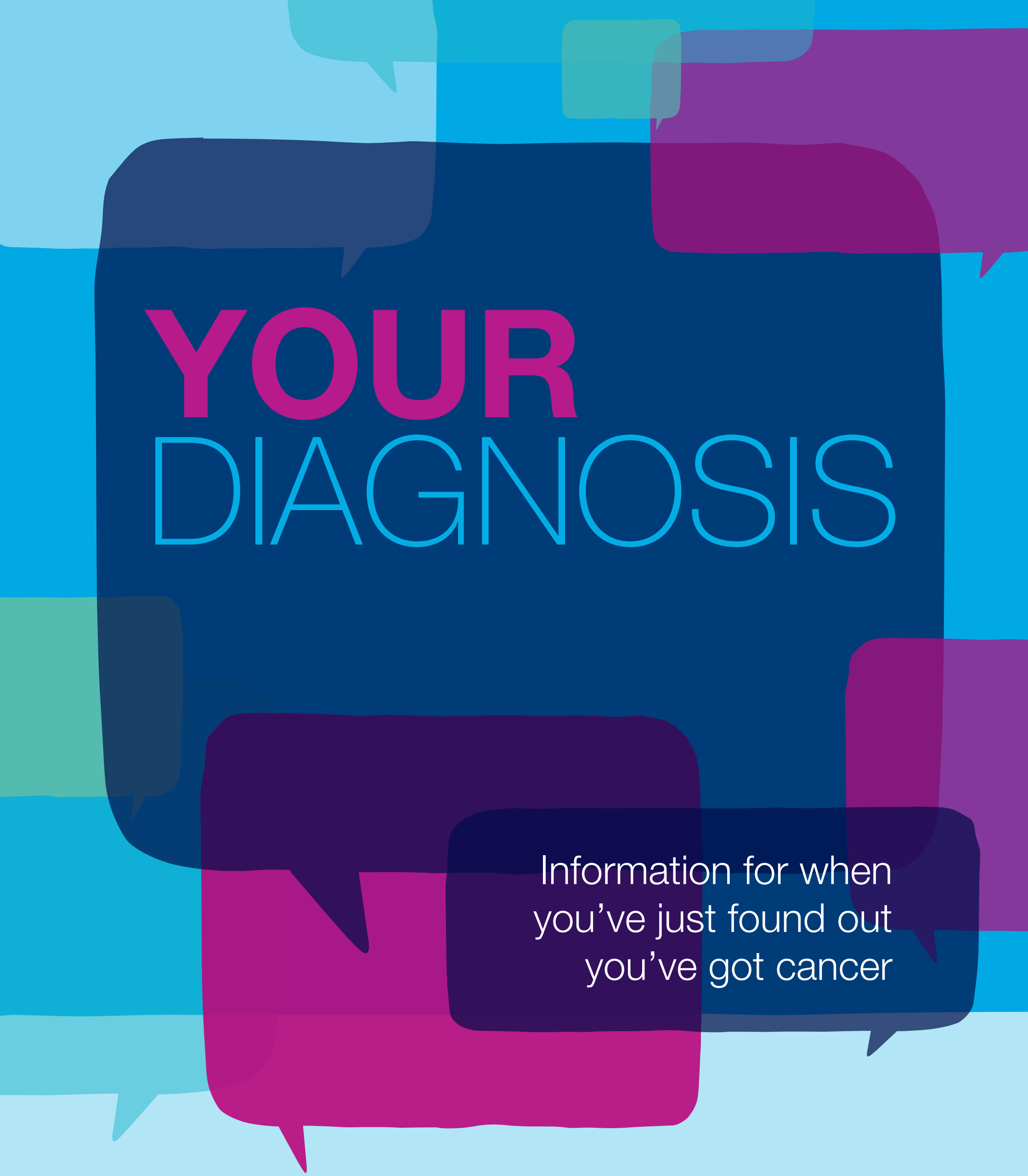


YOUR DIAGNOSIS

Information for when you've just found out you've got cancer

TEENAGE CANCER TRUST

YOUNG LIVES vs CANCER

Your details

We want you to make use of this book in whatever way works best for you. You can fill out the details below if you want to but if you'd rather not, that's OK too!

Name:

Age:

Diagnosis:

NHS number:

Treatment centre:

Key worker name:

Key worker contact phone number:

Emergency contact name:

Emergency contact phone number:

Contents

NOTE

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

Introduction

We know from speaking to other young people who've had cancer that finding out about your diagnosis can be a scary time. This booklet is a joint project created by Teenage Cancer Trust and Young Lives vs Cancer, two charities who work to support young people with a cancer diagnosis across the UK.

We've created this booklet to support all young people aged 13-24 facing cancer. It includes practical information about what to expect when you've just found out you've got cancer and it also has lots of tips and quotes from other young people who have had cancer.

This is by no means everything you will need to know, it's an introduction. Teenage Cancer Trust and Young Lives vs Cancer both have lots more information to offer – you can find this on our websites. You can also always turn to your care team for more information.

We worked closely with young people who have experiences of cancer, as well as healthcare professionals who work with teenagers and young adults with a cancer diagnosis, to create this information. It's been created **with young people, for young people,** and we hope you find it useful.

If you have any feedback or would like to know more about how this booklet was created you can get in touch with us on **healthinfo@teenagecancertrust.org**.

Look for the ℹ

This booklet is just a starting point when it comes to information. We've got so much more information and support available on our websites. Keep an eye out for the ℹ symbol throughout this guide – it indicates where you can find more information about a certain topic on our websites. Use the QR codes below to find more information.

If you're not able to access information online you can ask your care team for printed information.

www.teenagecancertrust.org/diagnosis

www.younglivesvscancer.org.uk/your-diagnosis

Who we are and what we do

Teenage Cancer Trust

Every day, seven young people aged 13-24 hear the words "you have cancer". They will each need specialised nursing care and support to get them through it.

We're the only UK charity dedicated to meeting this vital need – so no young person faces cancer alone.

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

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

Find out more about what we do: **www.teenagecancertrust.org**.

TEENAGE
CANCER
TRUST

Young Lives vs Cancer

Young Lives vs Cancer is the charity that helps children and young people (0-24) and their families find the strength to face whatever cancer throws at them.

Our social work team can help with everything, from cutting through medical jargon, applying for benefits and liaising with schools, colleges and work, to just being there when you need someone to offload to and help process what you've been through.

We understand the financial impact of cancer, whether that's travel costs, cuts in wages or the extras at home. We offer grants and will make sure you get the support you're entitled to from the government.

Your treatment may also be away from home, and our Homes from Home are free places to stay close to some treatment centres, available for young people and their families.

If you need to talk to someone after reading this booklet, our social work team is ready to support you, and you can message us via the 'Chat To Us' button on our website.

Find out more about what we do: **www.younglivesvscancer.org.uk**.

YOUNG LIVES
vs CANCER

Your diagnosis

Being told you have cancer can turn your whole world upside-down. Everyone reacts differently, and there's no right or wrong way to respond.

You might be feeling angry, numb, shocked, scared, guilty. You might be feeling one, all or none of these emotions. However you're feeling right now is valid. But there are two things that are really important to know: it's not your fault and you're not alone. There's lots of support available and you'll meet plenty of people whose job it is to help you get through this.

Whatever situation you're in – whether you're in education, work or doing something else – there are people who can help you with the things that are most important to you. If you have questions or you need help with something, don't be afraid to ask. If you forget the answer, or don't understand, it's absolutely okay to ask again. Making notes can help you keep track of things.

Health and social care professionals are used to explaining things lots of times. It can be hard to take in a lot of information in one go, especially when it's complicated medical information. Don't feel embarrassed or worry about asking too many questions, no one will mind and it's important to make sure you understand what's happening.

You might meet other young people whose situation is really similar to yours and others whose experience is completely different. Remember, every young person's experience of cancer is different, and everyone's experience is equally valid.

How do I talk about my cancer? ℹ

It's completely up to you. You can decide how much or how little you want to tell people about your diagnosis and you can also choose who to tell.

You might want everyone to know, and to tell them all in one go or you might prefer to only tell a few select people and take your time doing it. Either one, or anywhere in between, is absolutely fine. It's your experience and your choice.

You might be worried about how people will react when you tell them about your diagnosis, or be scared that your relationships will change. This might happen with some people but that doesn't necessarily mean it will be in a negative way – you could even get closer to friends or family members you weren't as close with before.

When you tell people close to you they might experience similar feelings to you when you first found out. Try to bear in mind that there's no right or wrong way to deal with this. Be open and honest with your friends and family about how you're feeling and how they can help you.

Family

We acknowledge for many reasons people might not have a close relationship with their family. We want you to know that we understand this, and your care team will do the best they can to support your needs. Lots of people, especially those over 18, have close friends and they may be the ones who are supporting you through cancer.

When you're diagnosed with cancer, you might suddenly find yourself spending a lot more time with your carer than you were expecting to at your age. It might feel like you've lost some of your independence, which can be difficult.

It's likely that your carers will also go through a range of emotions when they find out you have cancer. They could feel angry and scared or they might want to focus on the practical side of things. They might feel protective towards you, which could be a comfort or could feel stifling. Keeping your feelings to yourself doesn't usually help so try and talk to your family about how you're feeling.

You might want to discuss:

- Going to appointments by yourself (or with them)
- Being involved in decisions about your treatment
- Keeping doing the things you've always enjoyed
- Knowing they're always a phone call away, rather than with you the whole time
- Being left alone when you need space

It's not always an easy conversation, but your carer will probably appreciate it. You're all trying to figure your way through this, and talking about it honestly usually helps.

Partners

When we use the word partner, we are referring to people of all sexual orientations and gender identities.

A cancer diagnosis can have a big impact on a relationship, but that doesn't have to be in a negative way. You can help each other through the experience by trying to be open and honest about how you're feeling and what's going on.

You might be dating, in a new relationship or have been together for years. Whatever your situation, cancer is bound to throw some challenges your way. You both have a lot to deal with, but it doesn't have to come between you. As time passes, you'll both have good days and bad days. Like lots of things in life, these days might bring you closer or make you feel a bit distant from each other.

Try not to cover up how you feel. If you can be honest with one another about what's going on and how you feel, it can really help you both get through this.

Your partner might have lots of questions but you might not feel up to answering them. It can help to direct them to our websites for more information or encourage them to ask your care team questions too.

Friends

Your friends will hopefully be helpful and supportive when you tell them about your cancer diagnosis but some might not know how to react and become distant. People don't always react in the way you'd hope and it can be a shock when that happens.

If you feel like your friends aren't supporting you as much as you'd like it might be helpful to let them know how it's made you feel. You could suggest some specific examples of how they can support you if they want to.

Some of these suggestions could help:

- Ask people to keep calling and texting
- Ask friends to include you in plans even if they're not sure you'll be able to come
- Explain you sometimes might take a while to reply
- Keep in touch with them too
- Give your friends specific suggestions of what they can do to help, like sharing notes from school or being there when you tell other people
- Let them know it's OK to ask questions.

Remember that you're in control of how much you want to tell people about your cancer and your treatment. If you don't want to share certain things then you definitely don't have to.

If your friends want to learn more but you don't want to have to answer lots of questions, you might like to suggest they have a look at all the information on Teenage Cancer Trust and Young Lives vs Cancer's websites about how to help a friend with cancer.

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're diagnosed with cancer.

We know this can be a really tough time and there's so much information to get your head around, without having to think about where you'll be sleeping at night.

Hospitals can be big and overwhelming places so it can help to know what to expect before you have to spend a night (or more) in one.

How do hospitals work?

Hospitals are split up into different sections, called 'wards'. This means that there are different areas where people with the same or similar conditions are treated.

Cancer patients are usually treated on an 'oncology ward'. 'Oncology' is a word you might hear quite a lot and it refers to the area of medicine that diagnoses, treats and studies all types of cancer. Young people with blood cancer may be treated on a haematology ward or a ward which caters for young people with all types of cancer.

If you're staying in hospital overnight, you are considered an 'inpatient'. If you're only going in for an appointment or a morning/afternoon and then going home, you're considered an 'outpatient' or a 'day patient'. Some units also offer 'ambulatory care'. This is where your care is given as a day case and you don't need to stay in hospital overnight. A bed is always available should you need to come in as an inpatient.

Each hospital will have different rules about whether or not people can stay overnight with you and when people can visit you. The best thing to do is ask your care team to let you know what the rules are in your hospital.

Don't forget it's absolutely fine to tell people if you don't feel up to having any visitors. Even if people are planning to come in you can always send them a message saying you'd rather they came another day or time if you're not feeling well. It's always better to be honest about how you're feeling and your friends and family will hopefully understand.

Top tips from young people about staying in hospital

We know that hearing from other young people who have been through similar experiences can be really helpful. That's exactly why we reached out and asked for their top tips, insights and suggestions of all the things that helped them through their time in hospital. They gave us lots of great suggestions that might help you too – keep an eye out for more tips throughout this booklet!

What tips would you give to other young people who have just been diagnosed with cancer?

- Don't be afraid to ask questions
- Take each day as it comes and know that you are not alone
- Talk to people! Your doctors, nurses, Youth Support Coordinators, social workers and play specialists are all there to help you and they can really help cheer you up when you need it
- Do what's best for you, don't worry what other people think
- If possible, have somebody you love and feel comforted by with you when you can
- Bring an overnight bag with some essentials with you to appointments – day patient sessions can go on longer than expected so you might need to stay the night sometimes
- See how you feel. Don't try to organise everything, make/change plans just yet. Just wait and see

What were the most useful things you took with you to hospital?

Home comforts

- Don’t be embarrassed about bringing in things that comfort you
- Duvet, pillow and/or blanket from home
- Extra-long phone charging cable (often the plugs are far away from your bed)
- Sleep mask – this might help you sleep during the day
- A few sets of PJs – it’s good to have warmer and cooler options
- Dressing gown
- 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
- Soft toy
- Home comforts to decorate your area
- Calendar – you can lose track of time when you’re sleeping a lot
- Photos – these might be of your friends and family or pets
- Mini fan – in case you get too warm

Toiletries

- Soft toothbrush or a child’s toothbrush – chemo can make your mouth very sensitive
- Wash products that are gentle on your skin – don’t bring your favourites, you might be put off them when you finish treatment!
- Moisturiser and lip balm – chemo can make your skin very dry

> “The treatment was rough, and I tried to read to distract myself, but I had chemo fog and kept losing my place. Drawing has always been a hobby of mine and I found that I could put that down when I couldn’t focus and then just pick it back up again as I’m not confined to a time scale, as I would’ve been if I was drawing for a college project.”
>
> Seren

Things to do

- Headphones/earphones – to listen to music or watch TV/films
- Earplugs – to block out noise
- Something you can watch films or TV programmes on
- Books and magazines
- Things to distract you – puzzles, a book of crosswords or a colouring book
- Snacks and drinks – this can be especially useful if you have any dietary requirements that might mean what you can eat is limited
- Big water bottle so you don’t have to fill up too often

Keep an eye on our Instagram pages for opportunities to share your own tips for other young people!

@teenage_cancer **@younglivesvscancer**

Who could I meet?

You'll be treated by a team of experts who specialise in different areas of cancer. All of these people have an important role to play.

There will probably be quite a few of them, and they often have job titles that are difficult to remember. You won't meet all of these people in one go but it can help to have an idea of who's who when you do.

The group of people working with you to treat your cancer are also often referred to as your 'care team'.

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'.

Consultant: Specialist doctors who are experts in particular areas of medicine. They are in charge of your overall treatment.

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

General Practitioner (GP): Your GP is your family doctor. You might stay in touch with your GP throughout your treatment, as they can help you make decisions about things like where you want to be treated.

Haematologist: A doctor who specialises in blood cancer and other blood disorders.

Healthcare assistant: Support nursing staff with monitoring patients and helping with treatment.

Junior doctor: Qualified doctors who have a medical degree and are training in specialist areas of medicine.

Multi-Disciplinary Team (MDT): The group of health professionals who work together to diagnose, treat and care for young people.

Nurse: Nurses provide direct patient care in a variety of settings. They might specialise in particular areas like paediatrics (children), theatre nursing (surgery) or in a GP practice.

Occupational therapist: Cancer can affect our ability to participate in life as we usually would. Occupational therapists work alongside you during your journey, to help you to identify and overcome any difficulties you may be experiencing. They help you to do what you want and need to do, to be you!

Oncologist: A doctor who specialises in treating cancer.

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.

Play specialist: Experts in helping children and young people play in ways that help them cope, deal with anxieties, make friends and keep developing during cancer treatment. Play specialists usually work on children's wards.

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.

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

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.

Radiotherapist and radiographer: Experts who give radiotherapy treatment and control the machines used for X-rays, CT scans and MRI scans.

Social worker: Young Lives vs Cancer Social Workers and social work team can support you and your family to adjust to life during and after cancer treatment. They can help with a huge range of practical and emotional issues, from dealing with finances, to talking to your carer, to working through any problems at school, college or work.

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

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

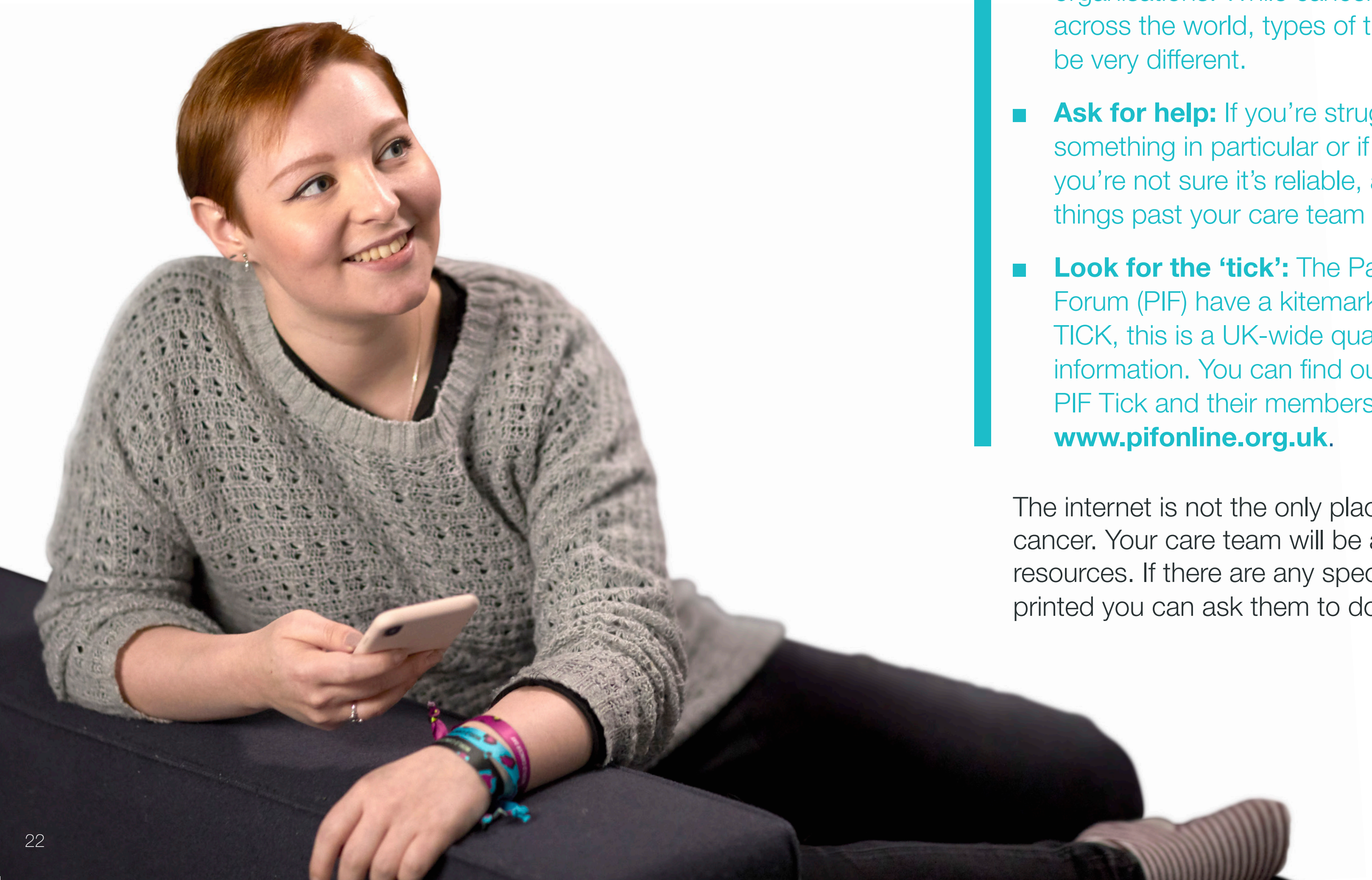
Ward nurse: They carry out day-to-day care and provide ongoing treatment, including giving injections and taking blood samples.

Youth Support Coordinator: 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.

Where can I find trustworthy information?

Some people might want to know everything possible about their diagnosis, treatment and cancer. Others might prefer to take it step by step and only find out more when they feel up to it.

It doesn't matter which you'd rather, it's your experience and your choice how to deal with it.



For those of you who want to find out more – the internet is the obvious place to start. You can find lots of great information online but there's also lots of confusing or inaccurate information out there. It can be hard to know what's accurate sometimes so we've got a few tips to help you work out fact from fiction:

- **Start with us:** Teenage Cancer Trust and Young Lives vs Cancer both have lots of information on our websites. These are good places to start. We also have a list of 'useful contacts' on our websites.
- **Keep it local:** Try and keep to information from UK-based organisations. While cancer diagnoses might be the same across the world, types of treatment and medical care can be very different.
- **Ask for help:** If you're struggling to find information on something in particular or if you've found some information but you're not sure it's reliable, ask someone. You might want to run things past your care team or speak to your carer.
- **Look for the 'tick':** The Patient Information Forum (PIF) have a kitemark called the PIF TICK, this is a UK-wide quality mark for health information. You can find out more about the PIF Tick and their members on their website: **www.pifonline.org.uk**.

Trusted
Information
Creator
Patient Information Forum

The internet is not the only place you can find information about cancer. Your care team will be able to give you printed information resources. If there are any specific webpages you want to have printed you can ask them to do that too.

Treatment side effects

Cancer treatments will have an impact on your body. It's important to remember that everyone reacts differently, and you might experience some pretty unpleasant side effects.

The type of side effects that you have depends on a lot of things, including the type of cancer you have and the type of treatment you're having. You might experience short or long-term side effects, or you might not have any side effects. Everyone is different so it's not a good idea to compare yourself to other people because everyone experiences their cancer differently.

Nausea (feeling sick)

Chemo and radiotherapy treatments can leave you feeling sick – this normally starts a few hours after treatment and can last for quite a while. Let your doctors and nurses know if you feel sick because they can give you medicine that will help you feel better and might stop you from throwing up.

Here are some tips for helping you manage nausea:

- Eat small, frequent meals and snacks – big meals can be hard to tackle and feeling really hungry can make you feel worse
- Chop up food into small pieces so it's easier to swallow
- Eat your main meal whenever you feel best, even if that means eating things at strange times
- Avoid foods that smell strong
- Avoid your favourite foods – you can put yourself off them
- Choose drinks that will give you a boost, like milk
- If you start to feel like you might be sick, try taking some deep breaths. It can really help

Tips from young people

- Have lots of iced water
- Try different anti-sickness meds until you find the right one for you
- Suck on mints or sniff them when your mouth is too sore
- Sea sickness bands work a treat
- Hard boiled sweets
- Try to distract yourself with music
- Anything with ginger in can help, like biscuits or tea
- Humming/singing to mask the feeling in your throat
- Have something with you to be sick in
- Get a good sleep when you can
- Eat small portions spread out so you're never hungry or full
- Go for a walk in the fresh air
- Ice lollies

Tiredness

Some cancer treatments – especially chemo – can leave you feeling very tired or fatigued. This can last for a number of months, even after you've finished treatment. It can be frustrating, but try and be patient. Give yourself time to recover. Eat well. Sleep often. Get active in a way that works for you – movement can help with tiredness and fatigue and help your mental health. Go to bed around the same time each night. Don't overdo it. And let other people help you out.

Tips from young people

- If your body is telling you to sleep just sleep
- Use an eye mask for daytime naps to help block out the lights
- Try not to go too far from home so you can easily get back if you feel tired
- Do something little every day to build energy
- Don't plan too much
- Find peace in saying no to things – don't feel like you always need to be available, people understand

Mouth ulcers and dental problems

Chemo can leave you with mouth ulcers and you might have a sore mouth and/or throat during and after treatment. This can also affect how food tastes temporarily.

If you had radiotherapy around your head or neck you might also get a dry mouth and have some problems with tooth decay. These problems should disappear after you finish treatment, but in the meantime, it's important you look after your mouth.

Brush your teeth regularly but gently, and schedule frequent check-ups with your dentist. They will be able to give you advice and information on dealing with mouth and dental issues so make sure to ask if you have any questions or concerns. Your specialist or dentist will be able to prescribe some fluoride tablets or fluoride mouthwash.

Chemo brain/brain fog

These aren't medical terms and sometimes you might hear your care team talk about 'cognitive changes' too. Some people say while they're having chemo they struggle to concentrate or find it hard to think clearly. It can be worrying or unnerving but don't worry if you feel like this, you're not alone. Putting reminders in your phone or a diary can help you remember important things. These symptoms usually slowly improve once you've finished chemo but talk to your care team if you're worried.

Infection

Chemo can have an impact on your body's immune system which might mean that you find it harder to fight off infections. This is sometimes called 'neutropenia' or 'being neutropenic'. It's one of the most serious side effects of chemotherapy.

It's important to be aware of the common signs of infection. If you think you have any of these symptoms, you need to get medical help as soon as possible.

- A temperature on or 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

When you start your treatment, your doctors and nurses will let you know which hospital to go to and who to contact in case of an emergency. Write this information down or keep it saved in your phone so you have access to it when you need it. It's also worth sharing this information with your family and the friends you see regularly so they know what to do, and who to contact, in case of an emergency.

Diarrhoea or constipation

The chemotherapy drugs may affect how your bowel works which could mean you end up either constipated or having diarrhoea. This can be helped by laxatives or anti-diarrhoea drugs.

Sensitive skin

Chemotherapy can make your skin very sensitive to the sun and chemicals, like the chlorine in swimming pools. You might get a rash or your skin might change colour.

If you're having external radiotherapy, you might notice your skin has a reaction, similar to sunburn at the site where you had the treatment. This usually begins about ten days after treatment. You might also notice these reactions on the other side of your body to where you had the treatment. This could be your skin reacting to where the radiotherapy has left your body.

This can affect people of all skin tones. For people with lighter skin tones, skin reactions can make your skin red. This can also happen to people with darker skin tones and it can also make your skin darker. It can be sore and itchy, look like sunburn and it might peel and blister. Your care team will keep an eye out for this but make sure you let them know if you notice any of these reactions on your skin.

The skin on your treatment area will be very sensitive and will need to be protected from the sun and cold winds. It's also really important to cover up and wear suncream when you're out in the sun.

Hair loss

Hair is an important part of lots of people's identity, so it can be really tough when you hear that your treatment might mean you lose your hair. Even if you're expecting to lose your hair, it doesn't make it any less of a shock when it happens.

Chemotherapy can cause hair loss and it usually starts about two to three weeks after the first course of treatment. Some people may lose all their hair, others may find it gets thinner or falls out in patches. It doesn't usually fall out all at once. It's not just the hair on your head that might fall out – chemotherapy can also affect your eyebrows, eyelashes, underarm hair and pubes. Radiotherapy can also cause hair loss on the specific part of your body where you have had the treatment.

Your hair will usually start to grow back a few weeks after your treatment finishes. It might look different – it could be thinner, thicker, curlier, straighter or a different colour.

Dealing with losing your hair can be difficult because it's hard to ignore – you see it every time you look in the mirror. There are different ways to manage this and lots of organisations that can help.

If you're worried about losing your hair, here are some tips to help manage the experience:

- Tell your family and friends that you're probably going to lose your hair – this can help make the process easier to manage when it does fall out
- If you have long hair and you've been told it's likely to fall out it might be worth cutting it shorter before treatment. This will mean there's less weight and pull on your scalp as it becomes more sensitive
- Use gentle shampoos like baby shampoo. Avoiding washing your hair won't prevent it falling out so you should continue with your usual washing routine
- Avoid dyeing or perming your hair – these can both damage your hair and the dye colours might not take in the same way they normally would
- Don't use heat on your hair (straighteners, hair dryers) and try to let it dry naturally
- Use a hairnet, headscarf or headwrap at night to avoid friction with your pillowcase

You might want to show off your hair-free head or you might feel more comfortable keeping it covered up – everyone will feel differently, and there's no "right" way to feel.

If you want to cover up there are a few different options you might consider:

- Wigs
- Turbans
- Hair wraps
- Hats
- Headbands

It's worth remembering that your scalp might feel particularly sensitive when you lose your hair, so if you want to look for different head covering options, have a think about what might feel most comfortable on your head.

If you want to try headscarves, headwraps or turbans, why not search simple phrases like "*how to tie a headscarf*" or "*easy turban styles*" on YouTube. There are lots of tutorials that can be really helpful.

All NHS recommended wig suppliers should offer wig colours and textures that work for everyone, including afro-hair wigs and Asian hair types. Search 'wigs' on **nhs.uk** to find out more about how to access wigs on the NHS.

Organisations that can help:

- **Cancer Hair Care** have worked closely with Teenage Cancer Trust for many years and are the UK's leading hair loss support charity. They have a team of cancer hair advisors and specialists on hand who are trained to listen and support children and teenagers. You can order one of their hair loss support packs from their website for free. **www.cancerhaircare.co.uk**
- **Look Good Feel Better** have worked with experts to produce tutorials covering lots of topics, including looking after your hair during chemo, how to choose a wig, styling your wig, how to tie headscarves and information on other types of headwear. They also have tutorials on skincare, nail care and make up. **www.lookgoodfeelbetter.co.uk**
- **Little Princess Trust** provides free real hair wigs to children and young people, up to 24 years old, who have lost their own hair through cancer treatment or other conditions. The charity has a network of salons across the country where wigs can be fitted. The wigs are all made of real hair so can be cut and styled however you would like. **www.littleprincesses.org.uk**
- **Maggie's** is a charity that provides free cancer support and information in centres across the UK and they have lots of information online, including tips on managing hair loss and head covering options. **www.maggies.org**
- **My New Hair** provides advice and support a national network of independent salons and professionals who provide a wig styling service for people with cancer and medical hair loss. **www.mynewhair.org**

Talk to your care team if you're concerned or have questions about any of the side effects you experience.

Tips from young people

- Shave your head when you feel ready, not when others want you to
- Embrace your baldness!
- A nice selection of beanies
- Enjoy saving time in the shower!
- Get some gentle oils because your scalp can get itchy
- Bandanas are good for protecting your head from the sun without making you too hot
- Not everyone feels comfortable in a wig – it's okay to flaunt your head as it is
- Silk pillow cases when it's falling out so it doesn't clump as badly at night
- Try different style wigs and colours you might not have dyed your hair before
- Your head and scalp will be sensitive so invest in comfy hats
- I got into baseball caps! I have loads, it's fun collecting them
- Use baby shampoo when you're washing your hair, it's a lot more gentle to your head
- The feeling of things touching your head will get better over time

Not everyone loses their hair

Not all cancer treatments cause hair loss, but this can be a different challenge. You might get comments like 'you haven't got cancer because you haven't lost your hair,' or people being less willing to help you because you don't 'look like' their image of someone with cancer. This can be hurtful but you don't need to put up with it. Talk to friends, family or your care team to help with any bullying behaviour.

Mental health support ℹ

Cancer doesn't just affect your body – it can have an effect on your mind, thoughts, emotions and relationships. While these emotions might be completely new to you, however you're feeling is valid.

There are two things that are important to remember: it's not your fault and you're not alone. Everyone feels differently when they're diagnosed, and there's no 'right' way to feel. You might experience some, or all, of the following emotions:

- Loneliness
- Fear
- Feeling low
- Anger
- Guilt
- Resentment

Maggie's provides free cancer support and information in centres across the UK and online, including information on managing emotions and dealing with day-to-day practicalities.

You can find your nearest *Maggie's* centre online: www.maggies.org.

***Young Minds* is a charity dedicated to supporting the mental health and wellbeing of children and young people. Find out more about how they can help online: www.youngminds.org.uk.**

> “My psychologist taught me a technique called 'Worry Time' where I was only allowed to think about things at a certain time of the day and for a set amount of time. This stopped me spending all day stressing about it.”
>
> Beth

Fertility ℹ

The word 'fertility' means your ability to have children. Some cancer treatments can impact your fertility.

You might not have ever thought about having children or think that it's something you don't need to consider for a long time. But, if your doctor recommends a treatment that is likely to affect your fertility it's worth thinking about your options.

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

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

Fertility preservation treatment might allow you to have children in the future – there are various ways of doing this.

> “ I knew I wanted children in the future, but I hadn’t thought about it that much and I didn’t know it could be taken away from me. Luckily, I had time to preserve my fertility, but I put so much pressure on myself as I thought it could be my only chance to have children. ”
>
> Amy

Being asked to make a decision about having children in the future and whether you want to preserve your fertility, especially if you haven’t really thought about it, could feel overwhelming. You might not feel ready to make this decision.

Try to talk about it with people you love and trust. You could also talk to your nurses or doctors because they’ll be able to help you understand more about the different options and answer any questions you might have.

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

You can find more information by searching ‘LGBT+’ on the *NHS* website: www.nhs.uk.

Questions to ask

As we’ve already said, don’t ever be afraid to ask questions about your cancer, it’s important you understand your diagnosis.

When you talk to your doctor about fertility, you might like to ask some of the following questions:

- Will my treatment affect my fertility?
- Will it be permanent or temporary?
- Is fertility preservation possible?
- Will my treatment affect my periods?
- What contraception is best for me during my treatment?
- What fertility treatments might be possible after my treatment?
- How long after treatment should I wait before trying to get pregnant?

You can find out more about the impact cancer can have on fertility on the *Cancer, Fertility and Me* website: www.cancerfertilityandme.org.uk.

What about my job? ℹ

Managing work and your career when you're going through cancer treatment can be difficult but there are lots of things in place to support you through it.

Who do I need to tell?

Legally you don't have to tell anyone about your cancer diagnosis – even your employer. However, your employer is legally required to make reasonable adjustments, but if you don't tell them then they're not required to offer you any additional support you might need to do your job.

This might include things like having extra breaks, flexible working hours, time off or letting you come back to work gradually once you've finished treatment.

Equality Act 2010

Even though you might not consider yourself disabled, The Equality Act 2010 (Disability Discrimination Act in Northern Ireland) classes everyone with cancer as disabled. This is not just during the time you are having treatment, but for the rest of your life.

Because of this, it's illegal for your employer to discriminate against you once you've told them you have cancer.

This can be quite complicated to understand, so if you have a social worker or Youth Support Coordinator they might be able to help you with this.

You can find out more by searching 'Equality Act' on **www.gov.uk** or 'Disability Discrimination Act' on **www.nidirect.gov.uk**.

Access to Work

You and your employer might also be able to get support from the Access to Work scheme. This helps you get, or stay in, work if you have a disability. You can apply for grants to help pay for practical support with work, get advice on mental health management at work and also money for communication support at job interviews. Visit **www.gov.uk** or **www.nidirect.gov.uk** for more information.

Will I still get paid if I can't work?

If you're too ill to work you're entitled to Statutory Sick Pay (SSP) from your employer for up to 28 weeks. If your company has a sick pay scheme then you might get more than this. Check your employment contract or speak to someone in HR at your company to find out more. Visit **www.gov.uk/statutory-sick-pay** for more information.

What if I'm self-employed?

Unfortunately, you won't be entitled to SSP if you're self-employed, however there are some other benefits that you might be entitled to apply for, like Employment and Support Allowance or Universal Credit. Visit **www.gov.uk/universal-credit** and **www.gov.uk/employment-support-allowance** for more information.

What if I'm unemployed?

If you're not working when you're diagnosed you won't be entitled to SSP but you may be allowed to apply for other financial support, including Employment and Support Allowance (ESA). If you're registered with Job Centre Plus and you're not able to work, you will need to let them know. Visit **www.gov.uk/contact-jobcentre-plus** for more information.

Healthcare Travel Costs Scheme (HTCS)

Travelling to and from appointments can be expensive. In some situations you can claim a refund for your travel costs. Search ‘HTCS’ on **www.nhs.uk** for more information and to find out if you’re eligible.

Grants

Young Lives vs Cancer also offer grants and financial support to help cover the costs of cancer. Find out if you’re eligible on their website.

> “We arranged for me to work Monday to Thursday, and then have my treatment on a Friday one week. I slept all weekend and worked for part of the next Monday. My main side effect was tiredness, and my colleagues were very flexible and supportive and allowed me to have a nap on the Monday when I needed it. I’d then work the rest of the week as normal.”
>
> David

What about my education?

You might need to take some time off school/college/university while you're having treatment. However, this doesn't have to mean you're going to fall behind with your education.

If you're under 16 you might be able to carry on with schoolwork while you're in hospital – lots of places have teachers on hand to help. Speak to your care team to find out if this is something that's available in your area.

If not, speak to your teachers or tutors and let them know what's going on – you can tell them you don't want them to share this news with any other staff or students if you'd rather. They can let you know how you can keep on top of your work. This might mean doing some classes online or having schoolwork sent to you over email to complete at home.

You could also ask your friends if they'd be happy to share some of their notes with you so you can see what they've been working on. You might want to ask your teacher to let you know which bits of work are most important so you can focus on those. If you need support in talking to your school, the Young Lives vs Cancer social work team can help you.

Disabled Students' Allowance (DSA)

You might also be entitled to apply for DSA to help cover any education-related costs you have as a result of your cancer diagnosis. You won't need to pay this money back at any point. **You can find out more about DSA and what you're entitled to online: www.nidirect.gov.uk**.

Education support

You might also be entitled to additional support with your studies. Support varies across the nations so be sure to check the government website for the country you live in to find out more.

Reasonable adjustments

You can also ask your school, college or university to make 'reasonable adjustments' that will help you carry on with your education as comfortably as possible. These are small changes that might make a significant difference to how you manage your education.

Some changes that you might ask for could include:

- Extra time for coursework and extensions to deadlines if you have fatigue
- Someone to help you make notes (this is sometimes called a 'scribe')
- Use of computers and specialist software
- A locker/place where you can leave things you don't need all the time instead of having to carry it around
- Special dietary requirements – this might be eating at different times, keeping your own food at school or being allowed to eat snacks during class
- Flexible attendance – if you need to go to appointments and treatment
- Additional support for practical or field work
- Being able to communicate with staff when away from school – this might be to catch up on work or to ask for additional support with work
- If you have a car you might be able to get a designated parking space to give you easier access to buildings
- Adaptation in sports sessions and PE classes

Glossary

When you're first diagnosed with cancer you'll probably hear lots of words you don't understand. This glossary can be a good starting point to look up anything you're not sure about.

If there are other words that come up that you don't understand you can always ask someone on your care team to explain them for you.

Alopecia: The medical name for hair loss.

Benign: The medical term for a tumour 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.

Cancer: A general term for lots of different diseases, all of which are caused by cells not behaving normally.

Care team: The group of people responsible for looking after you during cancer treatment. Your care team is part of your multidisciplinary team.

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.

Diagnosis: The identification of a disease.

Fatigue: An overwhelming feeling of tiredness, exhaustion and lacking energy. More than just being tired, and a common side effect of cancer treatment.

Haematology: The branch of medicine that focuses on blood. Doctors who specialise in blood are called haematologists.

High grade brain tumour: Grade 3 and 4 brain tumours are considered 'high grade'. They're fast growing and also sometimes called 'malignant brain tumours'.

Immune system: The cells and organs in your body that combine to protect you from illness.

Low grade brain tumour: Grade 1 and 2 brain tumours are considered 'low grade'. They tend to be slow growing and contained. They are sometimes called 'benign brain tumours'.

Malignant: The medical name for a tumour or increase in abnormal blood cells in your body that is cancerous and may spread.

Metastasis: A secondary tumour caused by cells from a primary (first) tumour spreading to another part of 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.

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.

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 and sometimes it's given from inside your body (using liquids and implants).

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.

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.

Terminal: A word used to describe diseases that can't be cured.

Tumour: An abnormal growth in your body.

TYA: Teenage and young adult. TYA is often used to describe young people with cancer who are under 25.

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YOUNG LIVES vs CANCER

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If you have any questions about the information included in this guide then please email us on **healthinfo@teenagecancertrust.org**.

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