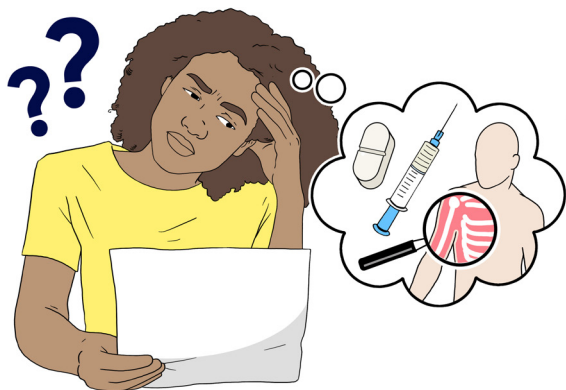


They make sure you have plenty of chances to make and meet friends, and talk to people your age.



They can also help with things like changes to the way you look, and going back to school, college or work.

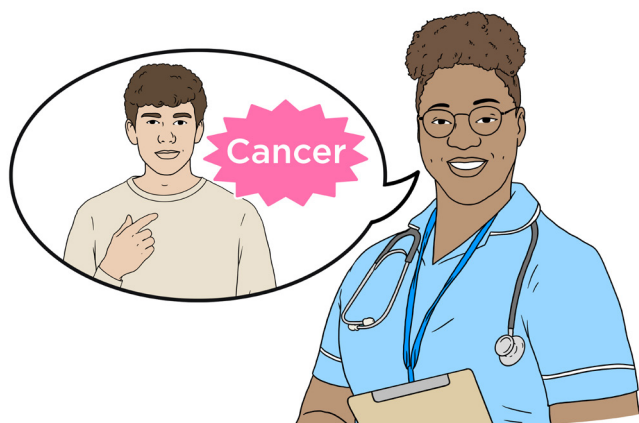
## Do you have any questions?



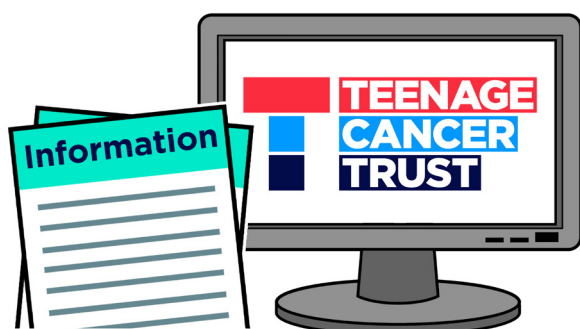
It can be hard to learn lots of information all at once. It can be even harder when it is complicated medical information.



If you have questions about anything you have read in this booklet you should talk to your care team.



They will be able to talk to you about your own diagnosis and your personal experience of cancer.



Remember, you can find lots more information on our website:

[teenagecancertrust.org/  
information](https://teenagecancertrust.org/information)



Not all information on our website is in easy read and you might want help to read it.



If you have any feedback about this booklet or any of our other information you can email us at:

**healthinfo@teenagecancer  
trust.org**

## Thank you!

We would like to say a big thank you to The Eloise and Katie Memorial Trust who very kindly donated the funds to produce and print this booklet. We are exceptionally grateful for their generosity in helping us provide this resource to support even more young people with cancer.

“This ‘easy read’ booklet has been created in response to feedback from Teenage Cancer Trust’s frontline staff. They identified that having information available in different formats would help young people understand their cancer diagnosis and treatment in ways which work for them.

The Eloise and Katie Memorial Trust is delighted to fund the booklet and hope it will be a valuable resource.”



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CHANGE



Trusted  
Information  
Creator

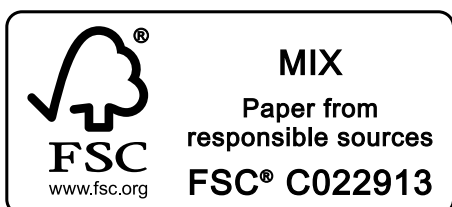


[www.teenagecancertrust.org](http://www.teenagecancertrust.org)

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