

SPRING 2026 | ISSUE 110

contact

MAGAZINE

Body image

How might cancer and its treatment affect someone's appearance? How might people feel? What support is out there?

+ WHAT RESOURCES ARE BEING DEVELOPED TO HELP WITH BODY IMAGE?

+ WHAT IS THE NORTH STAR CANCER COLLECTIVE?



Patient Story

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OVERCOMING
CHALLENGES AND
LOOKING TO THE FUTURE

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Contact

is a free, quarterly magazine for families of children and young people with cancer.

Contact aims to reduce the sense of isolation many families feel following a diagnosis of childhood or young people's cancer.

CCLG: The Children & Young People's Cancer Association brings together childhood and young people's cancer professionals to ensure all children and young people receive the best possible treatment and care. **Contact magazine was founded by The Lisa Thaxter Trust and CCLG and first published in 1999.**

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Past issues of Contact: The wide variety of articles published during the year in Contact adds up to a valuable and informative reference archive. If you would like any back issues, please contact the Editor. Details of key articles in previous editions are listed on our website.



The Children & Young People's Cancer Association

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KEEP IN TOUCH



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Your messages...

Praise for Contact's last edition...



"A very good edition
Really well balanced."



"Really informative,
particularly the articles
on stem cell transplants
and CAR T therapy."



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CCLG's research webinars are helping provide knowledge to professionals and families alike



"I manage a caseload of patients including those with neuroblastoma and am always keen to learn more. I really enjoyed it. Very relevant to my role and beneficial to share the information with others in the team."

All CCLG research talks are available at www.youtube.com/@cclg-uk



APRIL IS...

TEENAGE AND YOUNG ADULT CANCER AWARENESS MONTH

Every pound raised helps fund our research, provide trusted information for young people and their families, and brings together experts to improve treatment, care and outcomes.



Hello!

Changes in appearance can be distressing and tough to deal with for any child or young person, let alone one diagnosed with cancer. Already navigating identity and self-esteem, the effects of cancer and its treatment, both short- and long-term, such as hair loss, weight gain or scarring, can add to this pressure.

In this edition, we explore how children or young people might feel about their body image when confronted with changes to their appearance, as well as what might help them. We hear how parents and caregivers can play a key role by initiating honest conversations, providing reassurance, and celebrating strengths beyond appearance. Healthcare teams and charities can also help by introducing support like therapy or counselling, peer support groups, and practical tips for managing visible side effects.

As always, we're grateful to all those who have shared their experiences in this edition. Sharing what helped them navigate their own challenges will help other people facing similar issues feel less alone – and, hopefully, in a position to reach out for help when they need it.

Sally

If you would like to **SHARE YOUR STORY** in Contact or have an idea for a theme for us to cover, please let us know. Email us at editor@cclg.org.uk



Help us raise awareness of cancer in teenagers and young adults and support our work this April by selling our awareness ribbons



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MEDICAL ADVISER

Dr Ren Manias

Consultant Paediatric Oncologist at Southampton General Hospital and CCLG member

Body image is a topic that comes up frequently in paediatric oncology, sometimes directly, but often in more subtle ways. Many of the treatments we use have visible effects, and for children and young people this can influence how they see themselves and how they feel they're seen by others.

Changes in appearance may be sudden or gradual: hair loss, weight changes, scars, skin alterations, or the presence of medical devices. For some young people these are temporary, while for others, they're part of their long-term journey. Families often tell us that it's not only the physical change that matters, but the practical and social adjustments, too. Everyday tasks such as going to school, joining in activities, or simply being with friends can feel different when appearance has changed.

It's also important to recognise that body image is not only a concern for teenagers and young people. Younger children notice differences, too, even if they express them in simpler ways. Parents may find themselves balancing reassurance with honesty, wanting to support their child without minimising their experience. They also navigate public reactions, questions from peers, and the challenge of maintaining normal routines when their child looks or feels different from before.

As healthcare professionals, we have a role in acknowledging these issues early and consistently. A brief conversation about expected changes, or checking in about a young person's comfort with their appearance, can open the door to support before difficulties become entrenched. Psychological input, school liaison and peer support groups can all help normalise these experiences and provide practical strategies. Small adjustments, such as giving time to discuss hair options, helping families prepare for comments at school, or coordinating with allied health professionals, can make a noticeable difference.

Body image concerns can also intersect with specific conditions, such as hypothalamic obesity or long-term effects on hormones, which require sensitive, multidisciplinary management. Addressing the medical aspects alongside the emotional and social impact can help children and families feel better supported. Ultimately, our aim is straightforward – to ensure changes in appearance, whether temporary or lasting, are recognised as part of the overall treatment journey, and that young people and their families feel equipped to manage them with confidence.

NEWS IN BRIEF

CAR T-cells show promise for high-risk neuroblastoma

An Italian trial tested CAR T-cells engineered to target GD2, a protein on neuroblastoma cells. The therapy led to long-lasting remissions in children with high-risk or relapsed disease. Survival was highest when treatment was given early or in children with smaller amounts of cancer.

(Source: *Nature*)

Childhood liver tumours may block immune attack

Research shows that most hepatoblastoma liver cancers are able to exclude immune cells from the tumour, helping the cancer evade the body's defences. The study suggests the protein MDK, possibly controlled by β -catenin, may drive this protection. Understanding this could help develop new immunotherapies for high-risk patients.

(Source: *Journal of Hepatology*)

Nutritional problems common during childhood cancer treatment

A small study found that children with cancer don't just struggle with weight but can often also have vitamin and mineral imbalances and changes in growth. These issues may make treatment complications more likely, highlighting the need for monitoring and support.

(Source: *Nutrition and Cancer*)

Scans may help predict outcomes in childhood Hodgkin lymphoma

Scientists reviewing Hodgkin lymphoma scans have found that PET/CT scans measuring tumour size and activity could help predict whether treatment will be successful. Researchers suggest standardising how these scans are analysed across hospitals could help them be used for tailoring treatments.

(Source: *British Journal of Haematology*)

Dual therapy shows promise for childhood brain cancer

Australian researchers have found a promising new approach for treating childhood brain tumours. Their study lab-tested a combined therapy approach on a group of difficult-to-treat brain tumours: diffuse midline gliomas (DMG), finding that using two new-generation drugs, called epigenetic therapies, together may work better than using either on its own. While much more research is needed, the team hopes this work will one day lead to better treatment options for children with brain tumours.

(Source: *University of New South Wales*)



Katie Oates

“I’m stronger, determined and learning to love the body that carried me through so much”

Katie Oates was three years old when diagnosed with acute lymphoblastic leukaemia in 2009. Now 19, she tells us how her cancer and its treatment shaped her relationship with her appearance and how she has learnt to be proud of her body.

Being diagnosed with cancer was a moment that reshaped my entire life long before I could understand what was happening to me. My treatment consisted of three years of intensive chemotherapy, with daily blood tests, infusions and other painful treatments, which aren’t performed anymore.

These treatments saved my life, but I still have the scars they left. Chemotherapy not only took away my energy, but it took away my hair and the childhood softeners that everyone else around me still had. While other children had their first school photo taken with full heads of hair, mine were of me with half or very short hair, a reminder of a fight I never chose.

Body image and me

That experience shaped my relationship with my appearance for years afterwards. For a long time, I couldn’t bring myself to cut my hair, even when I wanted to try something new, because any change felt like a return to vulnerability. I felt like I lost all control over how I looked and was so aware of this at such a young age. My port scar, still visible on my side today, became another symbol of what I’d been through. It isn’t something I hide, but it is something I’ve had to learn to accept. An imprint of survival that also carries complicated emotions.

There were short-term impacts, like feeling different from other children, and long-term ones, like struggling with confidence and feeling as though cancer had marked me in ways that would never fully fade. Even now, at 19, I still feel the aftershocks, ongoing

hospital visits, chronic side effects and the fear of needles that never truly went away. But despite everything cancer might have taken, it never took away my smile. Every photo of me during treatment shows a little girl who kept smiling even when her hair was gone and her body felt beaten. That resilience came from my family, especially my parents, who refused to let my reflection become a source of shame.



Katie during treatment

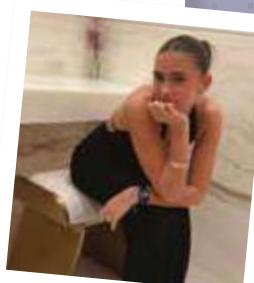
My world became so small because of my weak immune system, so there were no crowded places, birthday parties or any normal childhood moments, and yet my family made sure I never felt less than whole. Their support led to the creation of ‘Team Katie’, a group of runners who began taking part in the London Marathon the year I was diagnosed, raising money to push for better research and gentler

treatments for children like me.

Over time, Team Katie became a symbol of strength and belonging, reminding me that my appearance didn’t define me, my story did. And this April, I finally joined them. Running the London Marathon at 18 was one of the most emotional and empowering experiences of my life. As someone who once felt fragile and marked by illness, crossing that finish line felt like reclaiming ownership of my body after everything it had been through. Every mile was a reminder that the little girl who once lost her hair and confidence had grown into someone capable of extraordinary things.

My message to others

Life now looks very different from the years spent in hospital. I’m stronger, more determined and learning every day to love the body that carried me through so much. If I could give a message to young children facing treatment it would be this: your reflection might look different, but it’s not weaker, and it’s not less beautiful. Your scars, your hair regrowth, your changes, they’re all signs of survival, not things to hide. Be kind to yourself, allow yourself to grow at your own pace, and remember that your worth is never defined by how you look during or after treatment. You’re so much more than that, and the life waiting for you is bigger than anything cancer could ever take away.





“It feels like everything has come full circle, turning pain into purpose”

Kira Noble was diagnosed with neuroblastoma in 2014 aged 11. Now 22, she explains the impact hair loss had on her during treatment, and how her experiences have shaped her choice of career.

As a young girl, I was always somewhere doing something. I was sporty, energetic and always on the move. I spent every afternoon playing football, at netball matches, cross-country running, street dancing, cheer practice... the list goes on. If I wasn't at an after-school club, I was at a friend's house. I always loved being busy; I've always been a social butterfly.

But everything changed in the lead-up to my diagnosis. I began experiencing excruciating abdominal pain – the kind that made it feel like my right side was being torn apart every time it was touched. I had to cut down on all my sports as I would end up being too out of breath or not well enough to participate. After countless trips to the GP, I was repeatedly told it was "just growing pains" or "hormonal changes".

My mum, though, knew something wasn't right. She pushed for further testing, and blood results came back showing markers for coeliac disease to be higher than normal. I was then sent for an upper endoscopy at the local children's hospital.

That same day, the radiologist suggested an ultrasound "just to rule out anything else". But what they found changed everything. After more scans, I was diagnosed with neuroblastoma. The tumour was the size of a watermelon inside my 11-year-old body. This was the day that would change my life, and from that day, my life was split into "before" and "after" cancer.

Cancer, treatment and its impact

Over the next 11 years, I'd face cancer nine times (mostly back-to-back) with very few periods of being well. My treatments have included 26 rounds of chemotherapy, multiple rounds of radiotherapy, proton beam therapy,

differentiation therapy, and high-dose chemo with autologous stem cell transplant, chemoimmunotherapy – the list goes on.

Each round left its mark. My appearance swung between extremes: painfully thin one month, puffy from steroids the next. I didn't feel like myself and started to really struggle with my appearance. Losing my hair was the most devastating part. I no longer recognised myself. My eyebrows and eyelashes disappeared, too. Having my wigs helped and ended up becoming a safety blanket for me. Nothing could replace that positive feeling of looking in the mirror and seeing yourself with "hair."



Kira during treatment

I'd sometimes feel that when I was out and about with my wig on, eyebrows painted on and make-up done, and I felt like everyone else my age who was getting to live the normal life I wished I had. But then I would come home and wash off all the makeup and remove my wig to see how ill I really was.

Cancer doesn't just change your body. It changes your identity. You never come out of treatment the same person you were before. You just can't. I'd once been the athletic girl on every sports team who would never stop, but after years of harsh treatment, my fitness and mobility took a major hit. Rebuilding that part of my life has been a long, emotional process. My fitness has never been the same. I grew up with aspirations of going into a career in sports, specifically professional wrestling (I know, very rogue). But for me, in the end, that wasn't on the cards anymore.

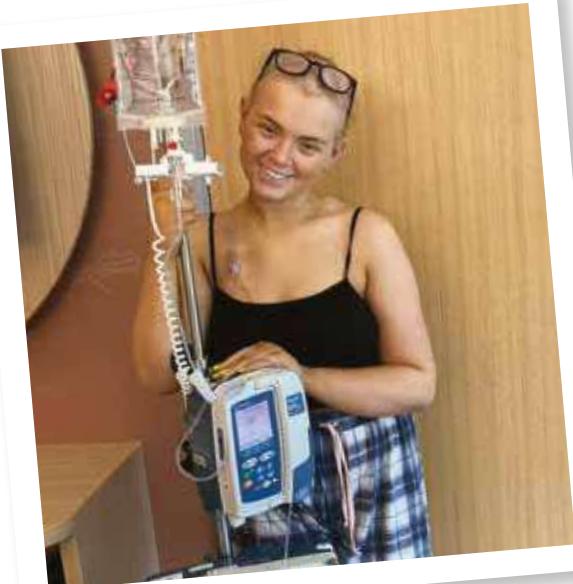
high school, it hit me just how much our hair shapes our sense of identity. Each time I relapsed, I'd get a new wig – different lengths, colours, and styles – and with each one came the realisation that this was my visible reminder of being sick. But somewhere along the way, my frustration turned into fascination. I started experimenting with all my wigs, learning how to style them, and doing my friends' hair when I couldn't do my own. Over time, that passion grew into a new dream. Today, I'm training as a hairdresser, learning in a salon under an incredible mentor. My ultimate goal is to specialise in hair loss and wig work, helping others going through the same struggles I faced. It feels like everything has come full circle, turning pain into purpose.

Embracing life

There's no going back to the life I had before cancer, but that's okay. I've learned to embrace a new version of normal. My days now include pilates with my best friend, long walks, and nights out at music gigs – I spend most of my 'adult money' on live music! Whether it's coffee dates or dinner with friends, just being able to get out and enjoy life feels like a gift. It's the small things you learn to appreciate.

My biggest piece of advice for anyone going through something similar is to take each day as it comes. No two days are ever the same, and that's okay. I try to fill my life with laughter, gratitude and positivity – because there is light even in the darkest moments.

I often say I wouldn't change what I've been through. As hard as it's been, it shaped me into who I am today. It gave me resilience, perspective, determination and a purpose I might never have found otherwise. Cancer took a lot from me, but it also gave me a deeper appreciation for life and the strength we can find within ourselves when we have no other choice.



What helped me

Through it all, I've been fortunate to have a circle of hugely supportive friends and family who lifted me up when I needed it most. They got me through a lot of my darkest moments, especially when there wasn't a lot of hope. My mum and I would just sit in the hospital day in and day out, laughing at the silliest things and try to see the positives and not dwell on the negativity we were faced with. I also spent seven years, on and off, in therapy, which became a vital part of my healing journey. At first, I was nervous as therapy can sound intimidating and can be daunting, but it turned out to be one of the best decisions I ever made. It gave me a space to talk openly, without fear of judgment or bias. I would look forward to my weekly sessions to be able to talk about the happenings in my week, as well as how I was feeling or what my concerns were.

How hair loss has shaped my career choices

The hair loss, for me, was the hardest part of cancer treatment. As a pre-teen, I didn't think much of it. But once I entered

I started experimenting with all my wigs, learning how to style them, and doing my friends' hair when I couldn't do my own. Over time, that passion grew into a new dream. Today, I'm training as a hairdresser

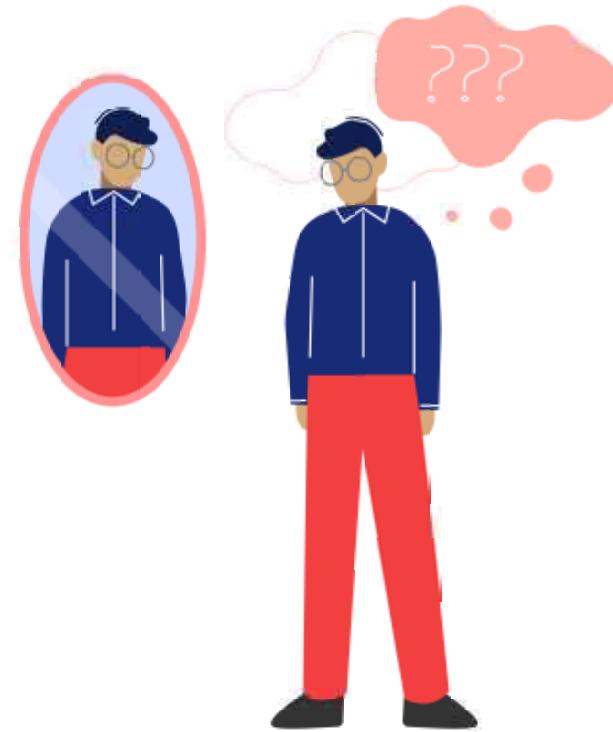


back to basics

What is body image and how can you support your child?

Dr Rebecca Mulholland is Senior Clinical Psychologist at Sheffield Children's Hospital. Here, she explains how a child or young person might feel about changes to their appearance due to treatment, and how you can support them.

Body image isn't necessarily about the way we look, but the way we feel about how we look, or how we perceive others seeing us. For a lot of children and young people, they're already aware of their appearance and how everyone is different to each other. But when changes happen because of cancer treatment, they're more noticeable for the child or young person, and this may impact on their body image. For them, it's like looking in a mirror one morning and looking different to how they did the day before.



What changes during cancer treatment?

Changes from chemotherapy affect most children and young people and can be difficult for them to cope with. Changes could include losing their hair, putting on weight from steroids or losing weight from sickness, or having lines or a nasogastric tube in, but there are a lot of other changes that can happen as well.

Some of these short-term changes may feel really significant for them. Even though we know their hair will grow back, at that moment they don't feel that it will (or it will be a very long time until it does). There may also be long-term changes to their bodies, such as scars from procedures or the loss of limbs from



Dr Rebecca Mulholland

life-saving surgery, or changes in the ability to freely move their body, as their muscles or joints may be weaker.

For all children and young people, their bodies are changing anyway: they're growing taller and changing shape, and they may be starting or going through puberty, so they already have feelings about changes to their body. Chemotherapy may also stop or delay these changes once they've started, which can also bring about more questions and worries about the future.

“For all children and young people, their bodies are changing anyway: they’re growing taller and changing shape, and they may be starting or going through puberty. ”

How could that make a child or young person feel?

Dealing with all these changes and thoughts about themselves bring about a host of different emotions. Sadness, worry, anxiety, or fear, but there may also be some glimmers of positive feelings such as being excited about their new wig, or proud at what they've achieved.

A child or young person may not say how they feel about themselves, but there may be signs to look out for such as avoiding looking in the mirror, refusing to eat or being careful what they eat, losing interest in new clothes, or not wanting to engage in activities that they've previously enjoyed.

When treatment is over, this doesn't mean the emotional connection to their body finishes. They may already feel that their body has let them down by being poorly, then ongoing changes throughout diagnosis and treatment can build a distrust with their body and can create a negative relationship. Their hair will grow back, the body shape will stabilise, and the scars may be hidden, but the emotional impact of how they felt/feel about their body can still have an impact. That trust in their body has broken down.

What might help?

If your child's appearance has changed, they may notice more people looking at them or asking questions about why it has, not because they want to upset them, but because they're curious. This may make your child feel embarrassed, anxious or nervous about going out or to new places. Talking with your child about this and having a plan for what to do or say in this situation can be really helpful.

- Talk about the feelings that have already come up or may come up when in these situations. Often, we hear children and young people saying they feel comfortable in hospital because everyone is the same as them, but when they're taken out of that environment, they feel different again
- Think about who your child may be talking to and what information they may want to give. Have a couple of rehearsed sentences for them to say if someone asks about their hair, a tube or a scar, such as, "I have cancer and I'm having treatment which makes my hair fall out, but it means that it will help me get better." You may want a different sentence for if your child doesn't want to talk about what's happening to them, or something more assertive if the comment seems unkind, something like, "I'd rather not talk about it right now"
- Talk with your child's school or other parents about the ideas you and your child have come up with and discuss any preparation that can help your child return to school or for meeting up with friends for the first time
- Often, once the questions have been asked, the conversation will naturally move on, but it might be helpful for your child to have some questions or topics of their own to talk about should they want to change the subject
- For older children, they may want to bring up their visible changes themselves. Again, having a few rehearsed sentences to do this is helpful. This is particularly useful if a child notices someone staring or knows that someone wants to ask a question but hasn't yet
- Distracting your child is a useful tool if you notice them becoming unsure or anxious in a situation. You can then ask them about how they felt later if this seems appropriate

if it makes them feel safe and more confident. Longer-term or more permanent changes may need more time to build up confidence.

It's really important to help them to see that it isn't just about how they look that makes them who they are, but it's all the other things about them. By noticing and highlighting their positives and strengths, they will start to remember this as well. Try to encourage them to do things they enjoy and try new things if they can. Building confidence in their abilities, while enjoying what they're doing, will help them to redirect their feelings about themselves.

It's hard to hear, but they may not want to be told how beautiful they still are to you (which they are), but to them they may not feel like that at that time and may not be able to hear it. Unfortunately, you can't 'fix it' but being able to listen to them when they talk about how they feel about their body image, understand how hard it might be for them, and remind them how much you love them no matter what, is just as important.

During treatment, you can often get advice from your medical team about how to manage situations if it feels out of your comfort zone. The play specialists or youth support coordinators (for teenagers) have a great deal of knowledge and skills and can offer great support. You're also able to ask for more specialist input from your hospital psychology team if you feel your child is more significantly impacted by their body image.

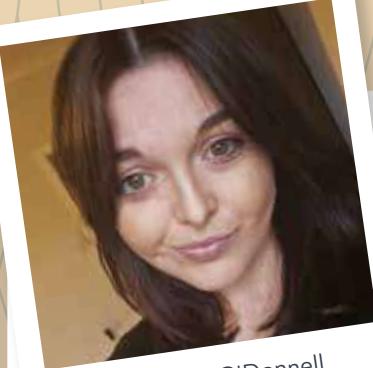
What might help with longer-term support?

Sometimes, there are longer-term changes to your child's body and appearance. This may impact on a child or young person's confidence going forward, as it may remind them of what they've been through. It's important they talk to someone about this to help them process their feelings and find ways to help them manage or cope with them. The clinical team will be able to advise you on local services that can help, either within or external to the hospital. There are also helpful organisations, such as the national charity, Changing Faces, on which more information can be found online.

Other ways to support them

Encourage your child to feel comfortable with themselves. This may be allowing them to wear things that are comfortable for them, which might mean they spend a lot of time wearing loose fitting clothes or their hoody up, or they won't leave the house without their wig. That's okay





Dr Nicola O'Donnell

The impact of treatment on body image: helping young people move forward with hope

Dr Nicola O'Donnell is a health psychologist and a researcher at the University of York. Here, she tells us about her research into the impact of retinoblastoma treatment on survivors' body image and how her team is taking it forward to help those treated for other childhood cancers.

For many, the end of treatment marks the beginning of another journey, with its own challenges. My research explores how growing up with the visible, and sometimes invisible, effects of childhood cancer can shape how young people see themselves, and how they navigate identity, confidence and body image through adolescence and beyond.

Regardless of cancer type, many children experience changes in appearance that can have a lasting emotional impact. These may include scars, hair loss, surgical differences, or use of artificial body parts. For example, children diagnosed with retinoblastoma (Rb) are sometimes required to have one or, very rarely, both eyes removed as part of their treatment. This leaves a visible, lifelong reminder of their illness. These facial differences are outwardly visible, even with the use of prosthetic eyes, and therefore shape body image in complex ways. In interviews I conducted with more than 30 teenage and young adult Rb survivors, many spoke about the enduring impact of these differences. Almost all recalled moments when they felt "different" or worried how others see them. Some described being bullied, stared at, or avoided – experiences which are echoed across the wider childhood cancer community.

Adolescence: when identity and body image collide

Many young people described adolescence as especially challenging, as appearance starts to matter more and mental health support is often hardest to access. For some Rb survivors, comfort with their prosthetic eye in childhood shifted to anxiety later. Survivors of other cancers describe similar experiences – scars, facial changes and long-term treatment effects like learning difficulties making them feel exposed or different. This can shape how young people see themselves and how they think others see them, affecting self-esteem and confidence.

However, not everyone felt negatively impacted. For some, feeling different sparked determination to avoid being defined by their cancer. Many young people want to shape an identity beyond their cancer experience, balancing the need to fit in with the wish to be recognised for their unique qualities.

“Many young people described adolescence as especially challenging”

Coping with visible differences and invisible emotions

Young people found creative ways to cope. Some expressed themselves through fashion, humour, or hobbies. Others embraced their differences – for example, by choosing colourful or personalised prosthetic eyes. But acceptance is rarely straightforward. Even confident young people were sometimes criticised for 'drawing attention' to their appearance. Approaches like Acceptance and Commitment Therapy (ACT) can help. ACT teaches young people to notice upsetting thoughts without letting them dominate, focus on what matters to them, and build confidence through valued actions rather than trying to look a certain way. Learning to relate differently to thoughts and feelings (whether your own or those of others) can be a big step towards self-acceptance.

Broadening our research

The challenges seen in Rb survivors – anxiety, identity struggles, body image concerns, isolation, and medical trauma – aren't unique to this cancer. My team at the Candlelighters Supportive Care Research Centre at the University of York is partnering with OSCAR's Paediatric Brain Tumour Charity to co-design research centred on young people's voices. We'll explore the impact of the visible and not-so-visible changes (such as learning challenges and rebuilding confidence). This builds on our work with the Childhood Eye Cancer Trust and is a key step towards developing evidence-based psychological and educational resources to help as many childhood cancer survivors as possible.

Moving forward with hope

The emotional, social, and body image effects of being diagnosed and treated for cancer as a child or young person can last a lifetime. Recognising these challenges is essential for holistic care. Families and young people, meanwhile, can be reassured that these challenges are common. We've created videos and podcasts featuring Rb survivors and will continue sharing insights with those affected by other childhood cancers. With understanding, compassion, and tailored support, young people can embrace their differences, develop a positive sense of body image, grow in confidence, and move forward with hope.

Don't wait to reach out for help

Jude Solley was diagnosed with mixed-phenotype acute leukaemia (MPAL) in 2021 aged 16. Now, 21, he explains how this caused him to struggle with body image issues, why he decided to reach out for help, and why he advises others to do the same as soon as possible.

For weeks before my diagnosis, I'd been suffering with a sore throat and a cold that seemed to never be helped by medicines or antibiotics. Eventually, my GP recommended I get a blood test. Thinking nothing of it, I went about my day until the very next morning I got a call from the hospital saying I needed to go in immediately.



Jude during treatment

There, I got redirected to an oncology wing. As a 16-year-old, I had no idea what that even meant, but I quickly found out. When a bed became available at the Royal Marsden, I was quickly transported there to immediately start treatment for what they thought at the time was a more researched and understood type of leukaemia, acute lymphoblastic leukaemia (ALL). However, after looking into my bone marrow, they saw some faults that were missed in earlier blood tests which showed me having traces of both ALL and acute myeloid leukaemia, hence the very rare diagnosis of mixed-phenotype leukaemia.

How cancer and its treatment affected me

After many discussions, the team at the Marsden decided to go ahead with a course of chemo similar to ALL treatment, lasting 12 cycles and three-and-a-half years, with treatment ending in August 2024 when I was 19. Treatment took up many key years of my teenage life, when everyone else was discovering who they were, getting their first jobs, starting university, or learning to drive. For me, none of this was possible, and it really impacted me mentally.

I think everyone's insecure in some way in their teenage years, but for a person with cancer, it's almost always worse. My treatment greatly affected my appearance and, in turn, my self-worth. My loss of hair and the effects of the aggressive steroids I was on were the worst parts of treatment. The steroids, although they helped my body, made me rapidly put on weight. The rounding of my face, along with the baldness, really made me conscious of my appearance.

As someone who'd always struggled with self-image issues, this sent me into a depressive spiral. After reaching 16 stone at 17 years old, I started taking drastic measures, such as starving myself or self-harming, anything that made myself feel better, no matter how extreme. In my mind, this was bigger than the fact that I had cancer. All I could think about was that I was a mess.

In a couple months, I dropped six stone through dangerous practices like starving or purging myself, causing me to eventually reach out for help. I was carrying out the rest of my treatment at Brighton Hospital, where the paediatric oncology

team referred me to a psychologist, therapist and dietitian, and eventually I received a diagnosis of atypical anorexia.

How I was supported

The team helped me realise that all this would pass just as quickly as it came on, and that there were ways to feel better about myself. I learnt what clothes made me feel good and I learnt how I wanted to present myself. That's how I discovered a love for fashion that has stayed with me to this day.

This only made me look forward to life after treatment, rather than thinking my life was over. Being someone that dresses alternatively, all I could think about was the tattoos, piercings and crazy hairstyles I'd be able to get once it was all over. For the meantime, I experimented with baggy clothing and proportions to make me feel better in the body I was in.

My advice to others

To anyone who is going through a similar situation, I urge you to reach out for help. Also surround yourself with positive people and close friends and keep yourself as busy as you can while still knowing it's okay to rest sometimes when your body needs it most.





Madison

Overcoming challenges, giving back, and looking to the future

Madison Joyce was 22 years old when diagnosed with breast cancer in 2015. Now 32, she tells us about the challenges she faced with her body image, how she overcame them, and what life looks like now.

Within two weeks of being diagnosed with cancer, I'd had my breast removed. I remember going home and thinking, 'What now?' I was sat at home, and though so many people were rallying around me, I couldn't get my head around it all. Around this time, my breast care nurse put me in touch with a Young Lives vs Cancer Support Worker, Bex. Bex gave me a ring and helped me make sense of what was going on and about to happen when beginning my treatment. This would be six rounds of chemo every three weeks, with the first three rounds being really intense because of how aggressive my cancer was. This was later followed by radiotherapy.

Bex talked about me losing my hair, which no one in the family wanted to talk about, even though we knew it was likely to happen. She put me straight in touch with The Little Princess Trust, who made me my perfect wig. This definitely helped, but it was still really hard losing the lovely long hair I had before my treatment.

Bex helped me so much, from both an emotional and practical standpoint. She was always there to talk about any problems I was having, and helped me sort out some of my finances, too. She also put me in touch with other young people. This really helped, especially as I opted against being treated on a teenage and young adult ward as I wanted to stay nearer to home in Stoke.

I remember travelling down to London with a shaved head to meet other young people diagnosed with all different cancers. My mum said this seemed to give me a real boost, being able to talk to and get advice

from others going through similar experiences, and to see them doing well.

Young Lives vs Cancer also supported our whole family which was vital to us. My mum was my rock the whole way through, and was with me 24/7, so any support for her was really important.

couldn't do, so I needed somebody who was sensitive to, and could help me navigate, this. A man called Simon, whose mum had breast cancer, quickly got in touch. He owned a gym and offered to tweak some sessions to help with muscle movements. Simon kindly offered to do this for free, simply to help other people with breast cancer.

I quickly joined his gym, going four or five times a week, and met a whole load of new friends there. They all supported me in losing all my 'chemo weight', and the fitness work itself was great for my mental health as well. We also did all sorts of extra activities away from the gym, like climbing Mount Snowdon twice, and taking part in a Tough Mudder. These were great experiences that I never thought possible before and really helped me in my recovery, both physically and mentally.



Madison with her mum, Janet

Navigating my body image issues

In addition to my hair loss, my treatment caused my appearance to change in other ways, too. The steroids I was on caused me to put on three stone in weight, which, along with having my breast removed and the hair loss, really affected me.

I knew I wanted to get back into the gym, so I put a post on Facebook, asking for a personal trainer. Because I had my breast removed, there were certain exercises and movements I

Because I had my breast removed, there were certain exercises and movements I couldn't do, so I needed somebody who was sensitive to, and could help me navigate, this.

Empowering experiences

Simon thought my story was amazing and encouraged me to enter Miss Staffordshire. He thought it would be

a great opportunity to celebrate my achievements while raising awareness of cancer in young people at the same time and inspire other people with confidence issues. I'm really proud of doing this, not only for taking part but for being a finalist in Miss Staffordshire, which allowed me to enter Miss England, where I came second in its 'Most Inspirational' category.



Doing Miss Staffordshire and Miss England really gave me a boost of confidence, one I probably needed at the time. I met lots of new friends, some of whom have also gone through unfortunate journeys themselves, and I still speak to some of them now. I really enjoyed it.

I also later took part in a bikini photoshoot for a body image campaign organised by The Sun, and in a 'Full Monty' show alongside other breast cancer survivors. This was to raise funds for The Pink Sisters & Misters, a cancer support group and charity that my mum and I have been heavily involved in and benefitted from. All these experiences were really empowering and, just as importantly, helped raise awareness of different charities and causes. I always wanted to make a difference, and to be able to do so, really meant a lot to me.

Charity support

I've been fortunate to benefit from the support of many charities, both during and after treatment. One, a lovely little charity called The Genie's Wish, paid for me to get my motorbike license,

putting me through an intense course of lessons beforehand and paying for my test. I'd always wanted to do it, but it was something I never thought I'd do. I hadn't saved any money for it as I'd been so poorly and only worked part-time in the first few years after treatment. It was incredible of them to do it. And even more incredible was when a year later they got back in touch and offered to pay for my first helmet and leathers.

The Make-A-Wish Foundation UK provided me and two friends with tickets for a James Bay concert and paid for all our transport and accommodation costs. These two were rocks for me during my treatment, going to every appointment and dropping their own lives to help me, and I knew whatever my 'wish' involved, had to include them as well. It was a great night, and it felt really special to say thank you by sharing this evening with them.



What life looks like now

While cancer is an awful thing to happen to anybody, let alone a young person, it's shaped my life incredibly. After my treatment, I knew I wanted to be a part of something that could help others. I remember thinking about when I met with my oncologist, and all the amazing medicines that he put me on and how they worked in so many ways. Years later, I'm now a medicines management technician in a hospital – my dream job – and get to help so many people with all sorts of conditions and illnesses, including cancer. I know what it's like to be lying in a hospital

bed and I carry that empathy with me in all my conversations with patients. I'll also always make them aware of charities that can support them. It's my little way of doing something else to help.

I'm now 10-years post-treatment and, though I still want to give back where I can, I'm also looking ahead. I've recently bought a house with my partner and I am looking forward to the future in it. I feel grateful for where I'm at.



▲ Madison raising funds for The Pink Sisters

“Doing Miss Staffordshire and Miss England really gave me a boost of confidence.”



Madison on treatment

A parent's view...

Turning heartache into hope

Ellen Vance's son, Todd, was diagnosed with a brain tumour aged seven in 2008. She tells us about the impact that hair loss had on Todd, and how, inspired by the support their own family received, she and her husband, Simon, set up their own charity to help others navigating a similar path.

Christmas Eve 2008 is a day my family and I will never forget. What should have been a festive evening filled with laughter and excitement turned into every parent's worst nightmare when my son, Todd, was diagnosed with a brain tumour after experiencing petit mal seizures.

Unsurprisingly, that Christmas was the strangest one we've ever had. We had a teenager and a tiny baby at home as well, so we were doing our best to keep things as normal as possible for everyone, even though inside, Simon and I were terrified.



Todd in hospital

After Christmas, Todd began an exhausting treatment plan of chemotherapy that was meant to last 85 weeks but eventually stretched to 92, as low blood counts and transfusions often delayed his sessions. Watching your child go through that, the sickness, the weakness, the endless hospital visits, is something you can never prepare for. But what really broke our hearts was seeing how anxious he became when his hair started to fall out.

For Todd, the hardest part of it all wasn't the pain or the countless

procedures. It was losing his hair. He was so self-conscious, and he didn't even want to leave the house. People often think children are more resilient about things like that, but I can tell you from the bottom of my heart, they feel it just as deeply as adults do.

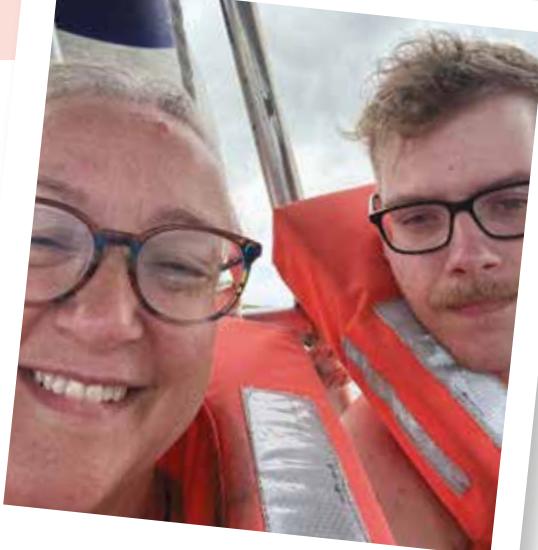
What helped us

An unexpected turning point came when we discovered Buffera Ltd, a company that made high-quality bandanas. They were amazing, soft, breathable and protective against the sun. But most importantly, Todd loved them. They didn't itch like hats or beanies, and they looked really cool. Before long, he had one to match every outfit.

With his new collection of colourful bandanas, he began to regain his confidence. It changed everything. People stopped asking about his hair loss and started talking about his funky bandanas instead. That shift, from feeling self-conscious to feeling stylish, made such a huge difference to him, and it was from that small but powerful change we had an idea that would soon help thousands of other children like Todd.

Starting our own charity

As a family, we'd raised money for various cancer charities, but I felt a real pull in my heart to do something more personal. Something that would directly support children going through the same thing Todd did. I wanted them to feel seen, supported, and a little bit special during such a frightening time. This inspired us to set up what would become Bandanas for the Brave, a registered charity that provides free bandanas to children and young people diagnosed with cancer who lose their hair through



Ellen and Todd

chemotherapy or radiotherapy.

Each bandana is carefully chosen by the child on our website, so they're personal to them, which is hugely important. The bandanas are very unique by being seamless, soft and offering UV protection to meet the practical and emotional needs of children facing treatment. It's about so much more than just a head covering. It's about confidence, comfort and identity. It's about helping children feel like themselves again.

“With his new collection of colourful bandanas, he began to regain his confidence. It changed everything. People stopped asking about his hair loss and started talking about his funky bandanas instead.”

Our impact

Over the last 13 years, Bandanas for the Brave has given out thousands of bandanas across the UK and Ireland. Each one carries with it a message of hope and solidarity – a reminder that no child has to face their cancer journey alone. The response from families has been incredible and really makes me

quite emotional. One beautiful parent whose child sadly died shared with us that her daughter's bandana is still a part of her life. She told me that she carries her daughter's bandana in her bag, so that if she feels she needs some help and comfort she reaches for it, and it really helps her in connecting with her little girl. That really moved me – to know that something so simple could bring so much meaning.



Todd in his bandana

As a family, we're as passionate about our mission now as we were the day we started the charity. For us, Bandanas for the Brave isn't just a charity – it's a promise to every child and family walking this difficult path. We know what it's like. We've been there. And if we can bring even one smile or one moment of comfort, then we've done what we set out to do.

People often say to kids, "Don't worry your hair will grow back", but hair loss can have such a huge emotional

impact on children. We want them to know they're not alone, and that they're brave, beautiful and strong, with or without hair. Today, Bandanas for the Brave continues to grow, fuelled by compassion, community, and the belief that small acts of kindness can make a world of difference. Every bandana we send out is packed with love. Because sometimes, it's the little things, like a soft fabric, a bright colour, a moment of confidence, that help children face the toughest days with courage and a smile.

What life looks like for Todd now

Todd is now a strong, independent young man. He's still attending the hospital for MRI scans every two years, but thankfully his tumour is still behaving and hasn't grown from his initial chemotherapy, which is wonderful. Although he has gone through a lot of hardships, he lives life to the full. He's driving and has got a full-time job working for Amazon. We're so proud of what he has achieved and will continue to achieve as he grows.

We also want this opportunity to thank all three of our boys. As an ordinary mum and dad who never thought we could do this, we have had them all behind us, and we're so proud of them all in helping us grow the charity into what it is now.



Todd with Pudsey

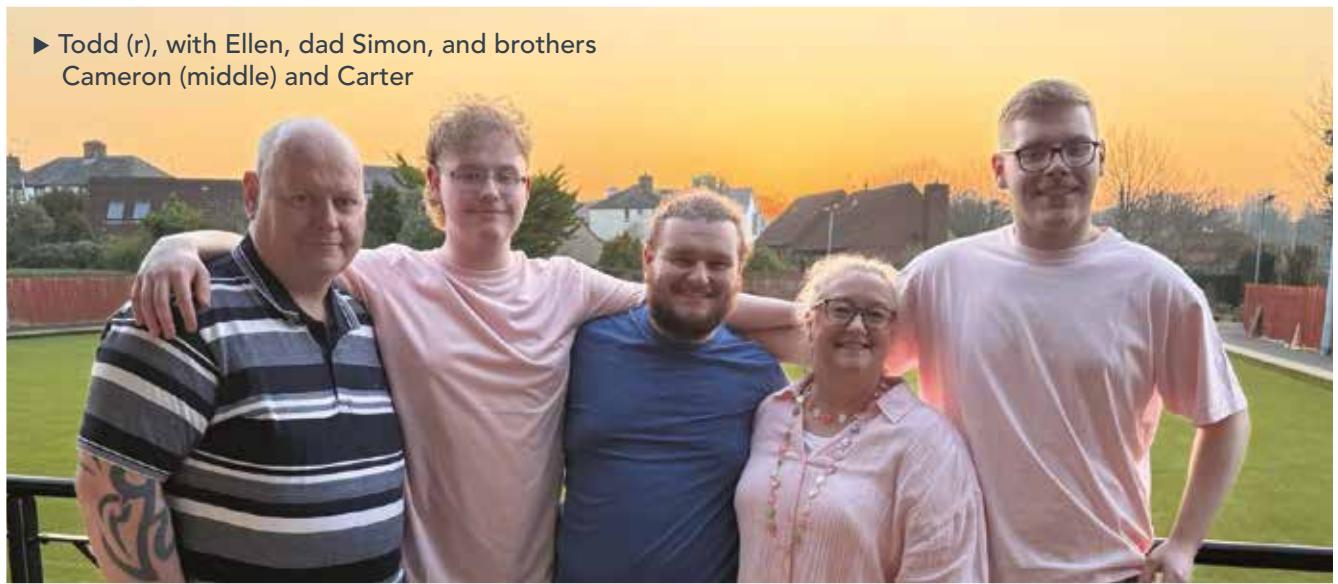


✉ info@bandanasforthebrave.com

🌐 www.bandanasforthebrave.com

FACEBOOK www.facebook.com/bandanasforthebrave

► Todd (r), with Ellen, dad Simon, and brothers Cameron (middle) and Carter



Don't waste your time worrying about what others are thinking



Toby Clough was diagnosed with rhabdomyosarcoma as a toddler in 2008, with the effects of his treatment altering the appearance of his eye. Now 19, he describes the challenges he's faced growing up, and what has helped him.

When I was 21 months old, I was diagnosed with alveolar rhabdomyosarcoma in the orbit of my right eye. I underwent surgery to remove the tumour, followed by 12 months of chemotherapy with the first six of those being particularly intensive. After that, I travelled to Switzerland for proton therapy. While the treatment was effective, it caused some tissue damage in the orbit of my eye socket.



Initially, my appearance didn't change much apart from some redness during proton therapy. However, as I grew older, my face developed normally while the damaged orbit struggled to keep up, resulting in noticeable asymmetry. I always felt different because of this, and as I got older, the difference became something others often noticed as well. Over the years, people's comments and questions, whether polite or rude, had a big impact on my confidence, as they reminded me of how visible the difference was.

The small, everyday moments caused the deepest breaks in confidence. Examples of this include being stared at on buses or in town, and sensing that people were judging me based on my appearance. Those experiences can be hard to deal with. I've learned that one of the best ways to cope is by surrounding yourself with friends who value you for who you are, beyond appearances. Finding those people wasn't always easy, especially at school where children can often be quick to judge and insensitive, but since moving to university to study finance and investment banking at the University of Exeter, I've found it easier to manage.

“I've learned that one of the best ways to cope is by surrounding yourself with friends who value you for who you are, beyond appearances.”

Recently, I took part in a trip organised by the Ellen MacArthur Cancer Trust in the hope of meeting others who had been through similar experiences. It made a huge difference to me as I could talk to people who understood what I'd been through and the after-effects. It reminded me how important it is to find the right friends as it's very easy to feel left out or separate from everyone else. It also allows you to

feel included and able to get on with life without it constantly being in your mind.

One thing I still struggle with is being in photos. I often avoid having my picture taken because I don't enjoy seeing myself in them, and sometimes even worry that my appearance might 'ruin' the photo for others.

While there are many unfortunate downsides to living with aesthetic differences, I think it's important to take the positives from these experiences, and I believe there are also some benefits to having experienced life in this way. For one thing, it has allowed me to develop a strength of character that a lot of other people don't have. Growing up visibly different teaches you important qualities like empathy and resilience and provides you with a difference in perspective. What's more, it has made me value authenticity in others as it reveals what other people are truly like, making friendships and connections more meaningful.

If I could offer one piece of advice to others, it is to try and focus on your own life, rather than worrying about what others are doing or thinking. This can be difficult, but everyone else is out there living their lives, so don't waste time not living yours.

► Toby playing hockey



Designing an immunotherapy for aggressive childhood brain tumours



Dr Laura Donovan

- ▶ **PROJECT TITLE:** Enhancing CAR T-cell expansion and prolonged persistence for the effective treatment of paediatric medulloblastoma
- ▶ **LEAD INVESTIGATOR:** Dr Laura Donovan
- ▶ **INSTITUTION:** Institute of Child Health
- ▶ **AWARD:** Approx. £120,000 (funded by The Little Princess Trust and administered by CCLG)

Medulloblastomas are the most common malignant brain tumours in children, and Group 3 medulloblastomas are the most aggressive group. These tumours often spread throughout the brain and spinal cord before a child is even diagnosed (called metastatic disease), and survival is strongly linked to whether the cancer has spread.

Our research project emerged from a clear clinical need: to find safe, targeted therapies that can treat both primary and metastatic disease while minimising long-term toxicity. Current treatments, surgery, radiotherapy and high-dose chemotherapy, can save lives but are extremely harsh. Many children experience long-term neurological and developmental side effects because these treatments are non-specific and often more intensive than necessary. Immunotherapies like CAR T-cell therapy, which train a patient's own immune cells to recognise and attack cancer cells based on specific markers on their surface, have revolutionised the treatment landscape for some cancers. However, many patients with medulloblastoma eventually develop resistance.

Our group's previous work showed that CAR T-cell therapy could be effective for medulloblastoma. We identified a molecule found on medulloblastoma cells, both from the initial cancer and metastatic disease, called IL13RA2. CAR T-cells that target IL13RA2 have already produced

extraordinary results in adult brain tumours, so we wanted to see if we could redesign IL13RA2 CAR T-cells to overcome treatment resistance for childhood Group 3 medulloblastoma.

“Our research project emerged from a clear clinical need: to find safe, targeted therapies that can treat both primary and metastatic disease while minimising long-term toxicity.”

We set out to re-engineer IL13RA2 targeted CAR T-cells to reverse the process of T-cell exhaustion, one of the main reasons immunotherapies lose effectiveness over time. In aggressive and metastatic cancers such as Group 3 medulloblastoma, CAR T-cells are repeatedly stimulated by tumour antigens and gradually become 'exhausted', losing their ability to fight the cancer. To prevent T-cell exhaustion, we had to activate

a protein called β -catenin that can affect T-cells' behaviour. β -catenin helps enable the T-cells to endure for longer periods and mount a strong response when they encounter tumour cells.

By enhancing β -catenin activity, we effectively counteracted T-cell exhaustion. The engineered CAR T-cells are more able to self-renew, survive for longer, and resist suppression. As a result, they retain their ability to seek out and destroy tumour cells over a much longer period than standard CAR T-cell designs.

In the lab, we found this combination treatment has improved persistence, reduced exhaustion, and enhanced anti-tumour activity. This work lays the foundation for next generation engineered immunotherapies for childhood brain tumours. If our strategies prove effective, they could be extended to other resistant or metastatic paediatric cancers.

With more research, this approach could transform the treatment of Group 3 medulloblastoma by offering a highly targeted therapy that avoids the long-term harm caused by chemotherapy and radiotherapy. By redesigning immunotherapy at the molecular level to target metastatic disease while sparing healthy tissue, we aim to bring safer, more effective, and more durable treatments to the children who need them most.

60 SECONDS WITH Chelsey Rowntree

Youth Support Worker
at Candlelighters



Q: What does your role involve?

A: I work with 13–18-year-olds on the teenage haematology and oncology ward, helping them be teenagers, not just patients. Every day is different: sometimes we're doing arts and crafts or having a games night, and sometimes it's simply me sitting with them while they talk about school, friendships, fears, or how treatment is affecting them. I'm not medical, so I never deliver bad news, which helps them feel like they have a safe space. I try to give them control over what we do, because so much of their lives feels out of their hands.

I also link them up with physios, dieticians, talking therapy, and other teams to make sure they're getting the support they need. Whether it's creating routines or just being there to chat, my goal is to help them feel like themselves and keep a bit of normal teenage life alive, even in hospital.

“I'm there to support, not to lead. I also signpost them to things that can help... wigs, skincare workshops, talking therapy, and other services”

Q: How do you help children and young people with body image?

A: When it comes to body image, I never force the conversation, it must come from them. I make space for it, but they choose when they're ready to talk. When they do, I let them feel

whatever they're feeling: anger, fear, embarrassment. I remind them that their body will keep changing throughout treatment, and while it might not go back to exactly how it was, this stage is temporary.

They have full ownership over the conversation, and I'm there to support, not to lead. I also signpost them to things that can help... wigs, skincare workshops, talking therapy, and other services that make them feel a bit more like themselves.

Q: What's the proudest moment of your career so far?

A: Helping Candlelighters run our first Teenage and Young Adult Cancer Awareness Month. We created a space for young people to share their stories and advocate for themselves and seeing them feel proud and relieved to have their voices heard was incredible.

Q: What's the most rewarding aspect of your job?

A: Firstly, it's seeing young people regain a sense of normality, whatever that looks like for them. Being able to witness their progress, the moments when they feel more like themselves again, is incredibly rewarding. Secondly, it's seeing a young person advocate for themselves. I love watching them ask questions, understand their treatment, and take ownership of what's happening to their body. It gives them back a bit of control and really strengthens their relationship with the medical team, too.

Q: What does your job mean to you?

A: It's hard to put into words. This job feels like a calling, I genuinely feel like I was meant to do it. Knowing I can make

even a small difference is what keeps me going. Every day I get to stand beside them, support them, and be part of their world during such a difficult time. It means everything to me.

Q: Do you have a message for young people and their families affected by cancer?

A: For young people: advocate for yourself. Ask questions. Speak up. And remember, you have cancer, but it's not who you are. It doesn't define you. You're still you, with your own personality and identity.

For families: don't be afraid to talk about what's going on. Connecting with other families can make a huge difference. And be honest with your child, they can usually sense when something's being kept from them, and honesty helps them feel included and supported.

Q: How can families and young people find out about accessing further support?

A: From a Candlelighters perspective, they can access our free talking therapy at any point in their journey. If they ever feel they need emotional support, they can just reach out to any of the team, and we'll help get them connected.

For those outside Yorkshire, there are lots of ways to find support. You can check local charities, speak to your GP, social worker, clinical nurse specialist, or consultant. They'll know what services are available nearby and can point you in the right direction. The main thing is that you don't let anything hold you back from getting the support you need.



ASK THE **Expert**



Enkay Rockson-Rapu,

Community Engagement Practitioner at Young Lives vs Cancer, supporting the set-up and development of the Lived Experience Advisory and Action Group for the North Star Cancer Collective, using prior lived experience

What is the North Star Cancer Collective?

The North Star Cancer Collective is a system-wide movement, bringing together people and organisations to improve cancer care for children, young people and their families. Guided by evidence, the North Star Cancer Collective works across the system – not just within individual organisations – to create a better future. **This collaboration is led by five charities:** Alike, CCLG: The Children and Young People's Cancer Association, the Ellen MacArthur Cancer Trust, Shine Cancer Support and Young Lives vs Cancer.

How did it come about and why is it needed?

In 2022, four children and young people's cancer charities commissioned independent research to better understand the needs, outcomes and experiences of young people with cancer and their families. This research revealed gaps and inequities that affect every part of a young person's life, often long after treatment ends, leading to the creation of a shared 'North Star Vision' – a unifying ambition for what cancer care should look like for every child or young person and their families.

The North Star Cancer Collective brings this vision to life, working together to shape a future where every child, young person and family affected by cancer receives the right support during treatment and beyond.

What does it hope to achieve?

The North Star Cancer Collective is not a frontline service. Instead, it creates the conditions where evidence, lived experience, innovation and influence come together. Its

work doesn't replace what individual organisations do. Instead, it makes those efforts add up to more. Its value is in convening and connecting.

Together, we aim to transform the cancer experience for children and young people by:

- prioritising, designing, testing and scaling solutions that improve the psychosocial experience of cancer care for children and young people
- driving systemic change in cancer care and support
- embedding lived experience into decision making
- creating a unified voice to influence policy and practice

Ultimately, the North Star Cancer Collective seeks to ensure that every child, young person and family receives the best possible care and support throughout their cancer journey.

What are its key focus areas?

The initial area of focus for the North Star Cancer Collective is to strengthen the mental health of children and young people with cancer, and their families – within and beyond treatment.

We believe that lasting change starts with learning. That's why we're testing new ideas and approaches, grounded in evidence and lived experience, to understand what works best for children, young people and families affected by cancer.

Our test-and-learn projects are small-scale initiatives designed to explore solutions to the biggest challenges identified in our research. Each project answers critical questions, helping us to understand how we might scale impact across the system.

When can we expect results?

Change takes time, but progress is already underway. We have recruited a Clinical Advisory Group and a Lived Experience Advisory and Action Group and are now working on embedding our test-and-learn projects. While some improvements will be incremental, the long-term goal is systemic change – ensuring that the North Star Vision becomes the standard for cancer care for children, young people and their families across the UK.

Read more and sign up for updates at www.northstarcancercollective.org.uk

Join us on our Big Hike

Saturday, 12 September 2026

Join us on CCLG's Big Hike to raise funds that will help us fuel groundbreaking research into children and young people's cancer.



The half-marathon hike will take you on a circular route through the stunning Peak District and is open to walkers of all levels, whether you're a total novice or seasoned hiker.

Find out more at
www.cclg.org.uk/big-hike



The Children &
Young People's
Cancer Association

www.cclg.org.uk @cclguk

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CCLG and The Children & Young People's Cancer Association are operating names of The Children's Cancer and Leukaemia Group, registered charity in England and Wales (1182637) and Scotland (SC049948).