CCLG The Children &
Young People's
Cancer Association

FREE

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contact

MAGAZINE

Communication

What does good communication look like?
How does it help?

- HELPING PROFESSIONALS COMMUNICATE WITH YOUNG PEOPLE
- HOW PLAY HELPS PROCESS INFORMATION AND EXPRESS FEELINGS

A parent's view

Mandy Berriman, whose son, Peter, was diagnosed with neuroblastoma aged eight, discusses the pros and cons of using social media to find information and connect with other families **Page 15**

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COMMUNICATION IS KEY TO SUPPORTING YOUNG PEOPLE THROUGH CANCER

Yami Moloteni was diagnosed with Hodgkin lymphoma aged 18. She explains the importance of good communication in teenage cancer care and how having someone to talk to can have a huge impact
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Spring 2025

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ON THE COVER

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 cancer.

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

Please let us know your thoughts and feedback about Contact by emailing our Editor at editor@cclg.org.uk

Editorial Team and Board:

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.

CCLG The Children & Young People's Cancer Association

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Editor: Sam Chambers
editor@cclg.org.uk
facebook.com/cclguk
x.com/cclguk
instagram.com/cclguk
@cclguk
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Your messages...

Praise for Contact's recent edition on 'Empowerment'

"Great edition".

Sarah's story highlights hope and positivity

"Thank you for sharing your story, Sarah, you are an inspiration."

Read Sarah's story at www.cclg.org.uk/Contact-magazine/Appreciating-the-small-things-and-embracing-every-opportunity

CCLG is supporting patients after treatment ends

"The Living beyond cancer resources created by your charity are incredible and makes it all feel very real now when looking forward!"

Praise for CCLG's insightful and accessible Research Discovery Day talks

"Great talks and sharing them like this made them so easily accessible."

Watch using the QR code:

Hello!

Effective communication brings clarity to the exchange of ideas, knowledge, thoughts and opinions, so messages are clearly understood. In the care of children and young people with cancer, this must be done with compassion and an appreciation that everyone is different in how they want to communicate, and the methods they like to use.

In this edition, we explore how each individual's communication needs are unique – shaped by their personal experiences and preferred ways of sharing and receiving information. Clear communication is more than just a tool – it's a bridge to support and the foundation of meaningful relationships, both of which are crucial during challenging times.

When done well, communication becomes a powerful enabler of connection and understanding.

Sam

PS: You may have noticed our new organisation name and logo. Check out our new website, with a fresh new look, at **www.cclg.org.uk**

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**

APRIL IS ...

TEENAGE AND YOUNG ADULT CANCER AWARENESS MONTH

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- Support our work in developing age-appropriate care for them
- Help us amplify the voices of young people with cancer

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MEDICAL ADVISER

Professor Bob Phillips

Candlelighters Chair of Supportive Care Research for Children and Young People with Cancer, University of York, Consultant Paediatric Oncologist at Leeds Children's Hospital and CCLG member

How we communicate holds immense power. For families and young people navigating childhood or teenage cancer, this couldn't be truer. No one ever asks to join the 'club' of those affected by it, yet here you are, navigating uncharted waters together. Communication becomes the glue that holds everything together — whether it's between parents, siblings, healthcare providers, or even within yourself as you process an overwhelming amount of information.

This issue dives into the many facets of communication within this community. We have teens explaining what medical teams do well and what they could do better in their interactions with young people with cancer (spoiler alert: consultants, you may feel a little 'called out' but in a constructive way), and we hear from parents sharing how they've supported each other through tough times. We also hear about the benefits, and challenges, of using social media to find support through treatment. It can be a source of connection, but also a place where misinformation and misunderstandings can be found, and the use of this platform needs careful management.

Elsewhere, this edition shows how play can be a powerful tool for explaining complex medical concepts to young patients. Through storytelling, toys and games, children can gain a better understanding of their illness, treatments and side effects in a way that feels safe and accessible. We also have tips on what can help in preparing for medical appointments, and hear about what goes on behind the scenes, with the medical teams who rely on strong communication to ensure every child receives the most up-to-date, equitable care.

Communication really does hold great power. So, here's to communicating with care, compassion and clarity.

NEWS IN BRIEF

Self-reporting symptoms could improve care for young cancer patients

A Canadian clinical trial has shown the effectiveness of SSPedi, a new survey tool that allows children undergoing treatment to self-report symptoms like pain, nausea and anxiety.

By regularly completing the survey, children were able to provide their care teams with a first-hand picture of their symptoms. This helped improve their supportive care and reduced the severity of symptoms compared to standard care. *(Source: National Cancer Institute)*

Blood test predicts heart disease risk in childhood cancer survivors

Scientists in America have designed a blood test that could predict the risk of cardiomyopathy, a term for diseases affecting the heart muscle, in childhood cancer survivors treated with anthracycline chemotherapy. By analysing blood samples, researchers found 27 proteins that can identify those at risk of cardiomyopathy before they show symptoms. These early findings could eventually lead to better early detection and improved care for survivors at risk of long-term heart problems.

(Source: News Medical)

Inherited genetic changes can influence cancer risk

American researchers have found new, rare genetic changes passed down from parents that may increase the risk of childhood cancers like neuroblastoma, Ewing sarcoma and osteosarcoma.

These changes, called structural variants, are big changes to DNA that can raise cancer risk. However, these changes do not always lead to cancer, meaning that other factors like environment are important. The research could lead to better ways to find and treat these cancers earlier in the future. *(Source: OncLive)*

Global trial offers hope for children with relapsed lymphoma

A new global clinical trial, Glo-BNHL, has opened in the UK to find new treatments for children with relapsed or treatment-resistant B-cell non-Hodgkin lymphoma (B-NHL). Unlike traditional trials, Glo-BNHL tests multiple treatments simultaneously, meaning that it can adapt and replace treatments quickly if they are ineffective. This approach is designed to have the best chance of finding safe and effective new treatments.

(Source: University of Birmingham)

The network I needed: Peer support and a shared cause

***Ellie Philpotts** was diagnosed with Hodgkin lymphoma in 2011 aged 15. She explains how she found support from other young people with cancer and how, through awareness raising, writing and advocacy work, she's hoping to help those who are newly diagnosed.*

When you're diagnosed with cancer, there are so many new things to get to know and start to follow. Your own body is rudely taken over by unfamiliarity, from the first cells running haywire to powerful medicines running through dangling Hickman lines. Or scans carried out and cannulas slotted begrudgingly into frustrated veins. That's not to mention a host of unwelcome and often unexpected side effects.

Beyond that, there's growing used to our 'new normals', lifestyles, images, identities, realities, and futures. This is a tough pill to swallow at any age – but especially when so young. However, what becomes obvious along the way is that having someone to talk to, who is going through a similar experience or who has done before, is a key component of the cancer journey. It makes all this adaptation easier to manage, whether you're brand new to it, or someone like me, who's been in remission for over a decade.

When you're young, you're figuring a lot of non-cancer things out – the world around you, how to live within it, and then who you want to become and what you want to achieve. When cancer comes knocking, you'll want some guidance to look to. It makes sense to benefit from the accidental expertise of those who have been there before. This is something I did, once I realised there was a whole network of other young people in the 'cancer club'.

Journeying from patient to advocate

After diagnosis, I was placed on the Teenage Cancer Trust (TCT) unit at Birmingham Children's Hospital. It had under 10 beds, and the ward's surprisingly sociable nature made it easy to chat to its other young residents. Then I began speaking about my experiences at events or conferences and attended TCT's Royal Albert Hall concerts. I soon realised being part of this shared cause was empowering and joined other networks. In the following years, these included sailing with the Ellen MacArthur Cancer Trust, acting as an ambassador for Blood Cancer UK and a volunteer for Lymphoma Action, and sharing my story for Leukaemia CARE.

Now, I'm a 28-year-old health journalist, grateful to have stayed in remission since my teens. Back then was also a time when cancer ever not being part of my life seemed hard to imagine. Admittedly, cancer is still part of it, but now, by choice.

I've made many amazing connections and met many inspirations along the way. That's why I've wanted to become one of them to others more recently diagnosed. So, I'm still busy trying to support others, raise awareness and write about youth cancer, and I'm even working on a book to help other young people navigate treatment and beyond. I plan for it to feature both my own reflections, and advice and guidance from other young patients, as well as psychologists, doctors and charities. It's my dream to complete this before I'm 30, so keep your eyes peeled!

My message to other young people with cancer

Unfortunately, young people's cancer doesn't end when treatment does, and a lot can linger, including late effects, as well as fears about fertility and relapse, and effects on things like education, employment, relationships and friendships. But at the same time, there's life to be discovered and enjoyed, with so many experiences to uncover and people to meet. And sometimes, these never would have come into your orbit if it wasn't for the connections created by cancer.

Although everyone's case is unique, there's definitely hope post-diagnosis, and many years post-treatment. With cancer support systems tailored for young people only getting stronger, as CCLG proves, I'd encourage any young person or family, newly affected by cancer or handling its effects years on, to go ahead and see what support, or friendship, is out there waiting for them.

Clear and consistent communication was key for us


▲ **Lisa and George**

Lisa Radcliffe's son, George, was diagnosed with rhabdomyosarcoma when he was three years old and sadly died when he was four. Here, she explains how she and her husband, David, quickly found their own approach to communicating with George during his treatment, and how this helped them.

George was wonderful. Even at three years old, he had incredible speech and an ability to articulate himself well. George was also very aware of those around him and watched carefully to pick up cues of changing emotions. He'd say: "Are you happy mummy?" while looking deep into my eyes. He had empathy that we didn't know a child so young could possess. He saw others' changing emotions and responded. If other children were sad, his face would change, and he'd feel some of that emotion with them.

When George was diagnosed, we were whisked into hospital life. We were grateful that we could communicate well with him and explain things to him, in an age-appropriate way. George was always satisfied if we explained what was coming and why it was happening. He was so watchful of our emotions that with this communication came the need for calm, confidence and positivity in our delivery. If we were happy with what was happening, he was satisfied.

Using clear and consistent language helped us

When you first arrive in hospital, people don't know you or your child. We were George's advocates and had to help medical professionals get to know him, quickly. We requested that conversations didn't happen across the bed, as if George wasn't there. We hated the thought that he may take some of what was being said and jumble it together to create his own unclear understanding. We had our narrative for his cancer and wanted to use consistent language with him to help him understand, as clearly as possible, without fear or confusion.

George's 'naughty' cells didn't know what their job was, and they ended up coming together in a naughty lump. He knew he had good cells that needed to be strong to help fight those naughty cells better. Chemotherapy was his 'strong' medicine to 'power up' his good cells. This was then 'special' medicine during his maintenance treatment and 'super' medicine after relapse. In time, medical professionals got to know our narrative and used this to support George and provide consistent and clear communication for him. Giving patients such a personalised approach is difficult in a busy hospital, but as parents using our consistent language with the medical team, sharing our narrative loudly, it allowed staff to pick up on it and use it as well.

Medical staff giving children time to communicate is important. The morning of major surgery to his head, to remove the tumour, the neurosurgeon asked George if he had any questions. George asked how many naughty cells were in his lump. Taken aback by the question, the neurosurgeon said he'd let George know. In recovery, with his head wrapped in bandages, George continued to return to his question until the neurosurgeon returned with an answer. Curiosity satisfied, he could get on and play. Taking the time to see if our three-year-old had any questions and then later providing him with an answer, demonstrated the shared value of communication between medical professionals, the young patient and his parents.

Staying in the present

George brought us joy even in the most challenging of times with his kindness and joy. We stayed really present and in the moment with him, focusing on the now, which meant every difficult procedure or tough moment passed, and a new adventure could begin.

One day sticks in my mind, when the nurse couldn't place George's nasogastric tube. In that moment, he was cross and shouting, not wanting the nurse to try again.

David held George in a firm cuddle as I continued to be calm, confident and positive, reassuring him that in seconds it would be over, with messy play waiting for him.

After many attempts, the tube was placed successfully and cuddles comforted and helped return the adrenaline to more normal levels. The 'brave box' appeared, and George chose a toy and smiled. Back at his hospital bed, we settled George to some messy play, as promised. He looked up at his daddy and said: "Sorry for shouting at you, Daddy." We both swallowed hard and told him how much we loved him. In that moment, George, despite his age, demonstrated a true understanding of how hard the difficult situation had been for his daddy, too.

Another challenge was when, because of lock jaw as a result of lost muscle during surgery, a breathing tube would have to access his airway via a tracheostomy. We could share what was going to happen and why he needed it, but we couldn't be sure how much oxygen he'd be able to get to his vocal cords. We couldn't be sure if he'd wake up with a voice.

This was one of our hardest days. We couldn't communicate this clearly for him and had no idea if he'd be able to use his superpowers – his beautiful speech, and ability to articulate himself and ask curious questions.

George woke with no voice, banging at his bed, pointing at his mouth, with tears rolling down his cheeks. We quickly developed non-verbal methods of communication, such as thumbs up and down and basic sign language, but it was far too simple for our curious boy. Fortunately, our superstar learnt how to push the oxygen up to his vocal cords by lunchtime and, despite the added complication of the locked jaw, continued to show strength in his communication throughout his hospital stays.

Maintaining our approach after George's relapse

George relapsed when he was four. The rhabdomyosarcoma returned and spread. He could see his face had changed, as the tumour grew behind his eye and into his cheek. He could taste dry blood as the tumour pushed its way into his mouth. George remained calm, guided by our energy and approach. We continued to communicate what was coming and why. We listened to him and allowed him to make choices and take control of his surroundings and activities. Communication was key.

Our verbal communication was clear and emphasised trust in his palliative care team, while our non-verbal communication demonstrated calm and joy in the moments that offered it. George never knew he was dying or that his good cells couldn't keep fighting the naughty cells. He trusted that if we were happy, he was safe.

Everyday continued to be a new day with something fun to do or learn no matter how tired he got or how much drugs he'd been given. He wanted to know what a two-humped camel was called, days before he passed away. One of the last conversations George had with his daddy, as they peered into a cup together looking at a caught spider, was pondering why it only had seven legs.

A final message

To finish what I hope has been a story highlighting the importance of clear communication, I must add how exhausting this was. Advocating for your child 24/7, gathering your thoughts and preparing your narrative, before then sharing with your child, takes brain power and energy from parents who are already 'full'. It's important that parents find time to communicate with someone, ask questions and share how they're feeling, to release a little of that 'fullness' and be able to keep giving what their children need.

Parents and medical teams, together, should plan time for communication where parents are heard and through which patients are truly seen. The result would be parents better able to be the best they can be for their child and medical teams better equipped to offer the best they can for their patients.

▲ **David, Lisa and George**

The importance of multidisciplinary team working in children's cancer care

Multidisciplinary team (MDT) working is essential in children's cancer care. ***Dr Ren Manias****, Consultant Paediatric Oncologist at Southampton General Hospital and Contact's medical adviser, explains how effective communication and shared decision making improve survival rates, enhance quality of life, and support children and their families during their cancer journey.*

A multidisciplinary team (MDT) is a group of healthcare professionals with different areas of expertise who work together collaboratively to oversee and deliver the best possible care for every child diagnosed with cancer. MDTs are especially important in paediatric oncology because managing childhood cancer is complex and multifaceted.

A typical MDT consists of paediatric oncologists, haematologists, surgeons, radiologists, pathologists, radiation oncologists, nurses, psychologists, dieticians, physiotherapists, social workers and pharmacists, with many members national or international experts in their field. Sometimes, other specialists are invited to join if their input would be helpful in a particular child's care.

MDTs allow professionals to pool knowledge and skills so every child receives a tailored care plan that addresses their unique medical, emotional and social needs. Being cared for by specialist teams who work and communicate well together offers clear benefits over being managed by one individual. Collaborative, multidisciplinary working is essential to providing a consistent, coordinated and holistic approach. It enhances decision making, reduces the risk of errors, and ensures each child is given effective, individualised treatment.

How does communication among disciplines impact the effectiveness of an MDT?

Effective communication is key to ensuring effective multidisciplinary working. In paediatric oncology, the complexity of treatment pathways requires seamless information-sharing between disciplines. For example, an oncologist must communicate with a surgeon to coordinate the timing of tumour removal after chemotherapy. Similarly, radiologists need to share imaging results promptly with the entire team to influence treatment planning.

Treatment for childhood cancer is often delivered in more than one hospital, and good communication between teams is crucial to allow effective delivery of care. Many children have treatment planned and coordinated by the oncology team at a principal treatment centre (PTC) and jointly administered locally at smaller paediatric oncology shared care units (POSCUs). Some children require highly specialist treatment, such as sarcoma surgery, carried out at quaternary centres far from home.

Clear communication ensures that every team member has a shared understanding of the child's condition, treatment goals and progress. Regular MDT meetings, shared electronic health records and well-structured communication protocols are essential for effective collaboration. Open and respectful dialogue allows every team member to contribute their perspective, enhancing decision making and ultimately improving outcomes for the child.

Can you provide an example of how shared decision making benefits individual children?

Shared decision making in paediatric cancer care is vital because it ensures that treatment plans are tailored to each child's unique circumstances. For example, in the case of a 10-year-old child diagnosed with a brain tumour, the oncologist recommends chemotherapy, but the neurosurgeon suggests surgery may offer a better outcome. Meanwhile, the radiation oncologist believes that radiotherapy could shrink the tumour more effectively. The psychologist raises concerns about the child's anxiety and the potential psychological impact of prolonged treatment.

During an MDT meeting, these perspectives are discussed in detail. The radiologist describes the child's scans and discusses the intricacies and potential morbidity of surgery and radiotherapy with the team. By integrating input from all disciplines, the team decides the best approach to recommend to the family: starting with surgery to remove the bulk of the tumour, followed by radiotherapy and chemotherapy to consolidate treatment. The psychologist devises a support plan to prepare the child and their family for the treatment process.

This shared decision making ensures the chosen plan maximises medical benefits while considering the child's mental and emotional wellbeing. The result is a holistic approach that improves both survival rates and quality of life.

What role do families play in MDT discussions, and how is their input integrated?

Families are central to the decision-making process in children's cancer care. Parents or caregivers often serve as the primary advocates for their child and provide critical insights into their personality, preferences and needs. In MDT discussions, the child's oncologist plays a key part in advocating for families to ensure the plan aligns with their values and goals. Final decisions should always involve discussion and collaboration with families to ensure decisions are made holistically in the interests of the child.

When considering a treatment plan, the team may present multiple options to the family, explaining the benefits, risks and potential side effects of each. If a family expresses a preference for a less invasive approach to maintain their child's quality of life, the team can adjust the plan accordingly. MDTs must communicate in clear, jargon-free language and create an environment where families feel heard and respected. Building trust and establishing open lines of communication ensures families are active participants in their child's care.

How do MDTs ensure continuity of care for children undergoing cancer treatment?

Continuity of care is critical in paediatric oncology, as treatment often spans years and involves multiple stages. MDTs achieve continuity by maintaining regular communication and consistent documentation across disciplines.

Clinical nurse specialists play a key role in bridging communication between disciplines and keeping families informed. This continuity not only improves outcomes but also provides families with a sense of stability during a challenging time.

When a child transitions from active treatment to survivorship care, the oncologist hands over detailed treatment summaries and follow-up plans to the GP and late effects team. This ensures the child receives appropriate monitoring for late effects of treatment, such as heart or endocrine issues, without gaps in care.

How do MDTs support the emotional and psychological needs of children with cancer?

Children with cancer face significant emotional and psychological challenges, including fear, anxiety and feelings of isolation. MDTs play a crucial role in addressing these needs by involving psychosocial specialists such as psychologists and social workers. A child undergoing painful treatments might benefit from sessions with a psychologist to develop coping strategies. A play specialist can use play therapy to explain medical procedures in an age-appropriate way, reducing fear and promoting understanding. These efforts are integrated into the overall care plan, ensuring emotional support is considered as an essential component of holistic care.

What's the impact of MDT working on long-term outcomes for children with cancer?

The long-term outcomes of children with cancer are significantly improved by MDT working. Survival rates have increased dramatically over the past few decades, in part due to the collaborative efforts of MDTs. By combining expertise from multiple disciplines, MDTs ensure that treatment is both effective and individualised.

MDTs are also instrumental in managing late effects of treatment. By involving specialists in survivorship care, MDTs provide ongoing support to children and their families, helping them lead fulfilling lives post-treatment.

How does MDT working contribute to innovation and research in paediatric oncology?

Collaboration among disciplines encourages the exchange of ideas and participation in clinical trials. For example, MDTs might identify a child who is a good candidate for a trial of a new immunotherapy drug, based on insights from oncologists, immunologists, and geneticists.

MDTs also contribute to the development of best practices and guidelines by sharing their experiences and outcomes. This continuous learning cycle drives progress, ensuring that children receive the most advanced and effective treatments available.

How play fosters effective communication

Becky Rodgers

Becky Rodgers is a health play specialist at Sheffield Children's Hospital. She tells us about her role in supporting children and young people (CYP) and their families during treatment, helping them to process information and express their thoughts and feelings.

As a health play specialist, part of my role is to provide therapeutic playful interventions and a sense of normality to children and young people in hospital, which can be a scary and often unfamiliar place for them. We use many different tools and methods to build rapport and a relationship with them, which allows an understanding to develop between us. It's important for them to know that I'm a person who can support them in any area of their treatment and, importantly, will be there for the whole process.

It can be difficult for many CYP to communicate their thoughts and feelings, but we use many techniques to support them in doing this in different ways. As a play specialist, it's my role to understand each individual and adapt to suit their needs. We use family members – mainly parents or carers who know the child best – to support us in this scenario as we want them to feel comfortable and at ease with us.

All CYPs are unique

It's important to acknowledge that each CYP will communicate in a different way that is age-appropriate to them and their needs. It's my job to navigate their communication style and adapt my own to fit with them to allow for the best possible support that I can provide.

I've used teddies and dolls, books, pictures and technology to prepare children and young people for procedures that they'll have to reduce anxiety, worry and uncertainty. All of these act as valuable tools to both communicate what they can expect medically and also for them to be able to share their thoughts and how they are feeling with me so that I can support them in the best possible way throughout what can be a difficult time. It's also important that healthcare professionals treat them as individuals, and not just as a patient but as a person, which is where my role comes in to support this. Communication with CYP we care for is back and forth as they speak with us daily. Seeing the same CYP regularly means we can be seen as friendly faces who are always there for them and are able to help them communicate their opinions and feelings back to members of staff, so they feel heard and understood by everyone providing their care.

Supporting family members

We strive to support the patient's family as much as we can as they also need supporting and communicating with in an appropriate way which can be challenging in a medical environment.

We do this for all the family by using language that we all understand as the medical terminology can be a challenge for all of us, especially in the beginning. We provide support for siblings to help them to understand what's happening – all with parents' consent – in an age-appropriate way. As trusted professionals, we can again allow them to communicate in a safe place to discuss their feelings, concerns and thoughts on what's happening.

Remember

Play specialists are here to support you, your child and your family throughout your time in hospital. We are always around to help you.

“Be as honest as you can and keep asking for support”

__Kate Hibberd’s__ daughter, Meredith, was diagnosed with b-cell lymphoblastic lymphoma in 2023 aged four. She tells us about how her family has navigated keeping people updated about Meredith's treatment, the importance of asking for support, and how connecting with other families of children with cancer helped them.

When Meredith was diagnosed, it came as a huge shock because she presented with no obvious history of symptoms other than a swelling on her forehead in the weeks before, which we thought was a bump to the head that hadn’t gone down. There had also been an intermittent but persistent painless limp in her left leg, which had been attributed to growing pains and she had been receiving physio for. Eventually, after many tests, scans and biopsies, she was diagnosed with b-cell lymphoblastic lymphoma, a type of non-Hodgkin lymphoma.

Deciding how to keep people updated

We soon found ourselves grappling with the task of updating all our family and friends. We were, of course, devastated and struggling to process the news ourselves and soon found that corresponding with dozens of people was impossible. We also experienced an issue with second- and third-hand information being passed on. Although this was done with the right intentions, it obviously didn’t help.

As a family, we sat down and discussed how we were going to manage this. We wanted full control over the details, and we wanted to be able to provide people with information on our own terms, when we were ready. We decided to use WhatsApp groups for close family and friends to provide updates in real time, while we also chose to use social media to update our wider network.

Asking for support has been vital

We knew we would need support, and it was obvious people wanted to do so. We would, however, need to be the ones to determine what help we’d need, and when. We soon began to realise where we’d need support, and we also quickly found out that those areas of support would change or be more intense or less frequent depending on the day or week. We again utilised WhatsApp to set up a group, adding people who’d offered to help. We’d ask for all manner of support: meals, shopping, housework, dog walking, and laundry. We’d often find that within 10 minutes of posting what we needed, the requests were fulfilled. This was such a weight off our minds. It was one less thing for us to be worried about for that day and enabled us to focus all our energy on our family.

Talking with other families has helped

We have some wonderful friends in the form of other cancer families. There are aspects of cancer that are universal, even if the cancer or prognosis is different. We also found that we could be honest, we didn’t need to filter anything, and we could talk about any aspect of our journey. Maybe the disappointments, the realities of hospital admissions, or the deep and troubling thoughts you have at times. Parents going through this collective cancer experience just ‘get it’. There’s never judgement, only ever compassionate support.

My advice to others

I think it’s important to try to be as honest as you can in your communication. There’s no sugar coating the difficulties you face, so don’t be consumed with doing so. You might think you’ll overwhelm people and decide on replying, “I’m fine,” when asked how you are, or: “No, it’s okay, I don’t need help,” but putting on a mask like this can be very exhausting. If I could give one piece of advice to others, it would be to stay humble, keep asking for support, and don’t think you’re expected to get ‘better’ at dealing with the fact your child has cancer.

Why good communication is key to supporting young people through cancer

***Yami Moloteni** was diagnosed with Hodgkin lymphoma in July 2021 aged 18. She explains the importance of good communication in teenage cancer care, what it looks like, and how having someone to talk to can have a huge impact on young people with cancer.*

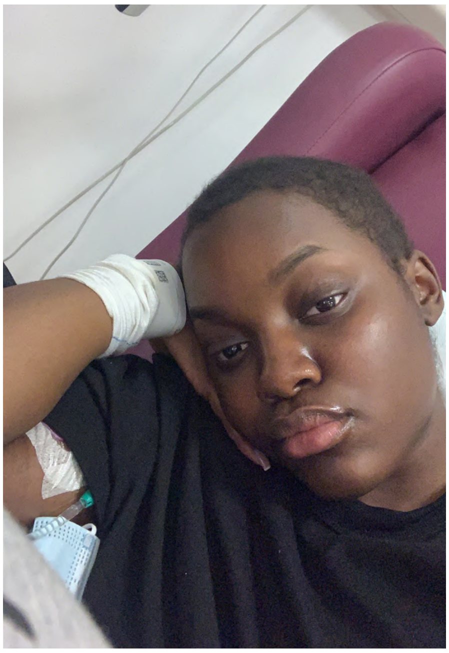
Autumn 2021 should have been a really happy time. I'd gotten the A-level results I wanted and was preparing to go to university. But then, just like that, I had all those plans ripped apart. Instead, I was thrown into the lonely, isolating world of cancer treatment.

I had chemotherapy from early September until December. The plan then was to try a new immunotherapy drug, but over Christmas I began feeling out of breath and had a temperature. I was told that in the short time since stopping chemotherapy, the cancer had grown again. The immunotherapy plan got pushed back and I did a few more months of chemo, before we finally got a scan that was looking positive. Everything was shrinking, but we went ahead with the immunotherapy just to make it a bit smaller. The immunotherapy, unlike chemo, wasn't attacking the body, but was boosting my immune system. So, I didn't feel all the intense side effects I'd been feeling previously, like sickness and fatigue.

Instead, I'd go into hospital for these hour-long infusions and then go home. That was a much kinder treatment to go through, and I could get on with my day-to-day life. However, it didn't work as hoped, so I did radiotherapy for a month. About halfway through radiotherapy, my lung collapsed. I was really struggling and ended up spending even more days in hospital trying to fix the segmental lung collapse while also having the radiotherapy.

After radiotherapy, we sat down with my consultant, who thought a stem cell transplant would be the best way to make sure we got all the cancer out and it wouldn't come back. I had the transplant in November 2022 and that was intense, mentally and physically. I couldn't eat and I stayed in hospital for just under a month, which was really isolating.

I took the transplant well and when I had a scan in January 2023, it was positive news. It wasn't remission, but it showed the cancer was basically gone and there was only a little bit left. I didn't go back to hospital for six months and started getting on with life again. I was busy working and went on four holidays. It just felt really good. And then, I was told I was in full remission at the end of July.



What can help to communicate with young people

I was 18 when I was diagnosed and knew nothing about the world, let alone cancer, and it was such a confusing time. Fortunately, my consultant, Dr Collins, was great. He was empathetic and adjusted the way he communicated to me, and I feel that's something that all professionals should be doing with their patients. He took his time speaking to me and would recognise that although, yes, I was an adult, realistically I'd been an adult for just six months. I was fresh out of school, with zero life experience and now trying to understand lots of medical terms and jargon. Dr Collins would suggest recording conversations in case I wanted to listen back to them and to email him with any questions. Just putting these things in place made me feel much more at ease.

However, I know from experience that not everyone is like Dr Collins and some people don't get that support at all, which could make a world of difference to them. We need to help educate professionals in communicating with young people and understanding the differences between them and an older patient, for example, is really important.

How talking has helped me

During my two years of treatment, I completely neglected my mental health. I didn't really speak about my cancer and didn't really process it until I got the all-clear. Therapy has really helped me to talk about my feelings. I don't know where I'd be without it. But I wish I had it sooner and, more so, I wish someone had properly explained the benefits to me.

I was 18 – I didn't know many people that age talking about their feelings. I didn't really want to sit there talking to a stranger about my problems. Why would I want to tell that person about my life?

It would have made a world of difference, and it did in the end, but maybe if I'd have been talking about the stem cell transplant, for example, when it was happening, that whole period would have been a lot easier for me to get through.

I'd advise any other young people to take this support when offered, but it's also important for hospitals to make sure that they understand how it may help them.

If they don't want it, it's really important that they at least have somebody to talk to. In my case, I received a huge amount of support from my Teenage Cancer Trust Youth Support Coordinator, Clare. Clare's amazing. She was always there when I needed her, and I couldn't have got through cancer without her.

We talked about medical things to start with, but then I got bored of talking about cancer, so we started to talk about day-to-day things. She was there to listen to my disappointment of not being able to go to uni. Everyone else would say that things would get better or try to give advice, but Clare would just listen to me and let me talk. She'd say: "I hear you. It's tough." Her validating what I was saying was exactly what I needed. Having her there made a world of difference.

Clare also introduced me to some other young people with cancer through social events which she ran. It was a real help to meet people who knew what I was going through. We didn't even have to talk about cancer the whole time. It was reassuring to just be around someone going through the same thing.

Speak up for yourself if you need to

Don't be afraid to ask for support when you need it. If you're really struggling with something, ask for help. That might mean opening up to random people about how you're feeling or speaking up if you don't understand something. For example, I had one drug, and it made me feel really sick. I just carried on taking it. It got to the point where the side effects became too much, and I had to ask for something new. It might not always feel easy, but the only person you're affecting by not speaking up and advocating for yourself, is yourself. Nobody's going to be upset that you've asked for help. Speak up for yourself and be confident in what you know.

Dr Liz Jestico

How friends and family can better support parents to make decisions

__Dr Liz Jestico__ is a senior lecturer in Children's Nursing at Oxford Brookes University and researcher at the University of Bristol. Here, she tells us about a study she conducted where she talked to parents of children with cancer about how people in their social networks had supported them to make decisions.

I knew from working as a children's cancer nurse that parents are faced with many decisions when their child has cancer and that this can feel very stressful. Other researchers have explored how healthcare professionals may support parents with making decisions, but I was interested to understand how other people in parents' lives may be supporting them.

So, I interviewed parents of six children with cancer (three mothers and three fathers). We started by talking about the types of decisions they'd faced, and then we created diagrams (called ecomaps) of their support networks. This led to conversations about how people from these networks had supported the parents (or not) with making decisions.

What did I find out?

Parents talked about many different types of decisions they were faced with. While many of these included decisions about medical care, they also talked about having to make many decisions relating to managing life outside of the hospital like childcare and school or nursery attendance.

The support networks around each family were unique, but often the network consisted of extended family members, friends, colleagues, other parents of children with cancer, and in some cases, healthcare professionals. The levels of support from people in the network varied, and sometimes relationships were a source of stress rather than support. Some parents explained that they often found themselves giving support to people in their network as well as receiving it and, in these situations, it became difficult for them to communicate what support they needed.

Support from friends and family decisions was important and could help decision making even if the support didn't directly relate to making a particular decision. Several of the parents I spoke to experienced a profound loss of confidence in themselves at the time of their child's diagnosis. They talked about feeling overwhelmed and 'lost at sea' with the decisions that they were facing. People in their social networks could play a very important role in shaping that confidence.

While there may have been times where it was helpful for a friend or family member to step in and give the parents advice about a particular decision, often this wasn't helpful as this could further undermine the parent's confidence. What felt more supportive was when other people showed compassion by avoiding any wish to help or offer suggestions, instead actively listening to whatever parents wanted to say. This could help reassure parents that they were able to make decisions that were best for their child.

How is this useful?

It's really important that members of social networks supporting parents living through situations like this know how to help. It may be assumed that if somebody is faced with a difficult decision, the best thing that we can do as friends or family members is to jump in and offer advice. However, we should be open to the possibility that this may not be helpful, and that instead, offering compassion and reassuring parents that they can make the best decisions, can be enormously powerful. The most important point is that friends or family members need to find ways to listen to what parents need and enable parents to communicate to others how they can be of support.

The next steps are to share these findings far and wide as any member of the general public may one day find themselves supporting parents whose child has cancer. I therefore plan to hold public-facing events and create a film to communicate the key messages from my research.

I'd like to thank the parents who took part in this study for sharing their time and experiences so generously.

Further information about the study

www.sites.google.com/brookes.ac.uk/liz-jestico-phd-study/home

A parent's view...

Social media: Finding the right balance for you

Mandy Berriman's son, Peter, was diagnosed with neuroblastoma in January 2019 when he was eight years old. She tells us how using social media to find information and connect with other families both helped her and presented challenges during Peter's treatment.

Mandy Berriman

Peter complained of backache at the beginning of December 2018. Within weeks, his symptoms escalated to wobbly walking and, days after being admitted to hospital, he suffered a spinal cord injury from a 'growth' that was compressing his spinal cord. Ten days later we were given the devastating diagnosis of neuroblastoma. We were on holiday in a hospital hundreds of miles from home and had just been given the go ahead to be transferred to our home hospital.

The consultant told us treatment would begin there but, in the meantime, he said: "Please don't google it." We didn't, but it was much later on that I came to truly understand why he said this. It's the same reason why, when I've shared neuroblastoma Facebook groups with parents of newly diagnosed children, telling them how valuable they can be, I also tell them to use them carefully.

▲ Peter with Mandy, dad, Martin, and brother, Sam

But back in the early days of Peter's frontline treatment, we didn't know or understand any of this. We allowed ourselves to be guided by his consultant and avoided looking elsewhere for information. We didn't need to – Peter's frontline treatment went to plan and by May 2019, surgery had successfully removed the localised tumour in his chest cavity, and he was officially no evidence of disease. He continued with radiotherapy and a six-month course of maintenance therapy until February 2020, when treatment stopped.

Turning to social media for help

In August 2020, Peter relapsed, this time with his cancer having spread to other parts of his body. With no set treatment path, I turned properly to social media for the first time. I read every post on neuroblastoma Facebook groups for anything that might help us make treatment decisions. There was a wealth of information on treatment trials, advice on side effects, links to scientific papers, and data. It all helped formulate questions to take to our consultant.

Through these posts, I found out about Solving Kids Cancer, a charity that supports families of children with neuroblastoma, and the annual online Neuroblastoma Parent Global Symposium which ran a series of talks on trials, research and breakthroughs in treatment. I also connected with other families and their shared experiences helped me to feel less alone, sometimes giving me much needed hope when they posted about their children ringing the bell, graduating, growing up, getting married, or having children of their own.

The difficult side to using social media

Parents are rarely medical professionals. Instead, they're mostly self-made experts in their child's very specific diagnosis and treatment. Neuroblastoma is complicated and unpredictable, and children with similar diagnoses can react in very different ways. Some of the information communicated may be inaccurate or biased, and sometimes your own confirmation bias works against you.

Some posts make you angry. Some make you scared. As a parent of a child with cancer you're desperate for any glimmer of hope and you need clear and accurate information. However, on these Facebook groups, you can't have that without also having the unhelpful.

Knowing when to step away

When I first used these groups, I felt I owed it to all the other parents to read and absorb their experiences and let them know that they'd been heard. I realise now that I have to look after myself first. I can choose to step away when it becomes too much.

Peter, now 14, currently has no evidence of active disease and we've no idea what the future holds. Another relapse will always be a possibility. So, on days when my anxiety is high and it's not good for me to read about other families' experiences, I stay away. I leave it for days when I'm more able to filter the posts and focus on those where I can be helpful to others or someone else can be helpful to me.

Creating a good practice guideline for communicating with young people with cancer

Nurse Debbie Critoph and Dr Luke Smith are healthcare professionals and researchers in clinical communication in young people with cancer. Here, they tell us about how they developed good practice guidelines to help peers effectively communicate with teenagers and young adults (TYA) with cancer to engage them in the level of communication they need.

Current research suggests that professionals find communicating with teenagers and young adults challenging. The reasons for this are likely because of a number of factors, including the developmental and transitional nature of adolescence, and the lack of formal training opportunities for healthcare professionals. Communication is a core skill for professionals who care for young people. Training is ad hoc and only a minority of training is interprofessional, despite the recognition of the importance of multidisciplinary care in this specialist field. If young people aren't heard and understood, they can be labelled as difficult or a challenge, which inhibits their involvement in decisions about their care, and undoubtedly affects their future care.

What we did

CCLG: The Children & Young People's Cancer Association offered us a grant to write a good practice guideline. Motivated by our work having a clinical impact, and limited communication training opportunities for multi-professionals working in TYA cancer, we welcomed the opportunity to write a guideline that would have clinical value.

We gathered a national group of TYA experts to work with us. The aim was to create a resource based on the latest evidence, relevant to a broad range of healthcare professionals. The guideline aims to equip professionals with tools to effectively assess young people's preferences and engage them in communication at the level they want and need.

The recommendations in the guideline were formed by combining the findings from a scoping review of the literature and a national questionnaire sent to professionals in the UK. The scoping review is now published and can be accessed for free here: *www.doi.org/10.1002/pon.6317*

A questionnaire was sent to patients about their own communication experiences and 24 responses were received and analysed by four researchers.

Developing the guidelines

Data from the two sources was then integrated into the guideline using a group of UK experts.

The guideline outlines the key findings, with three key themes covering:

- nature of adolescence and its intersection with cancer
- impact of supporters
- role of healthcare professionals

The guideline explores how to understand TYA individual perspectives, central to developing rapport, and the multifaceted role of supporters who can be both helpful and unhelpful in communication encounters. Healthcare professionals must assess the communication preferences of young people and engage with them at the level they want. What's more, communication preferences aren't static but instead change as young people move through the cancer trajectory and become more familiar with treatment and healthcare environments and fluctuate with symptom burden.

At times, young people want, and are able, to take the lead in communication and decision making with professionals and at other times they prefer someone else to take the lead on their behalf or do it together for a variety of reasons. Triadic communication (involving a patient, a caregiver, and a third party) is a key feature of young adult cancer care that healthcare professionals could benefit from specific training on. The final portion of the guideline provides practice recommendations linked to the Calgary-Cambridge guide to the medical interview (which incorporates the importance of patient-centred medicine including the building of a relationship and shared decision making).

The completed guideline was launched at the national CCLG conference in 2024 and was received positively. It's freely available to download on CCLG's website, to allow it to be shared widely to healthcare professionals. We hope it has clinical value and raises awareness of the critical role of clinical communication and gives professionals practical advice on communicating effectively.

Investigating how DNA communicates with cancer-causing genes


Dr Lisa Russell

- **PROJECT TITLE: Identifying critical interactions between super-enhancers and proto-oncogenes: driver events in T-cell acute lymphoblastic leukaemia**
- **LEAD INVESTIGATOR:** Dr Lisa Russell
- **INSTITUTION:** University of Newcastle
- **AWARD:** £100,000 (funded by Ruby's 'Live Kindly, Live Loudly' Fund, a Special Named Fund at CCLG)

Acute lymphoblastic leukaemia is the most common cancer in childhood, affecting over 600 children and young adults in the UK each year. Current treatments cure most children (around 90%), but this comes at a significant cost due to side effects including heart disease, reduced bone density, obesity, and fertility problems. The outlook for children whose leukaemia returns (around 70 to 90 a year) remains poor.

Regulatory regions of our genetic code, or DNA, are responsible for interacting with genes and switching them on and off. In healthy cells, regulatory regions carefully control important genes at the correct time to allow cells to do their job. Some patients with leukaemia have errors in their DNA that lead to these regulatory regions moving to a different location in the genetic code and switching on the wrong gene.

My research

I've spent 20 years discovering relocated regulatory regions that occur in the genomes of patients with a type of leukaemia that affects a white blood cell called a B-cell. This work has led to changes in the treatment that patients with leukaemia receive. Since these regulatory regions also change locations in patients with leukaemia affecting another type of white blood cell, called a T-cell, I'm now working closely with Dr van Delft, a clinical scientist with expertise in T-cell leukaemia. Together, we're currently investigating how these regulatory regions and the genes they switch on are communicating with each other, which will be key to developing new therapies targeting their interaction in cancer cells.

With the goal being to switch off our genes of interest, the team needs to shut down the regulatory regions. To do this, Camille Drai, a research technician in my team, has made a virus that will infect the leukaemia cells and deliver gene-editing proteins. Once Camille has everything inside the leukaemia cells, she can switch on the gene-editing proteins and observe any changes in the cells.

This process has taken over a year. More recently, Camille has been checking that the gene-editing proteins are working properly inside the cells, and she's been making sure that the gene-editing proteins will only make changes to our regulatory regions of interest. The exciting news is that Camille is now ready to switch the system on!

If we're successful in breaking the communication between the regulatory region and the gene it's switching on, we hope that the cells will grow more slowly and maybe even die. The next steps involve Camille checking if the cancer-causing gene is switched off. She'll need to monitor the health of the cells and also look deeper into how breaking this communication affects the leukaemia cell.

What will this work lead to?

The new knowledge we gain from this work will provide opportunities to develop new ways of killing leukaemia cells. By targeting the change in the genetic code itself, we hope that future treatment options will be kinder, with fewer long-term effects on the health of children and young adults as they get older.

With thanks to Rachel Saul, Emma Jones, Tabitha Fuller, Jon Waite, Kim Hodkinson, Tyler Hodkinson and Emily Saul of our Public and Patient Advisory Group who have contributed to writing this article.

www.cclg.org.uk/our-research-projects

60 SECONDS WITH

Hafsa Karim

Speech and Language Therapist, Paediatric and Adolescent Oncology, University College London Hospitals (UCLH), and CCLG member

Q: Tell us a little about your career so far?

A: As a paediatric speech and language therapist (SLT), I work with young people with swallow and communication challenges. Having worked in several community settings, UCLH provided the opportunity to bring my experience to the Paediatric and Adolescent Oncology team. The team here give support to children and young people with eating, drinking and swallowing needs, as well as supporting individuals with communication needs, which may have changed as part of their cancer diagnosis or treatment. Support is also provided to children and teenagers with pre-existing diagnoses which may give rise to SLT needs.

Having worked in community settings previously, I have a good understanding of the skills and knowledge of therapists working in the community. This ensures meaningful handovers are given to community teams, to ensure a streamlined approach and continued support for the families on this journey.

Q: Tell us about your role in supporting children and young people with cancer and their families?

A: In this role, we assess and offer treatment and supportive care to children and young people with both swallowing and/or communication needs. We like to get to know the young person, understand the ways in which they communicate, and make the necessary adaptations to support them through their treatment. We offer tailor-made therapy and advice to individuals receiving treatment, being mindful of their symptoms while also ensuring sessions are fun and engaging for them, which can boost their confidence.

Our job also includes assessing the safety of an individual's eating and drinking skills, and we make recommendations on the foods and drink textures that the individual can manage safely. This often requires discussion with the young person and their family, to understand what their preferences are, carrying out an assessment of their eating and drinking skills, and then liaising with the multidisciplinary team (MDT). This integrated approach ensures that the patients' preferences are heard and are in the centre of our decision making.

Q: What is the most rewarding part of your job?

A: Every session where we can make a child smile, communicate or show enjoyment on what is an otherwise very difficult journey, makes the job worthwhile! UCLH have a unique MDT where we work closely with each other. We meet on a weekly basis and discuss the patients receiving treatment, which ensures that we all know what's going on for the family and support them accordingly. Communication is the key to multidisciplinary working, and this is something the team here work really hard at.

Q: What does your job mean to you?

A: Speech and language therapists have a unique role in supporting young people on their journey. Having the opportunity to support a young person to find their voice again, reduce the frustration of not being able to communicate, or find the best medium for them to get their message across, is incredibly rewarding, and helps to ensure that the young person is always at the centre of the decisions being made. Watching them smile, laugh and enjoy sessions makes the job even more meaningful.

Q: Do you have a message for children and young people with cancer and their families?

A: Communication is the key to successful interactions – make sure you speak to the teams you're in contact with, ask your questions and tell them your preferences. If you don't voice your concerns or requests, the team will be unable to try and fulfil them.

ASK THE

Expert


Jeanette Hawkins


Jo Stark

Jeanette Hawkins and **Jo Stark**, Chief Nurses at CCLG

How can I prepare for appointments with my child’s doctor or advanced nurse practitioner?

Whenever you attend hospital with your child for an appointment, you´re likely to be in a state of heightened anxiety, so it really helps to prepare. Here are some top tips to get the most from appointments.

Make a note of questions you want to ask

Think about your questions or what you want to say in advance and make a note of them. It’s very common to have a lot of questions at home but only ask a few of them when you’re actually with the nurse or doctor, because of stress and forgetting what you wanted to say. It also happens because there were things worrying you at home that feel ‘silly’ to ask when you get there, or you think the doctor looks too busy today, so you put it off until another time. Please do ask everything you want to ask. Nothing is too silly or too small. Sometimes a thing that seems small to you, might be really important.

Gather information

Check the appointment letter to see if the hospital has asked you to bring anything. Even if it doesn’t ask, it may help to take all your child’s medicines or write a list of them, so you don’t have to remember what your child’s on, and the doses and the frequency. Professionals may ask this for several reasons. It checks that the child is taking what the doctor/nurse thinks has previously been prescribed and the family fully understand the medicines, and whether there have been any dose changes (maybe the child was having side effects, and you called for advice between appointments resulting in a change to medicines).

You’ll be asked about how your child’s been, and you may also be asked if you know what’s coming up in the treatment plan, or whether you’ve received appointments for scans or dates for surgery. It may help to write all the above down before you go, so that you don’t rely on remembering everything.

Prepare your child

Think about how your child likes to manage information. Is it best to tell them a few days before, talk about it, and find out how they’re feeling? Does your child manage better if you tell them just before and give them information as things are happening? You’ll still need to ask them how they're feeling and what they’re thinking to help you support them.

Ask them if they have any questions, too, and as soon as a child’s old enough and especially with teenagers, help them to speak for themselves. They may also have questions they think ‘aren’t worth asking’ but are secretly causing them lots of worry, or they may hide signs and symptoms if they find them embarrassing or if they think it will result in admission.

Your child may have questions they want to ask on their own with the doctor or nurse but feel uncomfortable doing so. If they have contact with their specialist nurse and feel comfortable, they could speak to them or maybe text them their questions before and they can help ask these with your child at the appointment.

If your child’s nearing the age where they’ll be transitioning to teenage and young adult services, there may be a time in the appointment when your child will be seen alone. This can feel strange, but with support from the team, this is an important step for helping to support your child’s confidence and independence.

Join us on our ...

Big Hike

Saturday, 20 September 2025

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

The half marathon hike in the stunning Peak District National Park is open to walkers of all levels, whether you're a total novice or a seasoned hiker.

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

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Century House, 24 De Montfort Street, Leicester LE1 7GB • 0333 050 7654 • Email: info@cclg.org.uk
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