YOUR DIAGNOSIS

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

TEENAGE CANCER TRUST + YOUNG LIVES vs CANCER

YOUR DETAILS

This booklet is for you to use 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:

Keyworker or nurse's name:

Keyworker or nurse's
contact phone number:

Emergency contact name:

Emergency contact
phone number:

FOR YOU

A message from young people

We know that finding out about your diagnosis can be a scary time. **We've been through it too.**

So, if you're between 13-24 and you've just been diagnosed with cancer, this booklet is for you. It has practical information about what to expect, plus lots of tips and quotes from us and other young people. You'll also see our handwriting and doodles.

The 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.

To make it, they asked us what we wanted to know when we were diagnosed. They also spoke to healthcare professionals who specialise in helping young people with cancer.

This is your diagnosis, so how you feel about it and what you want to read about will be unique to you, but hopefully this booklet can answer some of your questions.

It won't cover everything you need to know, it's an introduction. But Teenage Cancer Trust and Young Lives vs Cancer both have more information to offer – you can find this by using the QR codes at the bottom of this page.

You can also always turn to your care team for more information, as well as other cancer charities.

From us.

teenagecancertrust.org

younglivesvscancer.org.uk

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We use the word 'carer' to recognise anyone who is in the position of looking after a young person. We know that some people might not have a strong relationship with a parent or carer. If that sounds like you, you can talk to your care team about other types of support.

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 think or feel.

You might be feeling angry, confused, shocked, sad, scared, or guilty. You might just feel numb. You might be feeling one, all, or none of these things. What you're feeling might be new to you, and it might seem overwhelming or scary.

However you're feeling right now is valid.

There are two things that are important to remember:

It's not your fault

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.

It can be hard to take in a lot of information in one go, especially when it's complicated medical information. So, if you have questions or you need help with something, don't be afraid to ask. If you forget the answer, or don't understand, it's okay to ask again.

You can write in the margins, or skip to the journal pages where there is space for more notes

Don't feel embarrassed or worried about asking too many questions, no one will mind, and it's important to make sure you understand what's happening.

Making notes can help you keep track of things, so there are spaces on some of these pages for that. There's also space to write about your thoughts and feelings if you want to.

You might meet other young people whose situation is 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.

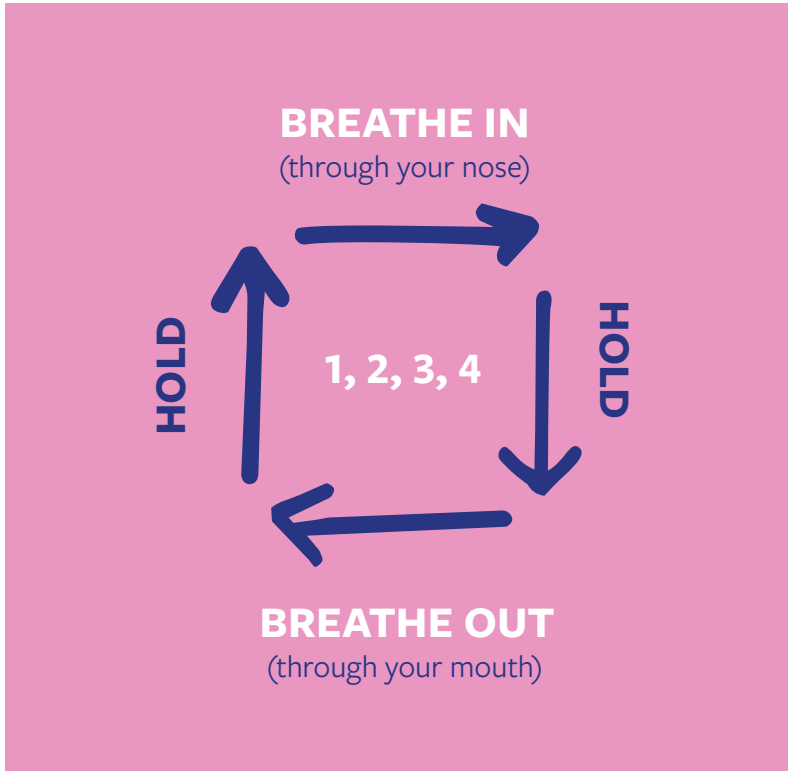
What tips would you give to other young people who have just been diagnosed with cancer?

- 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, specialist 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
- See how you feel. Don't try to organise everything, make/change plans just yet. Just wait and see

TAKE A MOMENT

Things might feel overwhelming. If they do, a breathing exercise can be helpful. **Deep breaths can help your body and mind to calm down for a bit.**

Box breathing
Breathe in for four counts, then hold your breath for the same number of counts. Breathe out for four counts and then hold another four counts before starting again. If four feels too long, try doing three counts.



RESOURCES

Maggie's provides free cancer support and information online as well as in centres in some parts of the UK. They have information on managing emotions and dealing with day-to-day practicalities. You can find more information, and your nearest Maggie's centre online **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 **youngminds.org.uk.**

HOW DO I TALK ABOUT MY CANCER?

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 also want to tell some people more details than others.

You might want everyone to know, and to tell them all in one go, or you might prefer to only tell a few people and take your time doing it. **It's your choice when and how you want to tell people.**

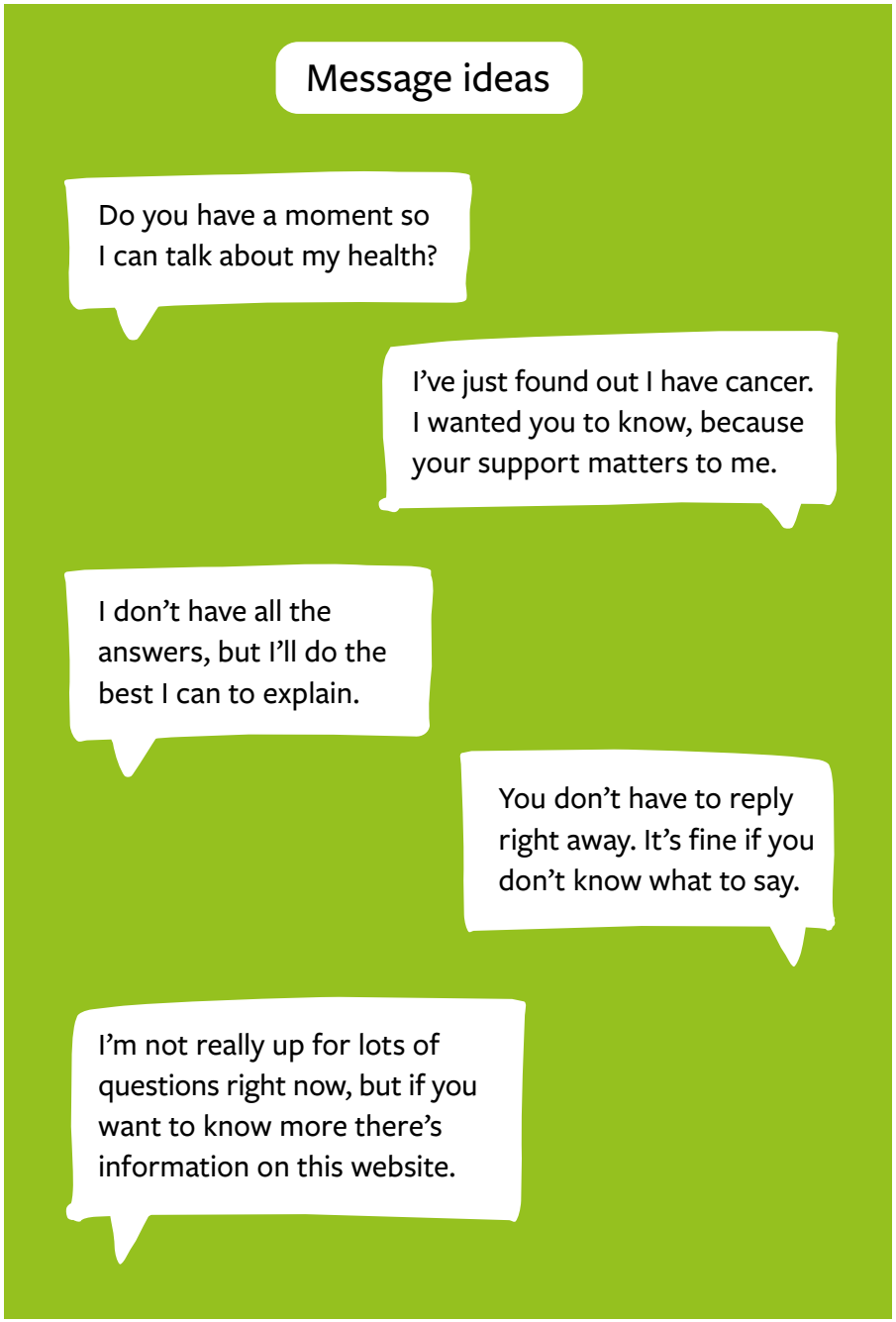
You might be worried about how people will react when you tell them about your diagnosis or be scared that your relationships will change. This can happen with some people but that doesn't mean it will always be in a negative way – you could get closer to some friends or family members you weren't as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

There's lots of ways people might react when you tell them. They might not know what to say or do. Try to remember there's no right or wrong way to deal with this.

It's best to try to be open and honest with your friends and family about how you're feeling and how they can help you.

Some people find it helpful to set up a group chat where they can put information and updates. This can make it easier to keep up with everyone. You might want to be in charge of it yourself, or you could ask your carer or a close friend to help.

Then you only need to send one message



FAMILY

When you're diagnosed with cancer, you might suddenly find yourself spending a lot more time with your carer than you thought you would at your age. It might feel like you've lost some of your freedom or gone backwards, which can be difficult.

It's likely that your carer 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 might be comforting or might feel too much.

Keeping things to yourself doesn't usually help, so try and talk to them about how you're feeling.

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

You can talk about these things at any time, and you might change your mind about some of them. Don't be afraid to bring something up again if you're feelings have changed.

There may be reasons that you don't have a close relationship with your family. For some young adults it might be friends or a partner who supports you. Your care team will also be there to support you as best they can.

PARTNERS

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

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

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'll both probably have good days and bad days. Some of the things you have to deal with might bring you closer, and others might make you feel a bit more distant from each other.

Try not to cover up how you feel. If you can be honest with each other 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 show them our websites for more information or have them ask your care team questions. You could also show them this booklet.

I'm not sure I can really answer that but there are websites that might help

teenagecancertrust.org/partner

FRIENDS

Your friends will hopefully be helpful and supportive when you tell them about your cancer diagnosis. You might even find that it brings you closer. Having friends who you can speak to and spend time with can help you get through tough times.

But some people 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.

Sometimes people aren't sure how best to help. You could suggest some ways they can support you. This could be things like sharing notes from school, uni, college, or work, or being there when you tell other people.

All feelings are valid

"I didn't like missing out on things and I got upset if my best friends went out and posted pictures on social media. I started spiralling and thinking that they didn't like me. My Clinical Nurse Specialist managed to stop me going down that rabbit hole and reminded me that I was very sick and they couldn't invite me out, so that it wasn't that they weren't including me, they just couldn't."

☆ BETH

Message ideas

I'd really like it if you can keep texting or calling me, even if I can't always answer.

It's totally fine if you have questions you want to ask me, but I might not always be able to answer.

If you guys are doing something I'd really like to be invited, even if you think I won't be able to make it.

I'm still me! I'm just going through a lot of stuff right now.

Try to keep in touch with your friends if you can. It can also help to explain that you might sometimes take a while to reply.

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.

younglivesvscancer.org.uk/friend

teenagecancertrust.org/friend

Find peace in saying no to things - don't feel like you always need to be available, people understand.

WHAT I WANT PEOPLE TO KNOW

Sometimes it's hard to say things out loud.
If you wanted to, what would you want people around you to understand right now?

This page doesn't have to be shared with anyone.

WHAT'S IT LIKE STAYING IN HOSPITAL?

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

You might not have spent a night in hospital before – you might not have even been inside a hospital before you were diagnosed with cancer.

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' or a 'haematology ward'.

on-KOL-uh-jee

hee-muh-TOL-uh-jee

'Oncology' is a word you might hear quite a lot. It refers to the area of medicine that diagnoses, treats, and studies all types of cancer.

'Haematology' refers to the area of medicine that deals with blood, including blood cancer.

Young people with blood cancer may be treated on a haematology ward or an oncology ward. It depends on the hospital.

If you're staying in hospital overnight, you are called an **'inpatient'**.

If you're only going in for an appointment or a morning/afternoon and then going home, you're called an **'outpatient'** or a **'day patient'**.

Some units also offer **'ambulatory care'**. This is where you come in as a day patient and you don't need to stay overnight. Instead of staying at the hospital you stay nearby, either at home, in a hotel or in accommodation like Young Lives vs Cancer's Homes from Home.

Each hospital will have different rules about whether 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 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.

Hey, I'm not feeling great today. I'd love to see you, but maybe we could do it another day?

WHAT ARE SOME USEFUL THINGS TO TAKE TO HOSPITAL?

often the plugs are far away from your bed

- Comfort items or something to make it feel homely, like a blanket to put over your bed and a cuddly toy
- Extra-long phone charging cable
- Eye mask – this might help you sleep during the day
- Lots of comfy clothes and pyjamas, it's good to have warmer and cooler options
- 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
- Calendar
- Photos – these might be of your friends and family or pets
- Mini fan – in case you get too warm
- Wash products that are gentle on your skin – don't bring your favourites, you might be put off them when you finish treatment!
- 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
- A reed diffuser helps take away the hospital smells
- Snacks and drinks – this can be really useful if you have any dietary requirements that might limit what you can eat
- Big water bottle so you don't have to fill it up too often

you can lose track of time when you're sleeping a lot

The small things will help ie. watching your favourite movie, book etc.

WHAT STUFF SHOULD I BRING TO DO?

to listen to music or watch tv/ films

- Headphones/earphones
- Earplugs – to block out noise
- Something you can watch films, TV or play games on
- Books and magazines
- Things to distract you

puzzles, a book of cross-words or a colouring book

- If you crochet or knit, bringing some bits and bobs with you will really help to pass the time
- A pack of cards to play with visitors

Hospital wifi can be hit or miss, so download some music, games, or movies so you don't have to rely on being online.

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

Search for Teenage Cancer Trust and Young Lives vs Cancer on TikTok and Instagram

WHO COULD I MEET?

You'll be treated by a team of experts who specialise in different things. 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 tricky to remember. So, don't worry if you forget somebody's name or what they do. It's OK to ask them to repeat their name or explain their job title or what they do as many times as you need to. They won't mind, and you need to be sure you know who is in your team and what they do.

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 called your **'care team'**.

Over the next couple of pages is a list of the different people you might meet

PEOPLE YOU MIGHT MEET

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

WHO YOU MIGHT MEET FIRST

General Practitioner (GP): Your GP is the doctor you see at a practice (doctor's surgery) close to where you live or study. GPs are sometimes called family doctors. You might stay in touch with your GP during your treatment. They can help you make choices about things like where you want to be treated.

Nurse: Nurses work in lots of places. They might specialise in a certain area like paediatrics (children), theatre nursing (surgery) or work in a GP practice.

DIAGNOSIS AND TREATMENT

Radiologist: An expert at reading scans. Radiologists can look at X-rays, CT scans, MRI scans or PET scans and check them for signs of cancer or see how your treatment is going.

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

Radiographer: Experts who give radiotherapy treatment and control the machines used for X-rays, CT scans and MRI scans. When they give radiotherapy, they are sometimes called radiotherapists.

SPECIALIST CANCER CARE

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

Oncologist: A doctor who specialises in treating cancer.

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

Clinical Nurse Specialist (CNS): An expert nurse who focuses on cancer treatment. They can give you advice and practical support, and they'll be there for you if you need someone to talk to. They might call themselves your 'keyworker'. There is space to write their name at the front of this booklet.

Resident doctor: Qualified doctors who are training in a certain area of medicine. They used to be called junior doctors.

Palliative care team: The people whose job it is to help with your cancer symptoms and help you manage any pain. Palliative care doctors can also help you and your family deal with how cancer affects your feelings and emotions. Sometimes people think palliative care is only for people who aren't expected to be cured, but it's actually any treatment that's given to relieve symptoms.

PAL-ee-uh-tiv

EVERYDAY CARE IN HOSPITAL

Healthcare assistant: They support nurses by checking on patients and helping with treatment.

Ward nurse: A nurse that works on a hospital ward. They carry out day-to-day care and give treatment. This includes giving injections and taking blood.

EATING, MOVING, TALKING AND DAILY LIFE

Dietitian: An expert who can help you plan your meals and snacks by looking at the type of cancer you have, how much energy you need and if you're having trouble eating certain things.

Occupational therapist: Cancer can affect how you do the things you usually would. Occupational therapists help you to do what you want and need to do, and to overcome any problems you may be experiencing with your everyday routine.

Physiotherapist (often called a physio): Experts in helping with physical problems that may be caused by cancer and its treatment. For example, feeling weak, trouble walking or getting out of breath. Physios can help you move better and get stronger, as well helping you stay active.

Speech and language therapist: An expert who can help you communicate and swallow. For example, if you have mouth cancer, throat cancer or a brain tumour that affects your talking or eating.

FEELINGS, EMOTIONS, AND COPING WITH CANCER

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

Youth Support Coordinator: Often funded by Teenage Cancer Trust, Youth Support Coordinators are youth workers who provide emotional support. They are non-clinical, but they are part of your care team, and are there to support you with the things that are important and useful to you.

*If you live in Northern Ireland, you might see a Youth Support Worker instead, funded by the Cancer Fund for Children.

Social worker: Young Lives vs Cancer Specialist Social Workers and the social work team can support you and your family with life during and after cancer treatment. They can help with lots of practical and emotional issues, applying for benefits, to talking to your carer, and working through any problems at school, college or work.

Psychologist and/or counsellor: A trained professional who can help you deal with difficult emotions, problems in relationships, choices about your treatment and worries about the future.

This might be socialising and connecting with people your own age, helping you to understand and make decisions, or giving you practical help with things like friendships, how you look, or going back to school, college or work.

THINGS THAT HELP

When things feel heavy, small things can make a difference.

This might be a person, a song, a routine, a distraction, or something comforting. If you want to, write a few of them down here. It might be helpful next time you feel like this.

WHAT TREATMENTS ARE THERE?

After you're given a cancer diagnosis, your care team might start talking to you about treatment options. Remember, you can ask any questions you have, and you can always get them to repeat something if it doesn't make sense.

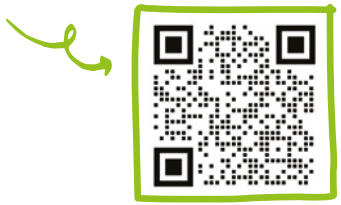
Some common types of cancer treatment for young people include:

- **Chemotherapy:** A drug treatment used to kill off cancer cells. Often called 'chemo'.

  kee-MOH-ther-uh-pee

- **Immunotherapy:** A form of treatment that helps your own immune system recognise and kill cancer cells.
- **Radiotherapy (or radiation therapy):** A treatment that works by targeting cancer cells using types of radiation. Sometimes radiotherapy is given from outside your body and sometimes it's given from inside your body (using liquids and implants).
- **Surgery:** An operation to remove cancer and sometimes other tissue around it too.

You might just have one type of treatment, or you might have more than one. Your care team will work out what's right for you by looking at all of your medical information. There is more information about treatments, how they work, and what they involve online.



WHAT ARE THE SIDE EFFECTS OF CANCER TREATMENT?

If you know you're going to have treatment, you might be worried about side effects.

The most important thing to know is that everyone reacts to treatment differently. That's because the type of side effects that you have depends on a lot of things, like the type of cancer you have and the type of treatment you'll be given.

You might get short or long-term side effects, or you might not have any side effects at all. Everyone is different. It's not a good idea to compare yourself to other people because everyone experiences their cancer differently.

We've listed some common side effects here, but there's more information on our websites.

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

Tiredness

Cancer treatments can leave you feeling very tired or fatigued. This can last for a few 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. Go to bed around the same time each night and try to put your phone away an hour before bed. Get active in a way that works for you – movement can help with tiredness and fatigue and help your mental health. **Don't overdo it.** And let other people help you out.

Give yourself permission to slow down

It can be helpful to plan your time around fatigue to try and make the most of the energy you have. If you have plans in the evening, it can be helpful to take it easy in the morning.

How can you deal with tiredness?

- Get 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

Nausea (feeling sick)
Some treatments can leave you feeling sick. This can start a few hours after treatment and can last for quite a while. But if you let your doctors and nurses know that you feel sick they might be able to give you medicine that will help you feel better and can stop you from throwing up.

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. These symptoms can also affect how your 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.

If you get mouth ulcers, let your care team know as soon as possible. Try using a soft toothbrush, or child's toothbrush, if your mouth is sore.

Chemo brain/brain fog
Some people say while they're having chemo they struggle to concentrate or find it hard to think clearly.

This is sometimes called 'chemo brain' or 'brain fog'. But these aren't medical terms so sometimes you might also hear your care team talk about 'cognitive changes' when they are describing them.

It can be worrying or unnerving but don't worry if you feel like this, **you're not alone.**

These symptoms usually slowly improve once you've finished chemo but **talk to your care team** if you're worried. Putting reminders in your phone or a diary can help you remember important things.

Diarrhoea or constipation
Chemotherapy can affect how your bowel works which could mean you end up constipated (pooing less than normal) or having diarrhoea (pooing more than normal). There are medicines that can help with both of these things.

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

More info on sensitive skin on the next page

If you're having external radiotherapy, you might notice your skin has a reaction, similar to sunburn, in the place at the site where you had the 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.

Immune system side effects

If you have immunotherapy, you might get other side effects related to your immune system. This can include things like itchy rashes, problems with breathing, and swollen joints (like knees or ankles). Your care team can help you understand any symptoms you need to look out for and give you more information.

"I lost my hair, and it bothered me to start with as I woke up with bits falling out. My mum and I buzzed it off and she bought me lots of caps, which I wore initially. Then I decided that I wasn't bothered, and I wasn't going to hide away. I didn't go out much, but people would stare when I did. I got used to it and I didn't really care."

★ GEORGE

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.

Chemotherapy can cause hair loss that usually starts between ten days and three weeks after the first course of treatment. Some people lose all their hair, other people 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, leg hair, facial hair and pubes.

Radiotherapy can also cause hair loss on the specific part of your body where you have had the treatment.

You can always **ask your care team** any questions you have about hair loss.

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. Removing weaves, extensions and braids can also be helpful
- 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 unless your care team says not to
- Avoid dyeing, perming, or chemically relaxing your hair – your skin might be extra sensitive during treatment, and your hair might be more fragile meaning it gets damaged more easily
- Be gentle with your hair. Don't use high heat on tools like straighteners, curlers or hair dryers, and let it dry naturally when you can
- Use a hairnet, silk cap, bonnet, headscarf or headwrap at night to avoid friction with your pillowcase. Silk pillowcases can also help

What would you say to someone who might lose their hair?

- Shave your head when you feel ready → not when others want you to
- Try silk pillowcases when it's falling out so it doesn't clump as badly at night
- The feeling of things touching your head will get better over time

Your hair will usually start to grow back a few weeks after your treatment finishes, but it can take about three months before you can really see the new hair. If you have certain types of radiotherapy, it can take longer for your hair to grow back.

When your hair grows back, it might look different – it could be thinner, thicker, curlier, straighter or a different colour.

"I had waist length hair which I loved, so it was painful when it was coming out in chunks. Cancer takes so much from you, but I thought I'm not going to let cancer take my hair. I'm going to take back control by choosing when I shave my hair off. I was relieved when I did it as it was my choice."

* KAYLA

Cancer Hair Care 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. They also offer a free Wig Bank service providing synthetic wigs. You can order one of their hair loss support packs from their website for free.
cancerhaircare.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.
littleprincesses.org.uk

Is there anything you'd recommend trying?

- Get a nice selection of beanies
- Bandanas are good for protecting your head from the sun without making you too hot
- I got into baseball caps! → I have loads - it's fun collecting them
- Your head and scalp will be sensitive so invest in comfy hats

use support when it is the right time for you.

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'.

new-troh-PEE-nee-uh

Getting an infection when you are neutropenic is very serious. So, 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 of 37.5°C or above
- Your skin feeling hot when you touch it
- Feeling cold or shivery
- Achy muscles
- Tiredness
- Stinging or pain when you pee
- Diarrhoea
- A headache
- Confusion or dizziness
- Pain when swallowing
- A sore mouth with any redness or mouth ulcers
- Having a cough
- Coughing up spit that's green, brown, or has blood in it
- Shortness of breath
- Pain, redness, swelling or discharge (liquid) from a cut or near your IV line
- Pain that you didn't have before your treatment

"My immune system was hammered and at one point I had five different infections. It meant that I started my maintenance treatment late and spent more time as an in-patient than planned. Maintenance treatment wasn't easy, but it was mostly steady, and I was able to go to the gym most days and play football".

* HARRISON

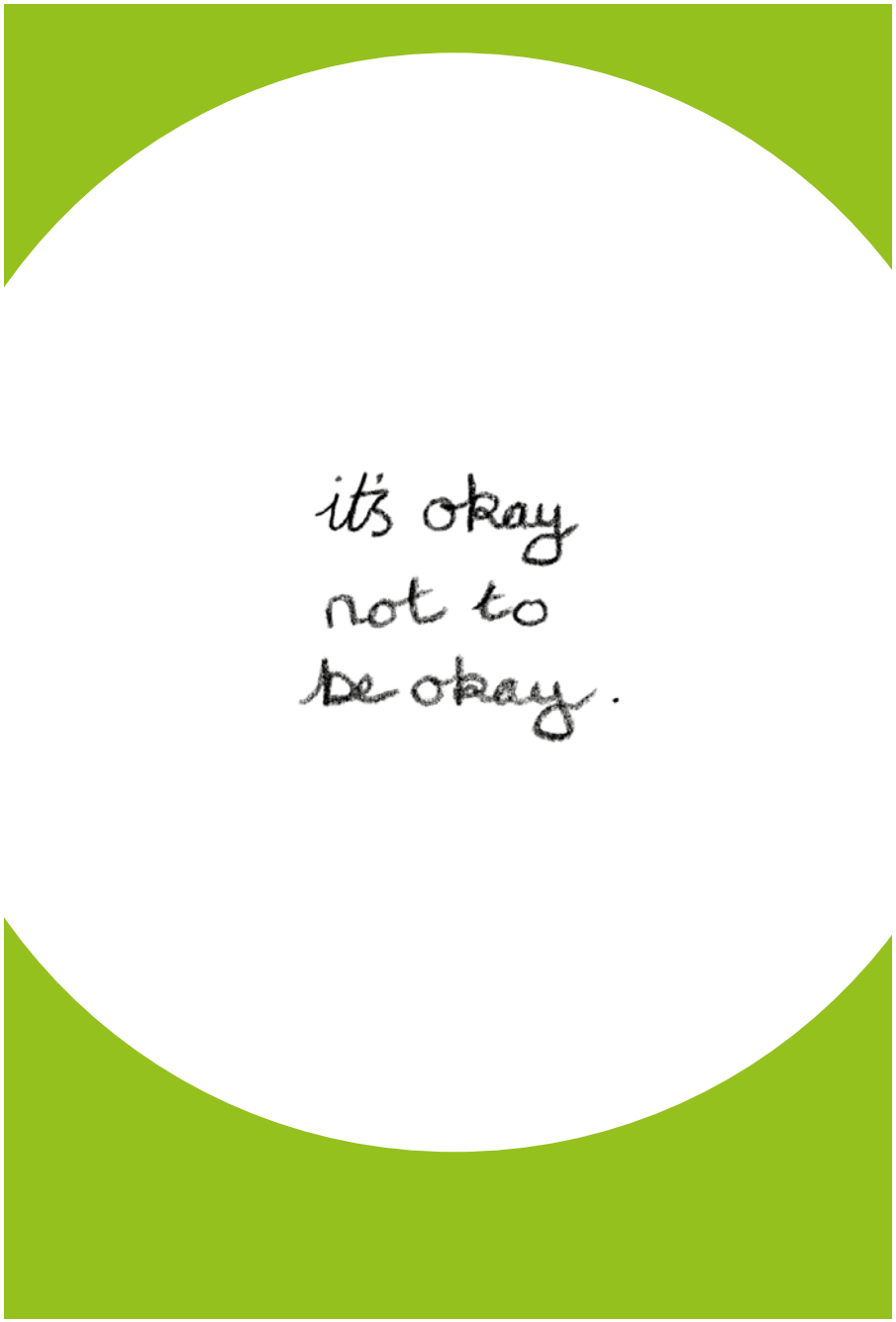
When you start your treatment, your doctors and nurses will let you know who to contact in case of an emergency and which hospital to go to. Write this information down or keep it saved in your phone, so you have access to it if you need it.

It's also worth sharing this information with your family and the friends you see often so they know what to do, and who to contact, in case of an emergency.

A PAUSE PAGE

You don't need to take all of this in at once.
If it helps, stop for a moment here.

Take a breath.
There's no rush.



WILL CANCER AFFECT MY FERTILITY?

The word 'fertility' means your ability to have children.

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

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

You might not have ever thought about having children, or it might feel like something you wouldn't be worried about for a long time. But if your doctor recommends a treatment that could affect your fertility, it's worth thinking about what that means for you.

You will be able to speak to a specialist team who will talk you through how your fertility might be affected and what your options are.

This conversation might happen soon after your diagnosis.

There might be things you can do that will help you have children in the future. This is called 'fertility preservation'.

Being asked to decide about having children when you're older, especially if you haven't really thought about it before, can feel overwhelming. You might not feel ready to make this decision.

Try to talk about it with people you love and trust. It can feel like a big deal, but it will probably help to talk things through. 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.

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

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.

There are some questions you might want to ask on the next page

"It was a difficult thing to have to think about at 22 and a hard discussion to have with my partner. At an age where infertility shouldn't have even been a thought, it suddenly became urgent. Cancer didn't just threaten my health; it forced myself and my partner to face questions and have difficult discussions that most couples our age never have to."

☆ LAYLA

Will my treatment affect my fertility?

Will it be permanent or temporary?

What fertility preservation options do I have?

How long do I have to think about my decision?

What would happen if I delayed my treatment to have fertility preservation?

Could I have a different type of treatment that doesn't affect my fertility?

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: **cancerfertilityandme.org.uk.**

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

OUTPatients is a charity that offers support to LGBTIQ+ people affected by cancer, including online and in-person support groups. **outpatients.org.uk/support**

"I'd always thought that my partner would carry our children, but after I was told that I couldn't wait for fertility treatment it did hit me. I've decided I just need to take it day by day though, and they are going to check my fertility after my treatment has finished."

☆ KELLY

THINGS I CAN COME BACK TO

There may be days when everything feels like too much.
This space is here for reminders – words, thoughts or notes you might want to come back to when that happens.

Stay away from Dr Google!!

WHERE CAN I FIND MORE INFORMATION ABOUT CANCER?

Some people might want to know everything 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 feels better for you, it's your experience and your choice how to deal with it.

If you do want to find out more, the internet is the obvious place to start – but there are some things to watch out for.

You can find lots of great information online, but there's also lots of confusing or incorrect 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 information on our websites. These are good places to start. You can find a list of 'useful contacts' by using the link here

Keep it local: Try and keep to information from UK-based websites. While cancer diagnoses might be the same across the world, the types of treatment and care people have can be very different.

teenagecancertrust.org/useful-contacts

Don't rely on AI: AI-generated information can get things wrong because it mixes information from different sources and not all of it will be accurate. It's best to go to a trusted website. Websites will also have extra information and more details you might find useful.

Stay aware: People online can use fake information, stories, and pictures to try and sell you things. They might say they have a way to make you feel better or even cure your cancer. It's important to know that this is not true, and nobody should be asking you to buy anything.

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 scheme 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: **pifonline.org.uk.**

Remember, you can always talk to your care team about any information you've seen online.

Trusted Information Creator

Patient Information Forum

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

Social media
It makes sense that you might want to search for information on social media when you hear you have cancer, and sometimes it can be helpful to hear about other people's experiences.

But it's also important to know that **everyone's cancer experience is unique.** Even if someone has the same diagnosis as you, they might still have different symptoms or a different type of treatment.

Information on social media can also be wrong. And sometimes it can be upsetting, overwhelming or stressful too.

If you hear something about cancer or cancer treatment from social media, it's a good idea to speak to your care team about it, especially if it's something that's worried you.

If you watch or read lots of posts about cancer on social media, your feed might show you more of them. If this is stressing you out, or just making social media less fun, you can usually reset your feed in the settings menu.

WHAT ABOUT MY JOB?

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.

If you have cancer, your employer is legally required to make **'reasonable adjustments'**.

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

That's because, even though you might not think about yourself as 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.

This can be quite complicated to understand, so if you have a specialist social worker or Youth Support Coordinator, they'll be able to help talk you through what this means.

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

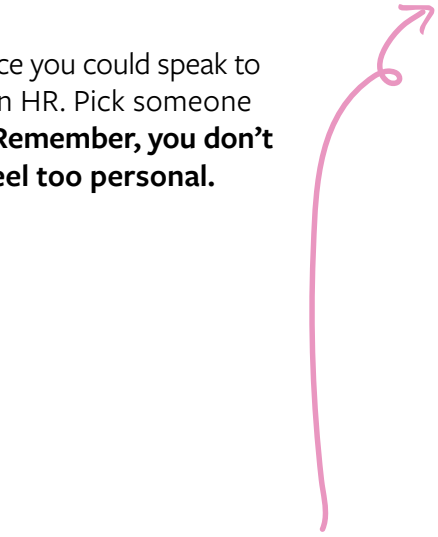
WHO DO I NEED TO TELL?

Legally you don't have to tell anyone about your cancer diagnosis – even your employer.

But if you don't tell them then they don't have to offer you any extra support you might need to do your job.

If you do tell them, it's illegal for them to treat you unfairly afterwards.

If you do want to tell your workplace you could speak to your line manager or somebody in HR. Pick someone you feel comfortable speaking to. **Remember, you don't have to share any details that feel too personal.**



What could I say in an email? You can copy the email here

teenagecancertrust.org/backtowork

Dear [manager/HR]

I have been diagnosed with cancer.

I will be starting my treatment on [date]. During my treatment I will need some support at work. This might mean taking sick leave, going to medical appointments, or working flexible hours.

It would be good to talk about my options for taking time off, as well as reasonable adjustments I may need during this time.

I would [like/not like] to share this information with my colleagues. It would be helpful to talk about how to handle this.

I'd be happy to talk over any questions you have on the above.

Many thanks
[name]

WHAT ABOUT MONEY?

If you have cancer, you might be able to get paid sick pay from your job. There are also benefits you can apply for to help you with money. Your specialist social worker can help you understand all of this.

Access to Work
You and your employer might 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 at work and also money for communication support at job interviews.

Visit **gov.uk** or **nidirect.gov.uk** for more information.

Will I still get paid if I can't work?
If you're too ill to work, you may be 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 **gov.uk/statutory-sick-pay** for more information.

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

What if I'm unemployed?
If you're not working when you're diagnosed with cancer you won't be entitled to SSP, but you may be able 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 **gov.uk/contact-jobcentre-plus** for more information.

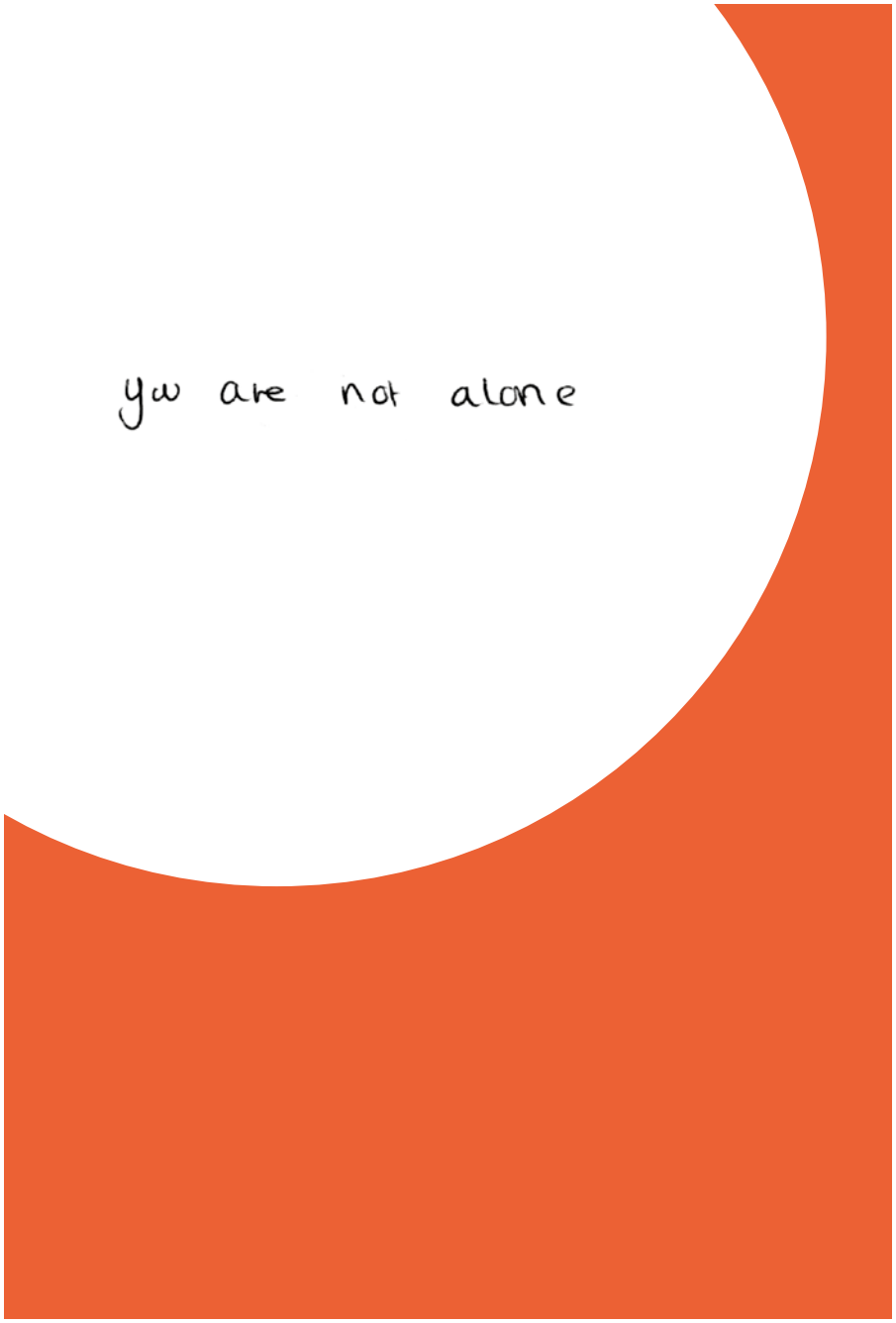
Healthcare Travel Costs Scheme (HTCS)
Travelling to and from appointments can cost a lot of money. In some situations, you can claim a refund for your travel costs. Search 'HTCS' on **nhs.uk** for more information and to find out if you're eligible.

Personal Independence Payment (PIP)
If you're over 16, you might be able to apply for Personal Independence Payment (PIP) (Adult Disability Payment in Scotland). This is paid to people who have a long-term health condition and who are finding it hard to get around or do everyday tasks. Search 'PIP' on **gov.uk** for more information.

Young Lives vs Cancer Grant
Young Lives vs Cancer may be able to provide a grant for things like travel, bills, food or other unexpected costs. Speak to your specialist social worker to find out more.

A grant is money that you don't have to pay back

younglivesvscancer.org.uk/finance



WHAT ABOUT SCHOOL, COLLEGE, OR UNI?

You might need to take some time off school, college, or university while you're having treatment. But this doesn't have to mean you're going to fall behind.

If you're under 16 you might be able to carry on with school-work 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 getting emailed schoolwork 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 talking to your school, the Young Lives vs Cancer social work team can help you.

younglivesvscancer.org.uk/education

Disabled Students' Allowance (DSA)
You might also be entitled to apply for DSA to help cover any education-related costs you have because 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: **nidirect.gov.uk**.

Education support
You might also be able to get extra support with your studies. It depends where in the UK you live, so check your government's website 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.

Reasonable adjustments are small changes that might make a big difference to how you manage your studies.

"I had all of Year 9 off school and was in for just under half of the time in Year 10. I've dropped some of my GCSEs but I'm still a bit worried about my exams. The school said that I could choose less GCSE options so I could spend extra time doing English and Maths."

☆ OSCAR

Some changes that you might ask for could include:

- Extra time for coursework and longer deadlines
- Someone to help you make notes (this is sometimes called a 'scribe')
- Being able to use a computer and special software to do your work or exams
- A place where you can leave things you don't need all the time instead of having to carry them around, like a locker
- Special dietary changes like 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
- Extra support for practical or field work
- Being able to get in touch with staff when you're away – this might be to catch up on work or to ask for extra support
- If you have a car, you might be able to get your own parking space, so you have easier access to buildings
- A space to go if you're feeling stressed, overwhelmed or overstimulated
- Adjustments to sports sessions and PE classes

WHAT I WANT PEOPLE TO KNOW

Sometimes it's hard to say things out loud.
If you wanted to, what would you want people around you to understand right now?

You don't have to share this page with anyone if you don't want to.

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.

(al-uh-PEE-shuh)

Benign: The medical term for a tumour in your body that isn't cancerous.

Biopsy: When a small amount of tissue is taken from your body so cells can be looked at 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 who look after you during cancer treatment. Your care team is part of your multidisciplinary team.

Chemotherapy: Often called 'chemo', chemotherapy is a drug treatment used to kill off cancer cells.

Clinical trial: A type of medical research. They can study a range of things, including how well cancer treatments work and their side effects.

Diagnosis: When a disease is identified from signs or symptoms.

Fatigue: An overwhelming feeling of tiredness, exhaustion and lacking energy - it's more than just being tired. Fatigue is 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 work together to protect you from illness.

Immunotherapy: Immunotherapy is a form of treatment that helps your own immune system recognise and kill cancer cells.

Intravenous (IV) line: A flexible tube that goes directly into a vein and can be used to give blood, drugs or fluids.

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 tumour that's been caused by cells from a first (primary) tumour which have spread to another part of your body.

(meh-TASS-tuh-sis)

Oncologist: A doctor who specialises in treating cancer.

Palliative care: Treatment designed to help with symptoms. Sometimes people think palliative care is only for people who aren't expected to be cured, but it can be given 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 types of radiation. Sometimes radiotherapy is given from outside your body and sometimes it's given from inside your body (using liquids and implants).

Relapse: When a disease comes back, usually after having treatment and after the signs and symptoms have gone away or got better for a while.

Remission: When the signs and symptoms of a disease go away or get better.

Secondary cancer: A type of cancer that has spread from a primary cancer to somewhere else in your body.

Side effects: Unwanted effects caused by treatments. Side effects can happen after chemotherapy, radiotherapy, immunotherapy and surgery.

Terminal: A word used to describe diseases that can't be cured. Sometimes the word 'incurable' is used instead.

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. AYA is sometimes used instead, which stands for adolescent and young adult.

RIGHT NOW

Right now, I'm feeling...

There's no need to explain it.
A word, a shape, or nothing at all is enough.

everyone's experience is different

WHO WE ARE AND WHAT WE DO

TEENAGE CANCER TRUST

Teenage Cancer Trust is the only UK charity providing specialised nursing care and expert youth support for young people with cancer. We're here for anyone diagnosed with cancer aged 13-24.

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.

Our 28 units across the UK are bright, contemporary spaces where you can feel at home, welcome family and friends, and be treated alongside others your own age.

Our expert nurses and youth workers are specially trained to help you navigate the physical, practical and emotional impact of cancer at every step – from diagnosis, through treatment and up to two years afterwards.

We also run events and activities, and provide easy-to-understand information about every aspect of going through cancer when you're young.

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

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 specialist social work teams 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, from extra costs to reduced income. We'll help you access the government support you're entitled to and can also provide a needs assessed grant for young people and their families experiencing financial challenges due to a cancer diagnosis.

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.

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

A BIG THANK YOU!

This project would not have been possible without the help and support of many people. We'd like to extend a big thank you to everyone listed below for the time they've given to make sure this is the best possible resource for young people with a cancer diagnosis.

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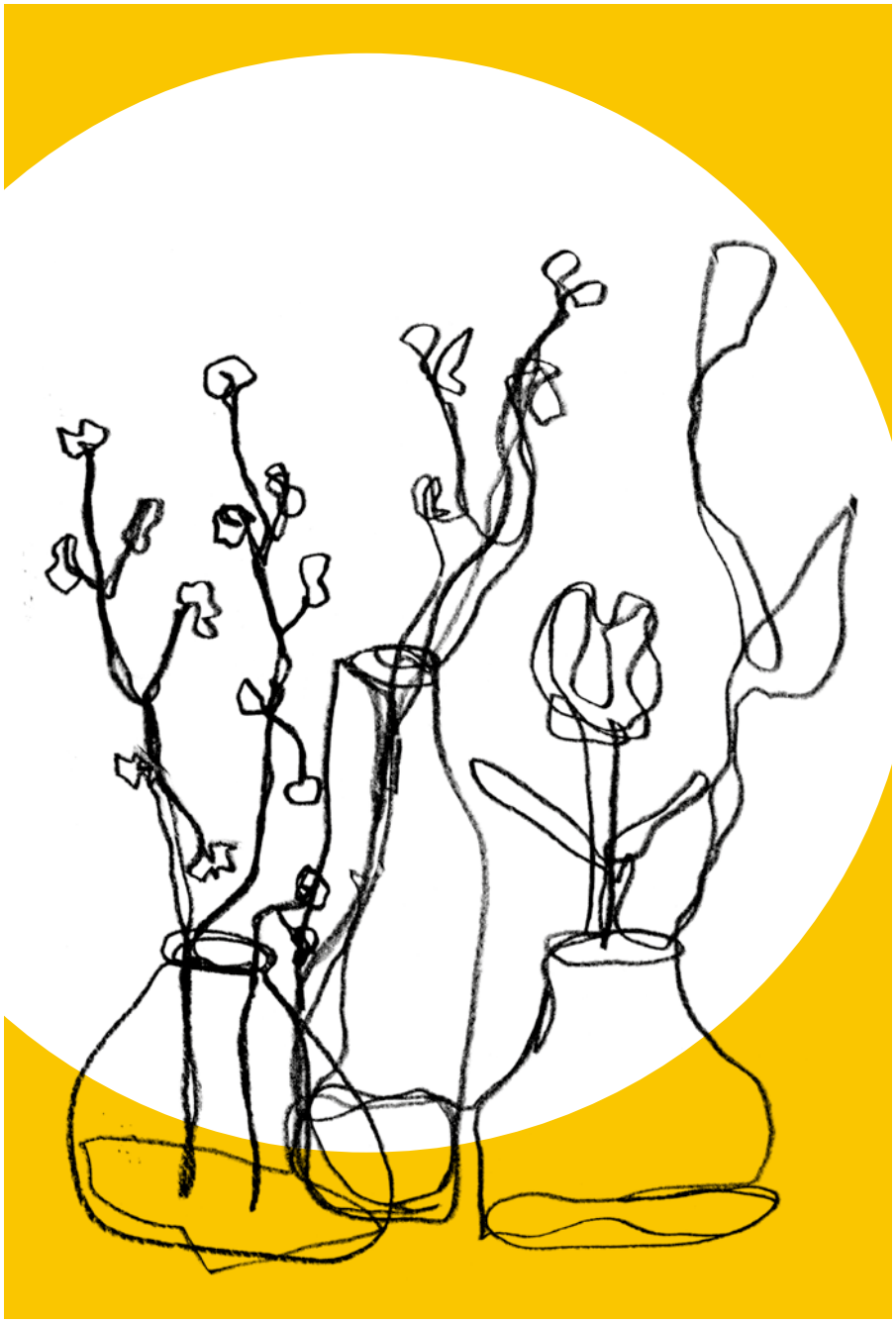

NOTES

TEENAGE CANCER TRUST + YOUNG LIVES vs CANCER

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