

# Together YOUR

**SUPPORTER MAGAZINE** 

"Teenage **Cancer Trust** gave me the best of both worlds."

Kenn, Newcastle

**ALSO INSIDE** THIS EDITION

- #NotOK: Our mental health campaign p8
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## HELLO...

Welcome to the first edition of your Teenage Cancer Trust supporter magazine, *Together*.

Sticking together has been more important than ever in the last two years. It's been tough for all of us in many ways, and young people with cancer have been hit especially hard by the pandemic.

Like everyone in the NHS, our specialist nurses and youth support teams have also faced immense challenges. But as you'll read in these pages, they've continued to be a lifeline for young people. We receive no government funding, so this simply isn't possible without your support – thank you.

There's lots to celebrate, including the progress of our #NotOK mental health campaign, and the return of our flagship Royal Albert Hall gigs. And as you'll see, there's lots more change we still need to achieve for young people with cancer. Together, we'll get there.



**Kate Collins**Chief Executive



#### Got a question?

#### **Get in touch**

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# ABOUT US

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.

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

When we started in 1990, there was no such thing as specialist cancer care for young people. They were treated alongside children or much older adults, and were unlikely to ever meet anyone else their age with cancer.

We've made huge progress since, reaching more and more young people with cancer through our units, nurses and youth support teams.



But there's still so much more to do. In an NHS that's been stretched to its limits by the coronavirus pandemic, young people with cancer risk being forgotten.

We're determined to make sure their voices are heard and acted on, and that specialist support is accessible to all, with no-one left behind.

Our ambitious new goal is that by 2040, young people with cancer in the UK will have the best outcomes and quality of life in the world.

Sign up for updates on how your support is helping: teenagecancertrust.org



I had a growth in my nose which got quite aggressive. I started getting double vision and I couldn't see out of my right eye.

My mum was with me when the results came back, and we were both quite scared. We just didn't expect it to be cancer.

The Teenage Cancer Trust unit wasn't what I expected. I'd been in adult wards, and I definitely felt more comfortable at the unit

When I started chemo, it was really tough. But Danielle, the Clinical Nurse Specialist. helped me with my anxiety, and questions about the side-effects I was having.

I made a lot of Lego in hospital and Gemma, the Youth Support Coordinator, often came and sat with me. Gemma put on online events and introduced me to other young people on the unit, who were going through the same thing.

There was a bed in my room so my mum could stay overnight. I was so grateful for that as I needed her the most then. Teenage Cancer Trust gave me the best of both worlds as I could have my mum there with me, and also have Danielle and Gemma for support.



There was a bed in my room so my mum could stay overnight... **Teenage Cancer Trust** gave me the best of both worlds.

I became good friends with a lad called Jordan. There were days when I was lying in bed feeling awful, but then I'd hear his voice and it would encourage me to get up so I could go and join him.

You can struggle to sleep during treatment. Jordan and Lstarted walking around in the middle of the night and tried to scare the nurses. It was nice being able to have a joke. Sometimes you have to choose fun.

I also made friends with Safia. whose mum and sister would bring home cooked meals for me. It's things like that that give the unit a real community feel.

## THROUGH CANCER TOGETHER







Nellie Louise

Clare

Consultant Nurse
Nellie, Lead Nurse
Louise and Youth
Support Coordinator
Clare told us how
they've found
ways to continue
putting young
people first, amid
the extraordinary
challenges of the
pandemic.



#### THE CHALLENGE



**Nellie:** As a nurse, touch is really important – just being able to hold someone's hand, hug

them or stroke their hair if they're feeling a bit yucky. We continued to do that, but we were wearing gloves, so you lose some of that human touch. Also, because of the masks, they can't see your face – I adapted so that I could smile with my eyes.



**Louise:** Before the pandemic, friends used to come in to spend time with their mates.

or partners would cook tea for their loved one in hospital. That spontaneity and flexibility hasn't been there.



**Nellie:** Our units have the drip stands, they have the beds, but they don't feel like hospital

- more like a home from home. But with the pandemic, patients had to stay in their rooms and couldn't use the social areas. So mental health was hugely affected.

"The thing I have, that some ward staff don't, is time."

Clare

#### THE RESPONSE



**Clare:** We started virtual events for young people – often there was something happening

every day – and it was clear how much they wanted to meet others in the same situation. Then in the summer we were able to start doing events in person, which was a real joy, as it was the first time they'd met face to face.



**Louise:** We've made sure young people can still have a family member. friend or

partner with them in hospital. We consider these 'plus ones' a really crucial part of our team.



**Clare:** The thing I have, that some ward staff don't, is time. If that means sitting with a

young person and listening to them talk about their friends, or just about how crap having cancer is, I've got an hour to spend. I know how much they appreciate that, especially when they've had no visiting at all. So you build really close relationships.

You know you're doing the best you can, but sometimes you're unsure until afterwards, when young people come back and say, "I couldn't have done this if you hadn't been there."



# CANCER AND MENTAL HEALTH

Some young people are facing cancer without the mental health support they need. That's not OK – so we've launched a campaign to change it.

Facing cancer at any age is hard. But in your teens or early twenties, the impact can be devastating – especially on your mental health. Depression, anxiety and panic attacks are common, and the psychological disruption can lead to lasting problems in adulthood.

While our nurses and Youth Support Coordinators do amazing work every day to support young people emotionally, many will need additional support from a specialist psychologist.

But that support isn't always available. More than a third of young people with cancer surveyed in April 2021 could not access a

> psychologist when they needed to in the last six months.



"I finished radiotherapy and I thought I'd feel really happy, but I just felt lost."

Georgina, 24



So last June, we launched the #NotOK campaign, calling on UK Governments to make sure every young person with cancer can access specialist psychological support right from the point of diagnosis, wherever they live.

Over 2,000 people emailed their MP or elected member to help us put this issue on the parliamentary agenda, and more than 30 politicians publicly backed the campaign. Following this, nearly 7,000 members of the public pledged their support, helping us call for ring-fenced funding to address the issue.

As a result of the campaign, after meeting with eight remarkable young people with cancer to hear their experiences, in early 2022 the Cabinet Secretary for Health and Social Care in Scotland, Humza Yousaf MSP, made a public commitment to prioritise ensuring all young people in Scotland can access specialist psychological support.

This is a huge campaign win for Scotland, and wouldn't have been possible without everyone who's supported #NotOK so far - thank you.

Together, we'll keep fighting to make sure the right support is in place for every young person with cancer across the UK.

### Sign up to our email newsletter to stay updated:

teenagecancertrust.org







Chloe was 20 when she was diagnosed with thyroid cancer. She had to have both thyroid glands removed but didn't need chemotherapy or radiotherapy.

Chloe had been told she had the 'good type of cancer' which made her feel guilty and stopped her asking for psychological support.

"I didn't feel like I could ask for help. I would have felt like a fraud. You feel like you don't deserve it, and that they should be spending their time helping people who had had chemotherapy or radiotherapy instead. It was a throwaway comment, but those four words really messed things up for me.

"Because it all happened so quickly and because I had surgery rather than going into hospital for chemotherapy or radiotherapy, I don't think I had time to get my head around it and get closure.

"Three years later it's still sinking in. Seeing a counsellor or a psychologist would have helped me get that closure. If I'd got that help, I would have had a more positive outlook overall and been in a much better place."

# UNSTOPPAB

**FUNDRAISE** 

This edition's unstoppable fundraiser is Sean Kellv. who's clocked up hundreds of miles each year for the last 14 years to raise money for Teenage **Cancer Trust.** 



In 2008 my son was diagnosed with leukaemia. We were lucky as he survived. I pledged that I would support this charity forever, and I cannot praise its work highly enough.

All I do is run. This year will be my seventh London Marathon for Teenage Cancer Trust, and my eleventh Great North Run. I've also run numerous other events.

My son spent months on the Teenage Cancer Trust unit in Leeds, and over the next two years we were back there every week for treatment and check-ups. We benefited firsthand from the wonderful work our NHS does, and the superb work carried out in Teenage Cancer Trust wards and clinics

We also saw how cruel cancer can be. Girls who lost the chance to become mothers, young lads being stretchered in with their football kits and then having legs amoutated as they had bone cancers. Many young people lost their battles.

Whenever I'm struggling for motivation or feeling tired. I take myself back to 2008 and push harder. I want to honour the memories, the spirit and the fight of the people we met on our journey.

Inspired? Get involved at: teenagecancertrust.org/join



# **2022** AT THE ROYAL ALBERT HALL

After two years of cancelled shows, this March saw the return of our iconic Teenage Cancer Trust gigs for its 20<sup>th</sup> year, and together we raised over £1.5 million for young people with cancer!



Some of the biggest names in music and comedy joined us to support young people with cancer.







# SUPPORTING A FRIEND WITH CANCER

If you've got a friend who's going through cancer, you probably want to be the best friend you can be right now. But it's also totally normal not to know what to say or do.

**3 in 4** young people we surveyed in 2021 said their friendships were affected by cancer.

So, we asked some young people with cancer for their top tips on how you can support a friend during their treatment and beyond.



#### **Jake**

Communication is key. The stuff you can talk about with friends is essential to your wellbeing and sanity, giving a sense of normality to what you're going through.

09.42

#### Rian

You don't need to treat them any differently. You are fundamental to their escape from 'cancer duties'. Bring normality back to a world that is currently feeling more abnormal than ever.

09:43

#### **Alisha**

They will need your support after the treatment ends too. A lot of people think that once cancer treatment finishes there's this big celebration and the person can move on, but sometimes people are so focused on the treatment that it actually hits them the most once it's over. 09:44

#### **Kathryn**

If you are wanting to reach out to someone with cancer, just do it. Rip that band aid off and do it. It is better to do it now than even further down the line. It is not too late. 09:45

#### Lauren

Some of my friends drifted away. But others stuck by me the whole time. Most importantly they were just there to reassure me when I needed them.

09:46

# GET INVOLVED

Inspired to do even more? There's a whole host of ways you can help. Scan the code below to visit our website and join the team!



#### **RAISE MONEY**



Whether it's a pub quiz, a bucket collection in a shopping centre or a sponsored walk, your support makes our work possible.

#### DONATE

A single or monthly gift will make a real difference for the seven young people diagnosed with cancer every day in the UK.

#### CHALLENGE YOURSELF



Hike, bike, jump, swim or run
- whichever fundraising challenge you're inspired to take on, we've got it covered.

## GET YOUR WORK INVOLVED

Nominate Teenage Cancer Trust as your workplace's charity of the year, or get your colleagues involved to raise money.

#### **VOLUNTEER**



There are loads of opportunities to spend a spare hour (or 20!) helping us out, across the UK and all year round.

#### Find out more:

teenagecancertrust.org/join



