Involving young people in the production of clinical information

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About Teenage Cancer Trust

- Every day, **seven young people** aged 13-24 hear the words “you have cancer”.
- Teenage Cancer Trust is the **only UK charity** dedicated to providing the specialised nursing care and support they need to get through it.
- Cancer doesn’t just devastate a young person’s health. It threatens to take away everything they care about – their **identity**, their **independence**, and their **dreams**.
- We fund **specialist nurses, youth support teams and hospital units** within the NHS to provide the very best care and support during treatment and beyond…
- …making sure cancer doesn’t stop young people living their lives.

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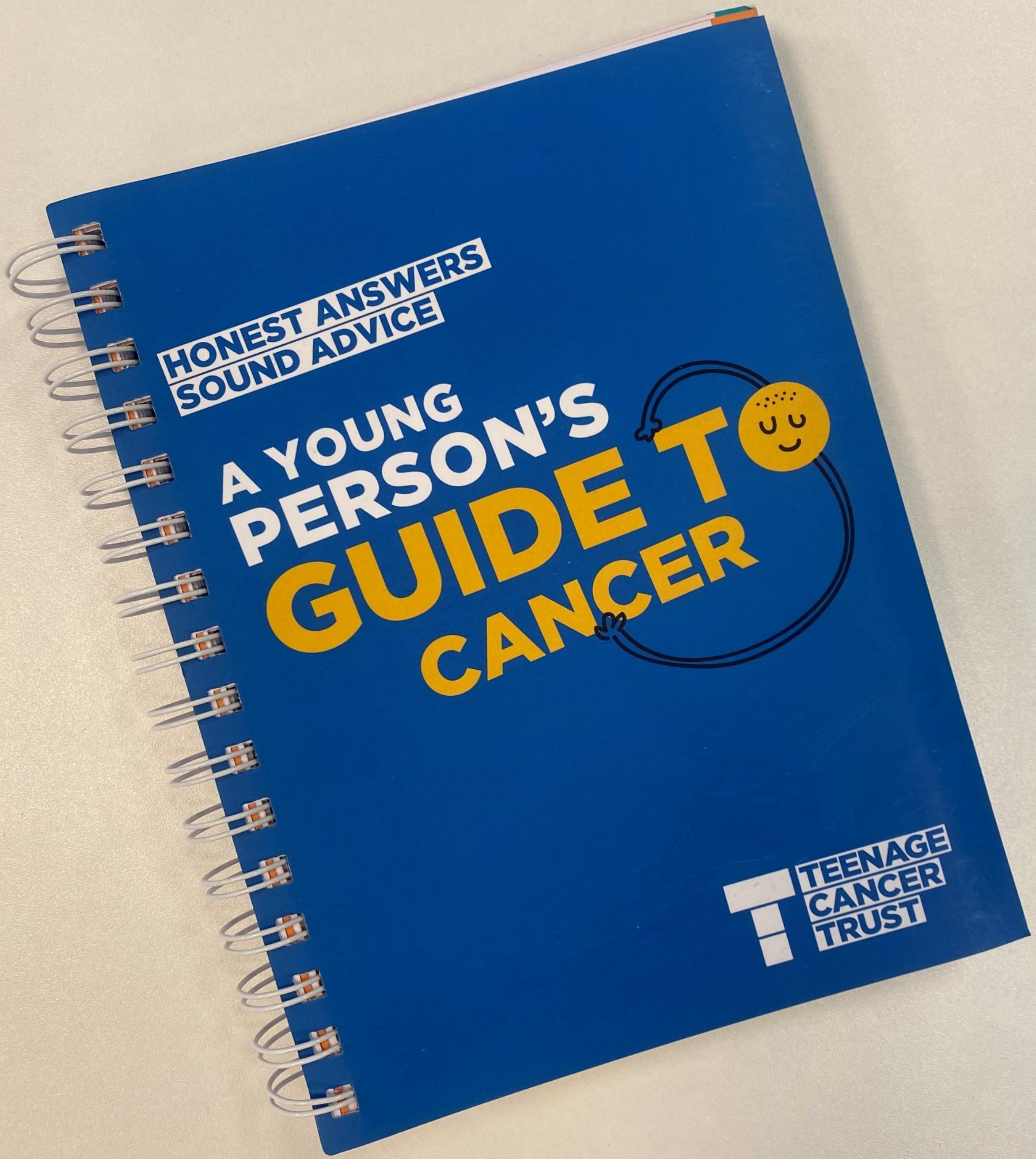
What did we have?



A Young Person’s Guide to Cancer

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- Our flagship information guide for young people with cancer was originally called: *Honest Answers, Sound Advice: A Young Person’s Guide to Cancer*
- This was first published in 2015 and updated in 2018
- Well overdue a review and an opportunity to make some significant changes
- An opportunity to bring the guide in line with our recently updated branding as well

What did we want to do?

1. Content review and update
2. Design review and update
3. Include young people’s voices
4. Make the guide more ‘interactive’
5. Incorporate more visual information

Design

Asking young people to share feedback on initial designs

- We used of our Find Your Sense of Tumour (FYSOT) U18 residential weekend to collect feedback
- 35 young people in attendance, aged 13-18
- Asked young people to feedback on cover design, which would in turn influence design style throughout

- Free form market stall feedback option

- World café, individual sessions, more in-depth feedback
  - Write the number of your favourite cover design
  - One reason why you like it
  - Two words to describe the design
  - Anything you would change?

CONCEPT 1

FINDING 'YOUR' WAY

CONCEPT 2

FINDING 'YOUR' WAY

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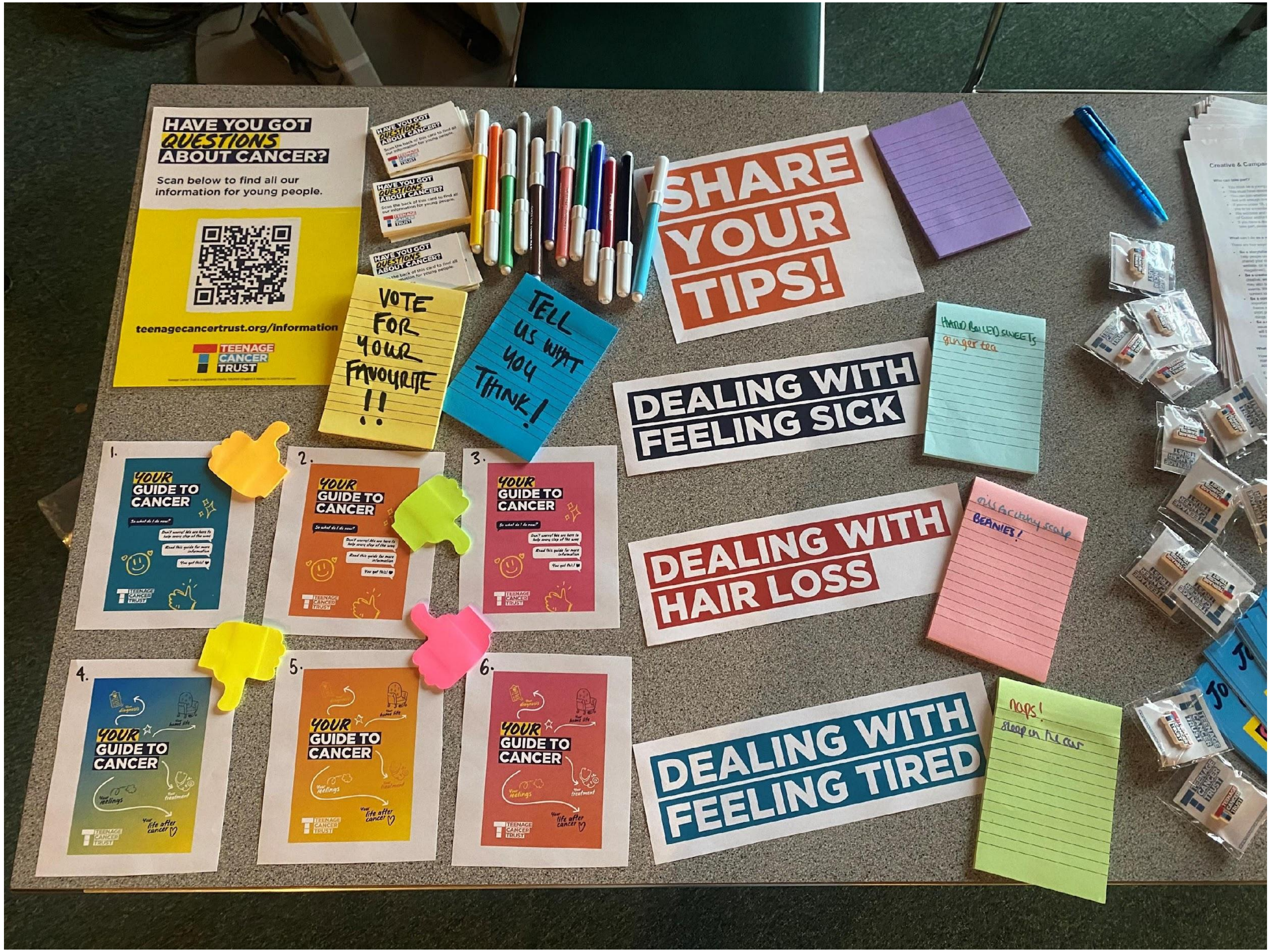

What did they tell us?

Reason: I like the colours and they work together

Two words: Bright and warm

Anything to change: Maybe make the pictures bigger

Reason: It's gender neutral

Two words: Bright and colourful, warm and inviting

Anything to change: More illustrations

Reason: The colours are warm and go well together

Two words: Welcoming and cosy

Anything to change: The design colour on the background is difficult to see

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Content

Asking young people to review content

- We have two review panels who help review all our information
- One is a group of young people who have had a personal cancer diagnosis
- The other is a group of young people who have not had a personal cancer diagnosis but have registered to volunteer with us and specifically in this role
- Both groups reviewed sections of the new guide and offered comprehensive feedback

Sharing young people's voices

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QUOTES

- We have shared the stories of significant numbers of young people who have had cancer
- We reviewed these stories to find quotes that matched and supported the information content in the guide
- We confirmed with young people they were happy for these to be shared in the guide

AIM

- A lot of young people with cancer feel isolated and might not meet many others the same age with cancer
- The aim of including quotes was to allow young people to relate their own experiences to others

Other sources of feedback

Nursing staff

- Teenage Cancer Trust funds nearly 100 roles in the NHS, including nursing staff at various levels
- We're lucky to be able to regularly engage with them
- We had 5 nurses agree to support with reviewing and feeding back on Your Guide to Cancer
- They provided a vital clinical and overall insight into the information and were an essential sounding board

Youth Support Coordinators

- Youth Support Coordinators are non-clinical roles funded by Teenage Cancer Trust
- They provide emotional support and help young people relax in hospital
- They create opportunities for young people to socialise and connect with people their own age, as well as giving practical help on things like physical changes and going back to school, college or work
- Two of our wonderful Youth Support Coordinators supported with the development of the guide and provided essential insight in the overall experiences of young people with cancer

The end result…

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YOUR TREATMENT

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

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

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

teenagecancertrust.org

Tests

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

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

What tests might I have?

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

Biopsy

What is it?

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

What's involved?

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

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

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

YOUR FEELINGS

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

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

Your emotions

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

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

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

You might be feeling...

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

  If you're worried about anything, it often helps to try and find reliable information about what you're going through so you understand what to expect. See page 22 for more tips on finding trustworthy information.
- **Uncertain** - Not knowing what's going to happen is one of the toughest things about cancer. It's easy to feel overwhelmed, but it can help to focus on the things you can control, like looking after yourself and eating well
- **Angry** - Cancer isn't fair. And it's totally natural to feel angry because of that. The fact that it's not your fault probably won't make you feel any better either.

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

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

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

YOUR LIFE OUTSIDE HOSPITAL

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

Dealing with relationships

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

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

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

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

They might be feeling:

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

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

Going backwards?

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

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

YOUR LIFE AFTER TREATMENT

Remission describes when the signs and symptoms of cancer are no longer visible.

'Remission' is probably the word you've wanted to hear for so long, congratulations!

When you're living with cancer and having treatment, you tend to spend a lot of time thinking about it – and about doctors, nurses, hospitals, tests, side effects and everything else that goes with your diagnosis.

When the day comes that you don't have to think about those things anymore, everything can feel a bit strange and slightly scary.

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

What does life look like now?

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

In fact, it can be hard to work out what 'normal' is now. That can be exciting, but it can be confusing too.

So give yourself time and don't rush into any decisions. It might help to think about what you want your life to look like now, rather than trying to rebuild your exact life before cancer.

Redefining your plans

Now can be a good time to look into different options for your future. It can help to talk to family, friends, careers advisers, social workers, religious leaders: anyone whose advice you trust. Writing down short or long-term goals can help too.

The most important thing is to do whatever feels right to you.

You might want to pick up where you left off with some goals, while others might need a rethink...

- If cancer has affected your body, your energy levels or your emotional state, you might not feel able to follow the plans you had before. This can be hard to adjust to, but don't rush to find a new direction. The time will come when you feel ready to think about different opportunities
- Maybe you're thinking about aiming for a totally new career. Whatever you're thinking, speaking to a careers adviser can help you figure things out
- Maybe you've got no idea what you want to do. That's nothing to worry about. This is a tough time, and no one will blame you for feeling confused. (And plenty of people live a happy life without ever really knowing what they want to do.)

Quotes

"Hanna (a Teenage Cancer Trust Lead Nurse) had given me a copy of this book and I read it all in about two hours before my treatment. It was so informative, and it made everything feel so normal as I knew other young people had been through this too.

Nobody I know had had cancer, but reading the book made me feel that this was something I could manage to get through.

It wasn't as scary after that. She also made me feel like there was no stupid questions and I could ask anything I wanted."

Lakita

"People say that once they hear the word 'cancer' that you switch off and don't hear anything else, which I think is what my mum did.

But I was the opposite. I was hyper aware and asked what we needed to do.

I felt reassured to know there were good treatment options"

Ellie

"My mental health was alright during the diagnosis and treatment; it was after my treatment ended that it got to me.

I went from seeing the staff every week to not going in. It's a big change as I was used to their reassurance."

Beth

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Quotes

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

Amy

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

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

Ellie

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

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

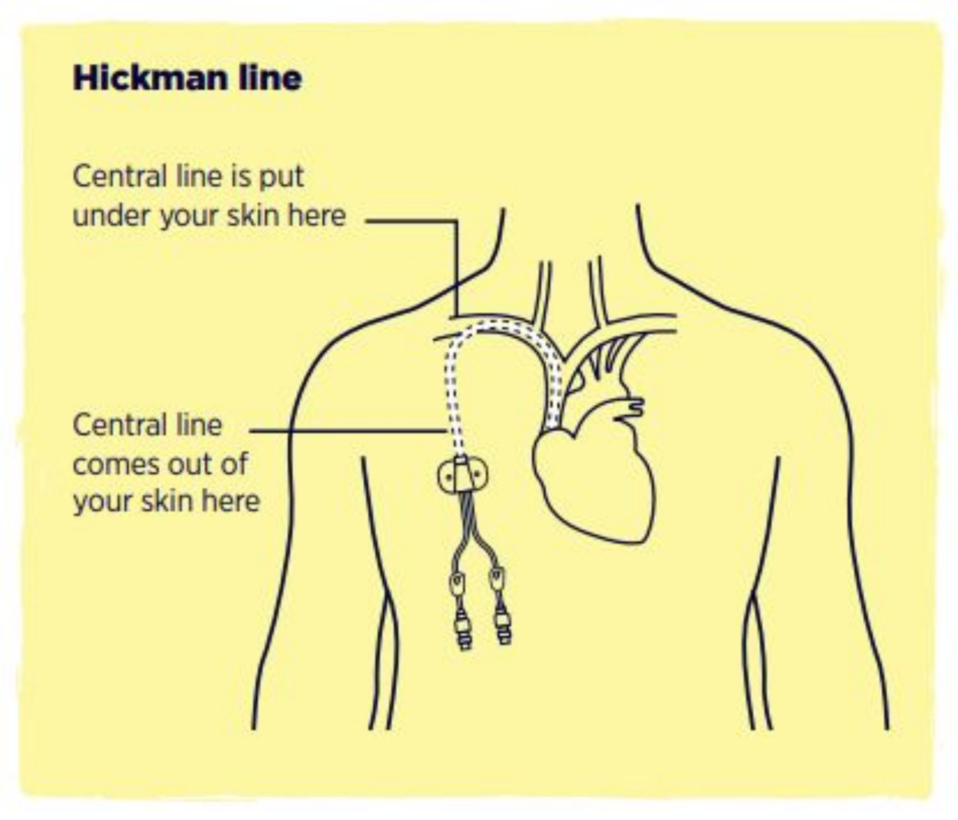
Katie

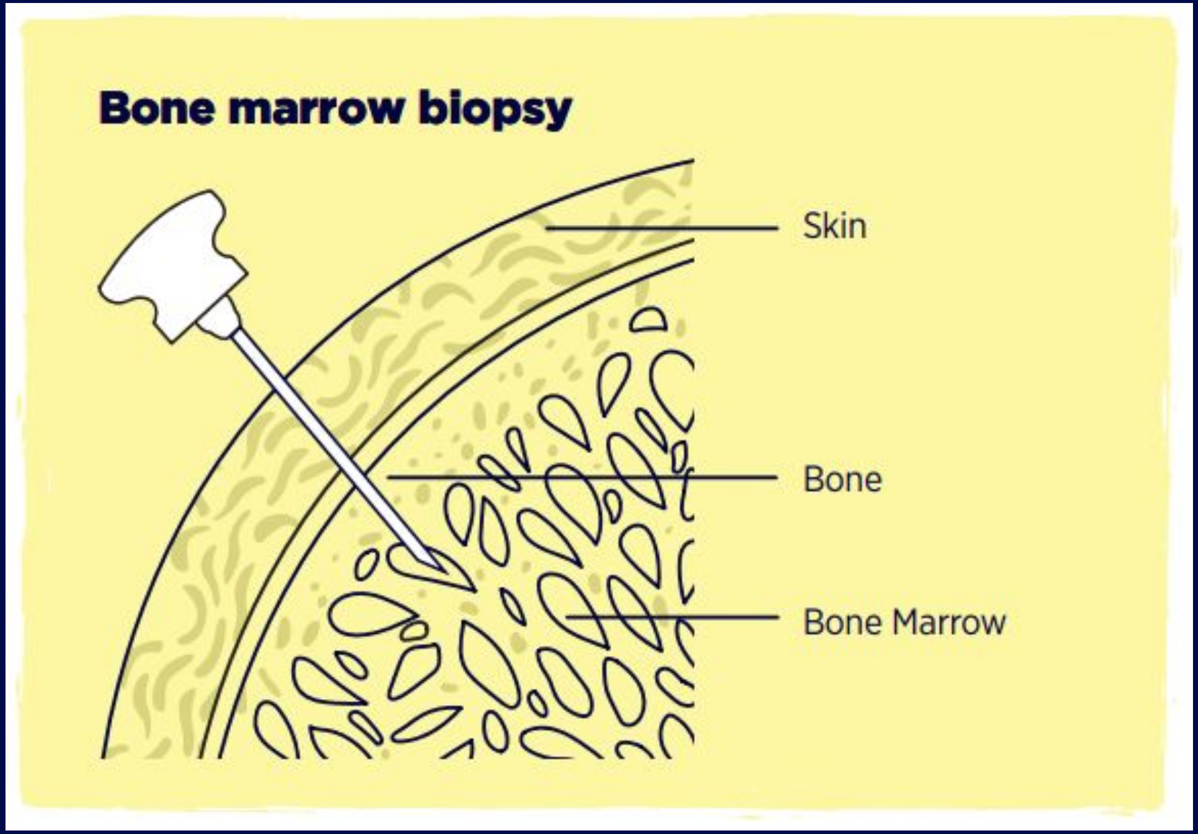
"Losing my hair upset me a lot.

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

Jake

Medical illustrations





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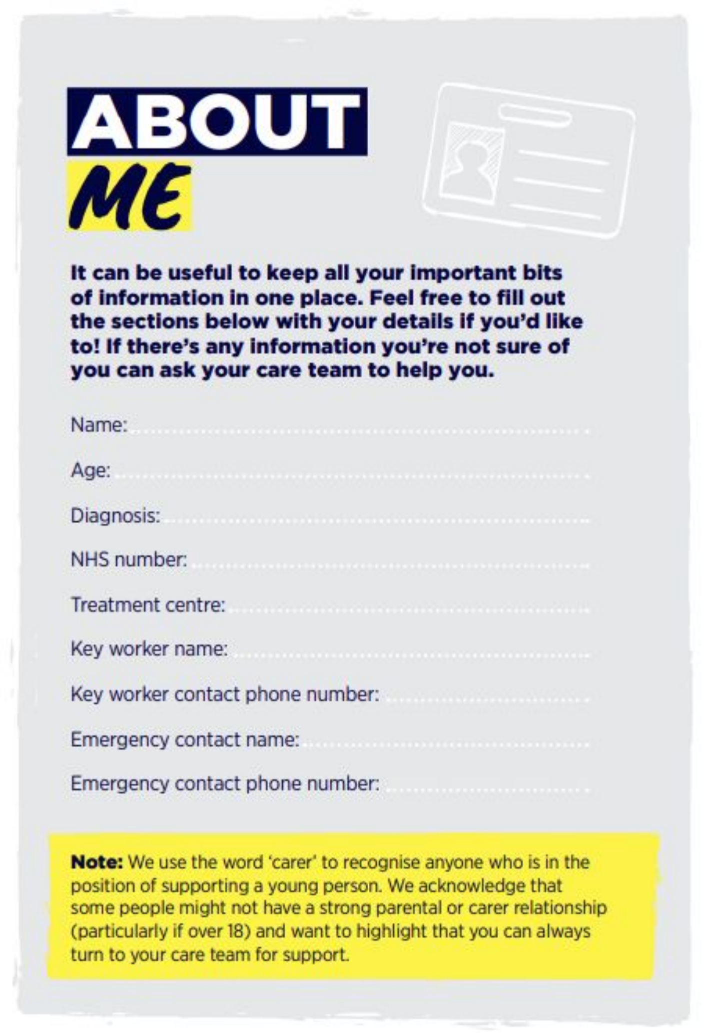

ABOUT ME

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

Name:

Age:

Diagnosis:

NHS number:

Treatment centre:

Key worker name:

Key worker contact phone number:

Emergency contact name:

Emergency contact phone number:

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

MEET YOUR TEAM

You can use this page to keep track of the names of everyone in your care team.

Clinical nurse specialist (CNS)

Consultant

Dietitian

General practitioner (GP)

Palliative care team

Physiotherapist and/or occupational therapist

Psychologist and/or counsellor

Social worker

Surgeon

Youth Support Coordinator

Any other details?

NOTES

The details…

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- Your Guide to Cancer was published in January 2023
- We did an initial print run of 2,000 copies
- We have already distributed approximately 1650 copies to young people around the UK with cancer
- 2,500 young people (13-24) are diagnosed with cancer every year – we expect to reprint soon
- The guide will be reviewed and updated in 2026

“It serves as both a teacher and a friend, introducing complex, often intimidating, medical concepts with kindness and clarity. It's empowering and effective, epitomising the very best of Teenage Cancer Trust and medical communication as a whole. It's been a privilege to have a tiny input into this fantastic book.”

> “Involving users is invaluable. It might sometimes make projects lengthier or feel difficult to do, but it’s so important. It means you can complete and deliver a project with the confidence that you’ve created something that’s appropriate, useful and valuable to your target audience”

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Feel free to get in touch with any questions!

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