

FREE

AUTUMN 2024 | ISSUE 104



Children's
Cancer and
Leukaemia
Group

the EXPERTS
in CHILDHOOD
CANCER

contact

SUPPORTING FAMILIES THROUGH CHILDHOOD CANCER

MAGAZINE

Relationships

How may relationships strengthen or splinter following a childhood cancer diagnosis? What can help to navigate them? How can they help?

+ HOW CHARITY SUPPORT CAN HELP BRING PEOPLE TOGETHER

+ THE IMPORTANCE OF COMMUNICATION



A parent's view

Claire Bailey, whose daughter, Poppy, was diagnosed with neuroblastoma aged three, writes about the value of mutual support between families both during and after treatment **Page 15**

BACK TO BASICS:

**Relationships after a
childhood cancer diagnosis**

Dr Amandeep Samrai writes on relationships during childhood cancer treatment and offers advice on navigating them **Page 8**

**IT'S THE LITTLE ACTS
OF KINDNESS THAT CAN
MAKE THE DIFFERENCE**

Kelly Scott, diagnosed with non-Hodgkin lymphoma when she was a teenager in 2001, explains how some thoughtful acts supported her during treatment.

Page 12

INSIDE THIS ISSUE... ON RELATIONSHIPS

Autumn
2024

- 05 Charlotte Hillyard, whose daughter, Jess, was diagnosed with a brain tumour aged three, tells us how her family has set up a peer support group for families affected by childhood cancer
- 06 Kay Lewis, whose daughter, Maisy, was diagnosed with retinoblastoma as a baby, explains what helped them after treatment
- 07 Sophie Hartley, who was diagnosed with bone cancer in 2005, explains how this affected her internal relationship
- 10 Teens Unite Fighting Cancer's CEO, Roxanne Lawrance, tells us how it brings together young people living with cancer and its lasting effects for crucial peer support
- 13 Scott Wilson, of The Ellen MacArthur Cancer Trust, tells us how it takes young people on free sailing and outdoor adventures to help rebuild their confidence after cancer
- 14 Caroline Cleaver, a proton beam liaison nurse and CCLG member, explains how the cancer care her sister received as a teenager inspired, and helps her in, her own career
- 17 **Young lives interrupted by melanoma: Exploring the experiences within a relational context**
A research study funded by Teenagers and Young Adults with Cancer (TYAC)

EVERY ISSUE

- 04 **Medical adviser**
Prof Bob Phillips introduces the theme of 'Relationships'
- 04 **News in brief**
A round-up of the latest updates in childhood cancer
- 08 **Back to basics**
Dr Amandeep Samrai, a consultant clinical psychologist in paediatric oncology, writes on relationships during childhood cancer treatment and offers advice on navigating them
- 16 Dr Ren Manias, a consultant paediatric oncologist and Contact's medical adviser, tells us how open and honest communication between doctors and parents is key to developing trust
- 18 **60 seconds with...**
Penelope Hart-Spencer, a health play specialist and CCLG member, tells us about her role
- 19 **Ask the expert**
Dr Sarah Evans, CCLG's Head of Research, explains what patient and public involvement is in research and why it's important

ON THE COVER

- 12 Kelly Scott explains how being diagnosed with cancer as a teenager in 2001 affected her relationships with peers and how some acts of kindness supported her
- 15 **A parent's view**
Claire Bailey, whose daughter, Poppy, was diagnosed with neuroblastoma aged four, writes about the value of mutual support between families during and after treatment

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.

Children's Cancer and Leukaemia Group 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.

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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.



KEEP IN TOUCH



Contact Letters,

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Your messages...

Praise for Contact's last edition on 'Education'...


 **"Thank you for sharing positive childhood cancer stories in Contact magazine."**




 "Great article by an inspirational young person, Sophie, in the @CCLG_UK magazine highlighting the crucial roles played by #teachers #SENCOs and #TAs in supporting pupils after an #acquiredbraininjury."




Read Sophie's story at www.cclg.org.uk/Contact-magazine/How-schools-can-adapt-to-flexible-learning

 "Just reading the brilliant Contact magazine from @CCLG_UK. There is an interview with a hospital teacher at Sheffield Children's Hospital, which really resonates."

CCLG's information resources continue to provide vital support

 "Your (downloadable) resources were, and continue to be, such a huge support to us as my daughter continues her treatment. Detailed information that's accurate and from a source we completely trust... thank you so much."

 "Information like this is vital to help parents understand even a little bit of what is going on when their world falls apart. Keep up the amazing work."

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**



Hello!

Relationships are a vital part of living and you can have many throughout your life. They can be friends, acquaintances, romantic partners or work colleagues, and they help to form our social support network that is essential for physical and mental wellbeing as humans. Relationships can change during times of transition such as starting a new school, a new job or local hobby group where deeper friendships can develop based on trust and shared experience.

This issue explores the range of different relationships that families face when their child is diagnosed with cancer. Patients and families begin an unfamiliar journey of trying to navigate existing relationships as well as forging new ones, such as when meeting other families on the ward and hospital staff. Each relationship comes with different expectations, benefits and challenges, but the importance of human connection in times of struggle is still the same.

Claire



Children's Cancer and Leukaemia Group



the EXPERTS in CHILDHOOD CANCER



Candlelighters
Supporting the families of children with cancer



FREE EVENT

Join us in Leeds for CCLG's Research Discovery Day

Creating a brighter future for children with cancer

Tuesday, 1 October 2024
9.30am - 3.00pm

CCLG's Research Discovery Day offers a fascinating insight into the world of childhood cancer research. This year we've partnered with Candlelighters to bring you more science and expert researchers than ever before.

Sign up by 18 September to secure your place.



To find out more and to book your place, visit:
www.cclg.org.uk/our-research/research-discovery-day



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

Relationships come in all kinds of forms and can develop in all different kinds of spaces. In this issue, we hear about how different relationships are impacted by, or in some cases, born out of, children and young people's cancer.

Times of upheaval are challenging – and none are more challenging than those following a childhood or teenage cancer diagnosis. Following a diagnosis, patients and families may find that some pre-existing relationships splinter while others will bind and grow. Some, even those with the closest family and friends, may feel strained while others will be relied upon for emotional and practical help as the demands of treatment are navigated.

Other relationships, those formed after being thrust into the world of treatment, will blossom and provide a vital lifeline of support. We explore the bonds made with those going through similar challenges, and how friendships forged this way can last for years. Some of these happen in hospitals or online, while there are charities working to facilitate these networks, to help bring together those who just 'get it'.

Then, there's the interactions with those whose care you're under or are supporting you through treatment, such as consultants, ward staff, play teams and social workers. Many of these will be slightly mechanical, polite and respectful, driven by the functions we're performing. Some will be deeply emotional and demanding. Working from this side of the desk, we know that every new family we meet will need us in different ways and will influence and change us as well as being influenced and changed by us. Speaking of professionals, there's the relationships between the staff, too. We have loads of colleagues, acquaintances and friends across many disciplines and professions. In these relationships, we can share our joys and sorrows and, importantly, our cancer-care knowledge. CCLG is a good place to nurture those relationships – this spider web of expertise and wisdom that feeds and improves practice, to the benefit of patients and families, is only possible because of it.

We all live with relationships which can enrich and empower us. Let's celebrate them and how they help us all.

NEWS IN BRIEF

New, kinder, take-at-home brain tumour treatment approved

A first-of-its-kind treatment for children and young people with low- or high-grade gliomas that have a specific genetic mutation has been approved by National Institute for Health and Care Excellence (NICE) and will now be available on the NHS for one to 17 year olds. The combination treatment, given at home rather than in hospital, works by targeting proteins made by the altered BRAF gene that's responsible for uncontrollable tumour growth.

Combining two drugs – dabrafenib and trametinib – it's been found to stop the disease progressing for more than three times as long as standard chemotherapy.

(Source: Sky News)

Promising new approach for hard-to-treat childhood cancers

US researchers have developed a functional precision medicine approach that targets cancer by combining genetic testing with a new way to test individual drugs on tumour samples. The combined approach has some advantages over existing precision medicine processes, including faster results and more treatment options. It involves taking a sample of blood or tumour and enriching and processing the cancer cells in the lab in a way that closely resembles how they'd normally grow in the body. Then, the cancer's exposed to more than 120 FDA-approved drugs, which also may be tested in various combinations recommended by the clinical team. The best cancer destroyers then emerge, with the entire process taking around a week.

(Source: medicalxpress.com)

Ten-minute test for medulloblastoma diagnosis

Children could have an accurate medulloblastoma diagnosis in 10 minutes. There are four types of medulloblastoma, the most common form of childhood brain cancer, and treatment differs between patients. Scientists at University of Birmingham have accurately identified the chemical signature of each type of tumour using MRI scans. Researchers took 86 tumour samples and used laboratory tests to identify chemical markers like a genetic fingerprint for each type of tumour.

Combining MRI scans with artificial intelligence, it was possible to identify the tumour without the need for biopsy. This could sharply reduce the current four-week wait for a full diagnosis, potentially improving outcomes. Identifying which chemicals are important for each type of tumour could also be a first step to finding new, targeted treatments for medulloblastoma.

(Source: BBC News)



How a walk-and-talk group is supporting families of children with cancer

▲ Lee, Joshua, Jess and Charlotte

Charlotte Hillyard's daughter, Jess, was diagnosed with a brain tumour in May 2023 aged three. Knowing the importance of peer-to-peer support, Charlotte and her husband, Lee, set up Walking Warriors Essex earlier this year to bring together families of children with cancer to share their feelings and experiences.

Our journey into childhood cancer was very fast. When Jess first presented with symptoms, we were blue-lighted to our local hospital and then to Great Ormond Street Hospital that same day. Jess underwent emergency surgery 48 hours post-seizure, and we were thrilled to hear the tumour was successfully removed. Following testing of the tumour, she was diagnosed with atypical teratoid rhabdoid tumour (ATRT), which was localised to her head. Her treatment consisted of nine cycles of chemotherapy and six weeks of proton beam therapy. She finished treatment last November, and we were thrilled to see her ring the bell in December.

When Jess, now four, first began treatment, we were told that this is a "marathon not a sprint". For us, getting through the marathon was helped enormously by talking to other parents. It can feel so incredibly lonely finding yourself in the world of childhood cancer, leaving your old life and witnessing the

trauma you're putting your child through to save their life. However, we found that meeting like-minded parents on the wards, in the kitchens and waiting areas was invaluable in 'debriefing' from the day. Those shared experiences helped us form the idea of Walking Warriors Essex. We wanted to set up a peer-to-peer support group to provide a safe space for people to share their personal stories of how childhood cancer has affected them.



carefree, without childhood cancer. However, over time, by talking to other families and coming to terms with a 'new normal', we were able to find a form of acceptance, which in turn shifted some of that weight. Although life is different, we personally feel we know the value of each day now. We can't change what's happened to us, but we can choose how we move forward and for us that means fundraising via our support group and ensuring that we lean on people.

People really are the answer. We hope our support group provides that avenue for others, to help them navigate their own new normal.

Our mission

We want to help unite families by arranging monthly walks and events around parks in Essex. Our growing community is full of parents, grandparents, brothers, sisters and caregivers who just 'get it'. It's an outlet to help normalise and validate feelings and, in turn, reduce isolation. It can be so easy to just wear a mask each day and hide how you really feel. Our support group provides a safe space where people can speak freely about their journey, without fear of judgement, and where everyone's experiences are treated as equally important.

Navigating life post-treatment can feel incredibly hard. At the start of Jess' diagnosis, we wished a lot for our old life back. A life that was seemingly



www.walkingwarriors.co.uk

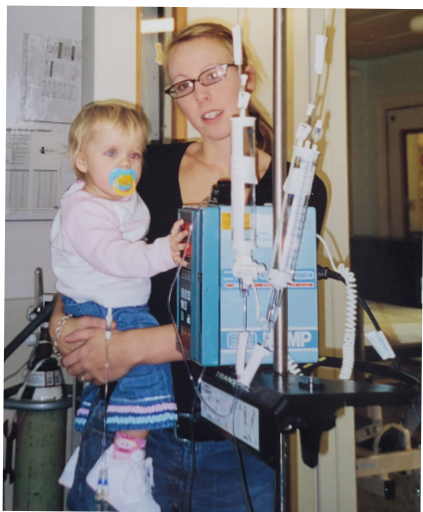


Appreciating every moment

Kay Lewis’ daughter, Maisy, was diagnosed with retinoblastoma in both eyes when she was nine months old. Kay explains what helped them after treatment, and how Maisy continues to inspire her.

Maisy was a happy baby, always smiling. At the time of her diagnosis, we’d recently moved to Tenerife and were settling into our new life abroad. The hospitals there were unsure what was wrong with her, and we were advised to return to the UK, which her dad and I did the day they told us something was seriously wrong with our baby. When we arrived at Moorfields Eye Hospital, it still took three doctors to diagnose her with bilateral retinoblastoma.

One of the tumours in her left eye was so big that she had to have that eye removed, with a false eye fitted a few weeks later. She also had three tumours in her right eye, which were treated with cryotherapy and six months of chemotherapy.



Maisy in hospital with Kay

She was extremely poorly during her treatment and spent most of that time in hospital. She was so tiny and had so many side effects from chemotherapy. Some days we’d be discharged from hospital and within a few hours, we’d have to return with a different symptom. It was emotionally draining. It was such a sad time, but I have an amazing family that supported us throughout.

During Maisy’s treatment, I decided to make an album for her. I thought one day, when she’s older, she’ll no doubt ask why she has poorly eyes. I added photos to the album of her in hospital, I kept her hospital tags, cards from family and friends, and details of charity events that we did raising money for the charity Childhood Eye Cancer Trust (CHECT). I kept notes of appointments and the reason why she was in hospital.



What helped us in the years after treatment

Maisy got the all-clear after six months, though we still had many check-ups which became less frequent as time went on. We were so happy with how strong she was. She was a lovely girl, who was always happy, smiling and dancing.

When she was five, she asked me about her eyes, and I sat with her and showed her the album. The photos helped her understand what happened and also helped in her early teens when she was getting bullied at school. She took the album in to show the other children in her class and year group.

How amazing Maisy inspires me

During the COVID-19 lockdown, I decided to write a book about what happened to Maisy. I always wanted to write one for her so she could read how strong and amazing she is. But when I was writing, I realised how much it would help other families going through a similar experience. It took me a long time to write as it was so sad, but my book was published in February, with Maisy the first person to read it. She found it emotional yet interesting, as there was lots of information in it that she never knew about.

Maisy’s now 20 and incredible. We have a great relationship, and spend a lot of time with each other, always finding new places to explore. She doesn’t let being partially sighted affect her in any way. She’s very confident and has gone off travelling again this summer. She’s a very happy young lady.

When she was 18, she had her first tattoo – it’s a picture of her eye and underneath it says, ‘Appreciate every moment’ in Spanish. Maisy has a lot of dreams and exciting plans for what she wants to do with her life and having had cancer as a child won’t stop her.



Maisy helping to raise awareness of retinoblastoma



Me, myself and I

Sophie Hartley was eight years old when diagnosed with bone cancer in 2005. Now 27, she explains how this affected the relationship she has with herself.

I've been in cancer remission for almost 20 years, having been diagnosed with Ewing sarcoma in my femur (thigh bone) as a child. I had a year of chemotherapy and a full knee replacement, before going into remission around a year after my diagnosis. While in remission, I've had lots of surgery and orthopaedic care to treat the lasting effects of having a knee replacement. These were mainly leg-lengthening surgeries to treat my ever-changing leg-length discrepancy, where my left leg would grow naturally, and my right leg would need to be lengthened with surgery due to the metal prosthesis that replaced my knee.

How this has impacted me

In total, I had a dozen surgeries over a decade. So, my teenage years felt like a revolving door of limping, operations, leg pain and physiotherapy. This had a big impact on my life. I felt misunderstood and 'different', which presented itself in various ways in my relationships with my peers and family.



Sophie in hospital

However, the relationship that cancer remission has impacted the most in my life is the one I have with myself. When we think about relationships, and how cancer may change them, this isn't often considered – but, when you think about it, we're the person we speak to the most, spend the most time with and know the best.

This has given me the clarity to recognise remission for what it is: a beautiful second chance at life filled with joy, grief, pain, confusion and learning.

The constant re-learning of how to walk and loss of physical ability chipped away at my confidence and happiness as a child and teen. I held huge shame and embarrassment about my experience of childhood cancer and its long-lasting effects. This has an immeasurable impact on the relationship I have with myself. With distance from my diagnosis has come a lot of reflection on how I care for this. I have had to reframe a lot of my thinking. I had a Catholic upbringing where we were taught to treat others as you would yourself, but I've had to flip this to treat myself how I would others. I still catch me bullying myself for my disability and the mental effects of cancer treatment, talking to myself mentally in a way I'd never dream of speaking to anyone else in the same situation.

How I'm reframing my thinking

I'm currently trying to reframe my thoughts to be more compassionate toward myself. In remission, we must allow ourselves the space to be kind and considerate with ourselves. We don't need to tick off huge bucket lists to make our lives worth living, it's enough to simply be who we are.

A big thing for me has been changing my language around cancer. I describe myself as being in cancer remission, rather than as a cancer survivor. This is something I find important in reinforcing to myself, and others, that cancer remission is its own chapter. It also doesn't use fighting language, which I found increased 'survivor's guilt' and made me feel deep shame for any negative feelings.

This has given me the clarity to recognise remission for what it is: a beautiful second chance at life filled with joy, grief, pain, confusion and learning. And I get to live it with every past version of myself, bringing eight-year-old Sophie along from her hospital bed to experience it all with me. As long as I'm doing what is right for past and present versions of me, that's what's important, and the relationship I have with myself is improving more each day.





Relationships and childhood cancer

Following a childhood cancer diagnosis, parents may find relationships with those around them change, while they may also develop a number of new relationships during their child's treatment. Here, **Dr Amandeep Samrai**, Consultant Clinical Psychologist in Paediatric Oncology at Nottingham Children's Hospital, talks about how relationships can be both helpful and challenging during childhood cancer treatment.

Once you begin to settle onto the treadmill of childhood cancer treatment, there can be a change or shift in relationships. Your pre-existing support network may include your immediate and extended family, friends, religious organisations and other support networks. Parents may take different approaches to treatment, with one parent organising medication, speaking to the medical team or wanting to find out as much about the diagnosis as possible. The other parent may not want to find out more information and take things one day at a time.

Sole parents will find that juggling treatment, childcare and the household will fall to them, and it's important to ask for help in this situation. Couples who parent together may find that one parent stays with their child in hospital

regularly while the other parent works and/or stays at home to look after other children keeping the household going. There may not be as much time to spend together as a couple during treatment. It may be hard to see your support network or stay in touch as regularly as you want to.

It will be up to you to decide the boundaries of relationships during treatment, and there will be times when you want to spend time alone or with your immediate family. However, it's important to try and meet your own needs and this may involve meeting family and friends away from the hospital. Parents may understandably feel guilty for wanting to spend time away from the hospital or may not want to leave their child. However, taking a break allows for time and space to rest, and recharge.

DEMANDS AND STRAINS ON RELATIONSHIPS

The worry and stress of treatment, hospital stays, finances and employment are all likely to cause a strain on relationships. It's very common to feel worn out by all the different roles a parent has to take on during treatment, and support from others can be beneficial. It usually helps to have open and honest communication with people you're close to, such as partners or grandparents.

Friends and family may want to offer help, but don't know how to. If you're able to, tell your support network what you need. The type of support you may want could be more practical, such as food shopping, dropping off meals, bringing clothes to hospital, or picking up children from school. At times, you may need emotional support, such as meeting up to talk about how things are going. Sometimes, you may not want to talk about what's happening during treatment and prefer to go out for a walk or coffee without talking about cancer, hospitals or medications.



RELATIONSHIPS WITH YOUR CHILDREN

You may find that your relationship with your child changes during treatment. They might be understandably distressed during hospital stays or become angry with you. Their behaviour may be different, and sometimes they might act younger or older than they are or become very attached to one parent. This is a common response to treatment, and often, this readjusts over time. If it's an option, doing activities they enjoy, going out (even for a short time) and encouraging your child to spend time with their friends can help.

It may be that your partner/spouse, other family members or friends are looking after siblings. Often siblings don't see their parents as frequently during treatment and they may feel upset or resentful about this. Siblings might have to join you in hospital or attend appointments if you don't have childcare. They may also have their own worries about cancer and treatment. Where possible, we encourage parents to have one-to-one time with siblings, answering any questions they might have about cancer, or treatment in an age-appropriate way. It's important that they continue to attend school, engaging in activities, seeing their friends and having a 'normal' life.



FORMING NEW RELATIONSHIPS

As treatment progresses, you may begin to form new relationships with other parents. Many parents report how valuable they find their friendships with other parents, both during and after treatment. Other parents who are going through the same or very similar experiences are able to understand the difficulties of treatment. Once treatment ends, they may also have experience of managing the adjustment and transition.

The amount of time spent in hospital varies between each family, but it's likely you'll form close relationships with staff in your child's medical team. When you're in hospital, you will be able to speak regularly to doctors and nurses, and you may receive support at home from clinical nurse specialists and social workers. During treatment, it may feel reassuring to have these relationships and frequent contact with professionals. When treatment ends, there can be mixed feelings, such as feelings of loss and worry due to not having contact with the team as regularly anymore.

NAVIGATING THE CHANGE IN RELATIONSHIPS

Undergoing or completing cancer treatment is a difficult time and is likely to have an impact on relationships in different ways. There's no 'right' way to navigate relationships during treatment, but it can help to communicate what you need and how you feel.

Once treatment has ended, these relationships will begin to readjust or reconnect. Some relationships may become stronger, and other relationships may become more distant as you go through treatment. It may also be that some relationships and friendships come to a natural end.

If you, your child or family need help to navigate relationships, please speak to a member of your child's medical team. Most teams have clinical nurse specialists and social workers who provide emotional and relationship support. In some principal treatment centres, there are clinical psychologists who work in the paediatric oncology teams, and a member of the medical team can refer you.

There are also other organisations that may be able to offer support and advice, including Relate (www.relate.org.uk) and Maggie's (www.maggies.org).

Uniting young people with shared experiences

*Teens Unite Fighting Cancer brings together teenagers and young adults living with cancer and its lasting effects. Its CEO, **Roxanne Lawrance**, explains how surrounding yourself with others in a similar situation can often be helpful during cancer and in the years that follow, and how Teens Unite helps young people do this.*



Roxanne Lawrance

Cancer presents a specific set of challenges to teenagers and young adults. It affects their mental and physical health, education and employment, as well as their friendships and relationships, all of which are significant to their key developmental years. Many of them find cancer a lonely and isolating experience. It's a time when the support of those around you is needed more than ever, but there's also a likelihood of friendships and relationships breaking down.

Studies show that a huge number of young people report they've lost contact with their friends since being diagnosed with cancer. But why is this the case? And how do you rebuild your life without this support network around you? Following a cancer diagnosis, many young people will experience loneliness and as a result can become segregated from society and can feel abandoned by their friends following a diagnosis. Either when their friends don't know the right words to say, or they don't say anything at all and take a step back to avoid the situation. Or, the promise of support upon diagnosis is short lived, as there's a lack of understanding or appreciation of how cancer continues to impact their life even long after treatment comes to an end.

Reaching remission is often where the strain in relationships is most common. There's an unfair expectation that life simply returns to the way it was before, yet the mental and physical health implications of cancer last for years to come, and continue to affect daily life. To others, all may appear well, but deep down the young person may be experiencing side effects ranging from anxiety and depression, to fatigue and low self-esteem, which can be a barrier for socialising with others, and embracing new opportunities. It can be a struggle to keep the same pace as friends, join in the same activities, or simply act like everything is fine, when their life has become a battle of emotions, uncertainty, and decision making ahead of their years.

The world around them carries on turning, while their own life is put on hold. Often teenagers and young adults with, or who have had, cancer find themselves standing at the sidelines, watching their friends reaching the milestones they've been

dreaming of, enjoying new experiences and embarking on the next exciting chapters in their life – whether it's passing exams, starting university, trips away, or moving out. And, with the added pressures of social media, it becomes harder to avoid the constant reminder of everything cancer is depriving them of.

How we help

Teens Unite ensures that young people aged 13-24 don't have to face cancer and the long-term effects alone and are provided with opportunities to thrive in life. The teenagers and young adults we've supported over the past 17 years have informed our understanding of why a breakdown in friendships and relationships happens too often, and why improving social connections is a vital part of their overall recovery and wellbeing.

It's important for teenagers and young adults to have a support network around them who really understand what it means to face cancer and the lasting effects at this age. We bring together young people with a shared experience of cancer. Through activities and residential stays, they find friendship, learn new skills, regain their independence, rebuild their confidence and enjoy new experiences.

While cancer isn't usually the topic of conversation or the focus of the activities, there's a common understanding of the experiences they've been through, and the hurdles they continue to overcome. As their friendships develop, they face these hurdles together without any judgement, awkward silences, guilt, or endless questions.

Being part of Teens Unite and spending time with others their age who understand improves their mental, emotional and social wellbeing. It provides them with the reassurance they're not alone, the confidence to embrace new challenges, and the encouragement to reach their potential. As a result of our support, 100% of those we've helped say they feel better connected and less lonely, and 91% feel their mental health has improved.



Keryn's story

Keryn, who was diagnosed with acute myeloid leukaemia aged 18, tells us about the support she received from Teens Unite.

I found out about my diagnosis two weeks after my 18th birthday. It was a complete shock. I didn't tell any of my friends for a while. I didn't want them to feel like they had to feel bad for me or check up on me every day. To be honest, I didn't want them to worry about me.

Since signing up to Teens Unite, I've felt more confident and accepting of my diagnosis because I now know I'm not alone with what I've been through. I knew that I needed a place where I could escape for a while and just be around people that understand me when I say I'm tired and feel drowsy. Teens Unite has given that to me!

They always say that after a few years your body starts to get back to normal. That is wrong. I've been cancer free for nearly three years and I still get aches and pains and constant

bruising on my arms and legs. I still feel out of breath, tired and fatigued, but I have a great support system around me who understand and help if I ever need anything.

Through Teens Unite, I've met some incredibly inspiring people that I will connect with for ever. It's a bond that can never be taken away.

At Teens Unite, it's our mission to improve the lives of teenagers and young adults living with cancer, such as Keryn. Our support is free of charge, and accessible to anyone aged 13-24, no matter how long it's been since their diagnosis.



Registering with Teens Unite is free, quick and easy to do. Just visit www.teensunite.org/teens-sign-up or scan the QR code.

For further information, visit www.teensunite.org or email info@teensunite.org

It's the little acts of kindness that can make the difference



Kelly Scott was diagnosed with non-Hodgkin lymphoma when she was a teenager in 2001. Now working for Teenage Cancer Trust, she explains how this affected her relationships with her peers and how some simple acts of kindness helped support her.

I don't remember much of my early treatment as it was so intense. I was very sick, tired all the time, and got to the point where I couldn't speak above a whisper. I was being treated in a fantastic hospital, but with no other people my age and no idea how I should feel. Friends visited me, but I don't really remember them coming because of how poorly I was. I became very disengaged from the people around me. I really lost myself.

I didn't have a mobile phone at the time, so it was harder to stay in contact. That cut-off and things happening so fast impacted me hugely. It meant I didn't have much opportunity to share what had happened with people at school, so there were all these rumours. Friends found that difficult because they didn't know how much information I wanted to share and didn't like the way things were being talked about.

Around this time, many of them faded away. I don't hold it against them, I just think they'd no idea how to support me or what to say. But I did have a couple of friends who put in a huge amount of effort, as did their families. One, who's still my best friend now, used to bring hand cream over because my treatment caused me to get cracked hands. She'd give me a hand massage while we just sat and watched films, and she didn't really expect me to talk. She didn't expect anything from me.

When we did chat, she'd tell me about what was happening. People are different in whether they do or don't want to know what's going on without

them, but I did. I was interested in how people were. I felt like I was missing out, but at the same time I didn't want to not know anything or for people to think I didn't care. So, she'd say, "do you want me to tell you what's going on?" or "do you want to hear about this party?", which helped me feel engaged, at a level I was comfortable with.



There were also some friends who'd just passed their driving tests and would ask if I wanted to go for a drive and get a milkshake. I think they thought it was something practical they could do, and it showed a real kindness. Another thing that's stayed with me is when I was in hospital with an infection, meaning I couldn't go to prom. Having asked first

if I was comfortable with it, one girl and boy brought their outfits in and got ready on the ward with me. That they chose to do this meant so much to me.

All these things can make a world of difference. I think so many people want to help but they're not quite sure what to do. My advice to them would be to say, "I've thought about this, are you up for it?", and allowing the person to say yes or no.

Since 2010, I've been working for Teenage Cancer Trust, initially in its education team, going into schools to raise awareness of signs and symptoms. I worked in that team until 2019, and really loved working on the 'Mates Matter' programme, where we worked with young people with cancer to support them in school with their friendship group. We'd help their friends understand what they were going through and explain how they could help. It's a powerful thing for me to be able to support young people using my own experiences, and I feel very lucky to work in roles that I know would have helped me during my own treatment.



HELPFUL RESOURCES

[www.teenagecancertrust.org/
information-about-cancer/
how-support-friend-cancer](http://www.teenagecancertrust.org/information-about-cancer/how-support-friend-cancer)

[www.teenagecancertrust.org/
information-about-cancer/
after-cancer-treatment](http://www.teenagecancertrust.org/information-about-cancer/after-cancer-treatment)

All in the same boat: Vital friendships forged through free sailing trips



Rebecca and Simran

The Ellen MacArthur Cancer Trust (EMCT) takes young people aged eight to 24 years old on free sailing and outdoor adventures to help rebuild their confidence after cancer. Scott Wilson, of the Trust's communications team, and Rebecca and Simran, two of the young people it's supported, describe how the trips help bring people with similar experiences together and why that's important.

When young people are diagnosed with cancer, they might talk to their friends and families about how they're feeling. But, unless they know someone who's also gone through a serious illness, the conversations don't always go as planned. Instead of being able to honestly share what's on their mind, without judgement, they're often met with sympathy or pity. A lot of the time, people just really don't know what to say.

Which is why the friendships young people make on the EMCT's transformational sailing adventures are so different from those back home. At the end of a five-day sailing trip this summer, Simran, who is 16 and was diagnosed with acute lymphoblastic leukaemia when she was six, said there'd been none of the usual awkwardness that comes with talking about cancer.

Simran

"Often when you talk about it, people are like 'aww, you had cancer'. With the Trust, no one really feels sorry for each other. Everyone understands you, and everyone knows what you've been through. Unlike your friends back home, who you can talk to, but they'll never actually understand."

She reconnected with Rebecca when they sailed together this summer, having previously met on an EMCT adventure the previous year, and they soon picked up where they left off.

Rebecca, who's 17 and was diagnosed with lymphoma when she was 11, said her friendship with Simran allows her to 'feel how I want to feel'.

Rebecca

"When you're on a boat, you're together for four or five days, 24/7. There's not much we don't find out about each other, and it's so nice to have someone who's not going to judge you for a week. We've become really close friends again."



Without the post-treatment support offered by the EMCT, they agreed their illnesses would have left them feeling much lonelier. Neither of them met people their age in hospital, and both emphasise how important that is

having been through something that affects young people in unique ways.

After treatment ends, young people may be left with fewer friends and struggle with relationships. Their education may suffer, they may miss out on work experience, and they may develop body image issues, too. Adjusting to this 'new normal', while also feeling isolated from everyone around them, can be extremely difficult. That's why, when treatment ends, the Trust's work begins. Together, young people stop feeling like 'the only one'. Rebecca said the benefits come naturally.

Rebecca

"I don't really know how to explain it. It just feels like a weight has been lifted every time you go on one of the charity's trips. That weight can build across the year, so it's nice to have a safe space to talk about it. We never sat down and said, 'this is what happened', but if it comes up in conversation, I can say, 'I felt the same way'."

At the end of their trip, Rebecca and Simran both felt more able to make new friends. Because they met at the EMCT, they know they'll always have each other to talk to, even if others don't always 'get it'. They're both 'in the same boat'.



ellenmacarthurcancertrust.org



"It starts with a smile"

Caroline Cleaver is a proton beam liaison nurse at Manchester Children's Hospital and CCLG member, whose twin sister was diagnosed with leukaemia when they were 19 years old. She tells us how this inspired her career in children's cancer nursing and what helps her build relationships with patients and families under her care.

When my sister was diagnosed with cancer, it changed our lives, launching us into the unfamiliar world of treatment and busy hospitals. Over two-and-a-half years, we built great relationships with many professionals, particularly nurses. You could tell being a nurse wasn't just a job – it was so much more than that. They showed so much empathy and compassion and offered us all the time we required when we needed a minute to talk or cry. They supported our whole family, not just my sister. It really was family-centred care.

The nurses were with us the whole way through the journey – the good, bad and ugly – and we wouldn't be where we are today without them. They inspired me to change my career path and, after talks with them, I applied for children's nursing and never looked back. I wanted to make a difference to people's lives in the same way the nurses did for me, my sister and my family. I wanted to be able to offer hope to people in what's often the worst times in their lives, to be there to listen to, support, care for and build trust with them.

Being a proton beam liaison nurse is unique. My day-to-day role includes ensuring those children who get admitted unwell or for planned chemotherapy can still get across for their radiotherapy. I aim to communicate well and make sure all patients have a positive experience. Having been a sibling of a teenager with cancer, it really helps me to empathise with and support families. I have a real understanding of what it feels like to be so close to someone going through treatment. I can understand how they're feeling when they're reluctant to say how they really feel, and I also think I know what they want to hear, and don't want to hear, at different points in treatment. I really think it helps to have that deeper understanding when working with children going through treatment, and it's a privilege to be able to support them and their families.

As professionals, if we have a strong relationship with families, they'll put their trust in us and work with us to ensure they and their child get the best care and treatment. They'll come to us for advice, reassurance and support that can help them with making decisions, some of which can be difficult ones, so it's up to us to create a safe environment, and to take the time to listen and get to know children and their families.

For me, building good relationships with children, their parents and wider family is vital and starts with a smile. This and friendly, simple introductions go such a long way. I want everyone to know I'm approachable, friendly and always willing to help. Having a caring, compassionate nature and the ability to read the situation and

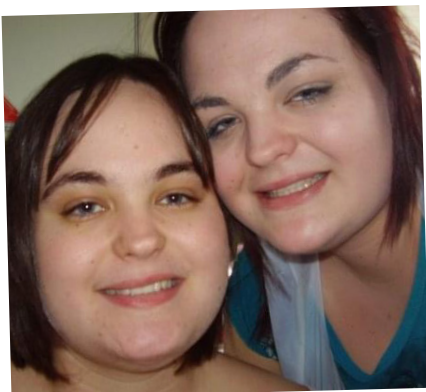
communicate effectively is important to building relationships. With children, it often helps to find a common ground – something they're interested in and love to do. If you can share that interest, they often open up.



Caroline and Tallulah

For patients and their families, communication is key

Be open and honest with us and talk to us whenever you need to. Even if you think the question is small or silly, we're here to support you through a difficult journey. Just remember to keep talking, we always have time to listen. Take one step at a time because each day is a new day. There are so many people who care and will be there to support you every step of your journey.



Caroline (right) and her sister

A parent's view...

Why there's so much value in parent-to-parent support

Claire Bailey's daughter, Poppy, was diagnosed with stage 4 high-risk neuroblastoma in July 2020 aged four. She writes on how the relationships she's formed with other families have provided support both during and after Poppy's treatment.

Before Poppy's diagnosis, she'd been gradually losing weight, becoming very pale and complaining of leg pain for a few months. After an X-ray found a large tumour in her chest, which had spread to several parts of her body, treatment began at Addenbrookes Hospital straight away.

Being on a children's oncology ward – thrown into a whole new world that you don't want to be in – feels very scary and lonely. I found having little chats with other parents on the ward really helpful in easing the loneliness, whether in the corridor, in the parents' kitchen while making breakfast, or a ward WhatsApp group. These other oncology parents all understood the fears, the sadness, and the isolation from the outside world. They were also navigating new experiences, such as learning to bath your child with a Hickman line in place or trying to understand all the new medical terminology.

at home. However, I didn't meet any other families with the same diagnosis as Poppy for a few months. I relied on social media to discover other children with neuroblastoma, and even then, they were all at different treatment stages.



Poppy and brother, Oscar

After 13 cycles of chemotherapy, we were told Poppy's disease was refractory (resistant to chemotherapy). Her consultant got her a place on the MiNivAn clinical trial which involved two rounds of internal radiation at University College Hospital in London, then six rounds of two immunotherapy drugs at Southampton. Discovering Poppy was refractory and would have to travel to other hospitals was a particularly lonely time as I didn't know anyone else in the same boat. After much searching on Facebook, I found another mum whose daughter also had refractory disease and had recently been on the trial. I phoned her and we ended up speaking for over an hour about MiNivAn. Hearing about it from a non-medical perspective eased my anxiety immensely.



Claire, Poppy, brother Oscar, and dad, Ross

The trial was successful for Poppy, so we returned to Addenbrookes where she underwent surgery to remove the tumour in her chest. We then travelled to Great Ormond Street Hospital for high-dose chemotherapy with stem cell transplant before heading back to Addenbrookes, for three weeks of radiotherapy to Poppy's chest, and five rounds of immunotherapy. She was declared no evidence of disease in October 2022 and finished treatment.

Being suddenly thrown back into the 'real' world felt a lonely time. But, having enrolled on a video course with Solving Kids Cancer called 'Life after Cancer', I met other parents all at similar stages. It was nice to have my feelings validated by people who really understood my ongoing fears.

We were lucky to have an amazing consultant to talk very openly with throughout treatment and ask any questions. However, it really helped to have non-medical conversations and to share experiences with other parents, so I'd advise newly diagnosed families to seek support from those going through similar experiences. I found this invaluable and still do nearly two years after treatment finished.

Poppy, who's now nine, attends school full time and has many hobbies including swimming, indoor climbing, Cub scouts, drama and playing the violin. She loves Harry Potter and animals and wants to be a scientist when she's older. She's also still friends with a little girl she met at Addenbrookes, whose mum I still speak to, and we've all met up at the seaside. During her treatment, I met many other parents through Poppy – she's such an energetic and confident girl, she spoke to everyone around her, breaking the ice for me!



Poppy on the ward

The parents who'd been on the ward longer offered advice, like where to buy the best NG tube tape or get the nicest coffee nearby, or how to balance spending time with your other children



Dr Ren Manias

Building a good relationship with your child's doctor during treatment

*The relationship between oncologists and parents of children with cancer can be complex and unique, with each family having differing needs. **Dr Ren Manias**, Consultant Paediatric Oncologist at Southampton General Hospital and Contact's medical adviser, tells us how open and honest communication between doctors and parents is key to developing trust and understanding, and why this is important.*

When faced with a cancer diagnosis, parents must entrust the health of their children to oncologists they've only just met. The relationships that subsequently develop can be very special as we work together to support the child through their long treatment journey.

As a paediatric oncology consultant, I meet children and their parents at one of the most vulnerable and challenging times in their lives. It's remarkable that so many parents are able to trust a near-stranger with the lives of their children, and often quickly develop a relationship of mutual respect and understanding.

A good parent-doctor relationship results in a better experience for children, families and their doctors. Parents want and deserve to be treated with sensitivity and care, be involved in decisions about treatment to an extent that feels right to them, and have relationships based on shared trust and respect.

Every child and family are different and have their own unique needs. It's hugely important for doctors to take the time to get to know patients on a human level to build organic and solid relationships. There really is no substitute to spending time connecting with families, finding out what's important to them, understanding their values, interests, fears and aspirations, and listening properly to what they have to say.

Open and honest communication is key to developing trust and understanding. I try to be direct and

clear with families and children and encourage them to be direct with me. The conversations we have are often difficult and emotionally challenging, especially when they involve delivering complicated and upsetting information. Parents (including individual parents of the same child) differ widely in terms of how much information they want to receive and how much input they want to have into decisions about their child's care. Attitudes towards this can change as the cancer pathway progresses and doctors need to be mindful of this fluidity. I find it helps to ask directly, while watching closely for verbal and non-verbal cues, and encourage parents to express their needs and concerns.

As doctors, we're also human. Relationships are complex and we can't get it right every time, especially in the highly emotive and high-stakes area of children's cancer care. I want parents to feel comfortable voicing their concerns and to tell me if they're not happy with any aspect of their child's care. If something has upset a family, I want to know so I can try to put it right – even if that something is me.

Not every parent-doctor relationship goes smoothly. Nearly a quarter of parents of children with cancer experience challenges in their relationship with doctors, most of which come down to issues with communication. Research has shown that doctors don't

always realise when a family is finding the therapeutic relationship challenging, but that they'd do their best to fix issues if they were made aware of them.

If you feel that there are problems with your relationship with your child's doctor, please let them know. If you don't feel comfortable speaking to them directly, you could talk to another member of the healthcare team and ask them to advocate on your behalf.

Working with children with cancer and their parents to build supportive and long-lasting relationships is one of the most rewarding and important parts of my role as a paediatric oncologist. The opportunity to be part of these remarkable families' lives is an immense privilege and responsibility which I will always value.



What are young people and their significant others' experiences of melanoma?



Dr Wendy McNally

- ▶ **PROJECT TITLE:** Young lives interrupted by melanoma: Exploring the experiences within a relational context
- ▶ **LEAD INVESTIGATOR:** Dr Wendy McNally
- ▶ **INSTITUTION:** Open University
- ▶ **AWARD APPROX:** £30,000 (Funded by Teenagers and Young Adults with Cancer (TYAC))

Skin cancer (melanoma) in teenagers and young adults (TYA) is on the increase and evidence from young people and their families suggest that they feel isolated, alone and unsupported. In November 2022, I was awarded one of the first TYAC research grants. This study aimed to explore the experiences of young people, between 16 and 24 years old at diagnosis, living with and beyond melanoma within a relational context in England.

When you hear 'skin cancer' you normally think about people who have exposed themselves to the sun or sunbeds. However, this isn't always the case. Over the last 10 years, I've undertaken research into TYAs' experiences of living with melanoma and those of their family members or significant others.

As a cancer nurse specialist and an academic, I've found that young people with melanoma are often forgotten about in the mix of broad cancer research because many of these patients might never be seen by a young people's cancer specialist team. This disease is becoming a global concern as it now affects many young patients, and many have no access to age-appropriate specialist care. That's why it's so important to research the challenges of young people with skin cancer, and those close to them, from diagnosis

through to post-treatment. This enables us to make improvements and get them the care they deserve.

What results can you share from the project?

Following interviews with young people with skin cancer, and some of their significant others (parents or partners), the core conceptual thread woven throughout the findings was that a skin cancer diagnosis is like "being on a rollercoaster". It represents the ups and downs of the cancer trajectory, the pace of being diagnosed, and the experiences of treatment. The four themes identified were:

1. 'Is something wrong?'
2. 'Suddenly, it's serious'
3. 'Out on a limb'
4. 'Finding our place'

Jack Brodie was diagnosed with cancer aged 16. Ten years later, he helped support my project as a patient consultant. His diagnosis was a complete shock, and he went from feeling "indestructible" to seeing the unforgiving reality of cancer first-hand. He reminded us that young people affected by cancer aren't just patients – they have names, worries, friends and families. This all needs to be considered if we're to produce meaningful support.

With the rising number of melanoma cases within the TYA population nationally and internationally, there are demands to improve young people's and healthcare professionals' understanding of this disease. This group of young people is hard to reach, as many TYAs with skin cancer are treated outside of specialist cancer services. Care delivery for this patient group and their significant other requires stronger links and communication channels between services – at the beginning of, during, and after treatment.

We've developed two educational podcasts for healthcare professionals caring for young people with melanoma, and we'll also be presenting the findings at the European Society for Medical Oncology (ESMO)/European Oncology Nursing Society (EONS) conference.

Moving forward, looking at where young people with melanoma and their family/significant others are receiving care and whether it's age-appropriate specialist care is a key question we'd like to address. We'd also like to explore current awareness levels and ask what action young people would currently take if they noticed a suspicious mole.



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

60 SECONDS WITH

Penelope Hart-Spencer

Health Play Specialist at the Proton Beam Therapy

Centre at the Christie in Manchester and CCLG member



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

A: I'm based within the proton beam therapy centre and I support children and young people who require CT/MRI scans, radiotherapy and proton beam therapy treatments, as well as other clinical procedures. I work within the paediatric team and together, alongside my three health play specialist (HPS) colleagues, we ensure those in our centre receive the best care and a well-supported experience during their time here.

Many of our families relocate to Manchester to receive their treatment, so we need to offer a high level of support to them. Being away from home with an unwell child can cause significant stress for parents and carers. We offer holistic care that focuses on the child and their family. We try to plan monthly entertainment events and have daily play and art and craft activities available for children and young people.

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

A: I was part of the team which developed the paediatric service for the UK's first proton beam therapy centre here at The Christie. I liaised with architects about the design of spaces for children and families and led on the patient information development for children and young people. I arranged a focus group of children who we'd referred overseas for proton beam therapy to help with the design of the booklets and the creation of our mascot 'Proton Panda', who's featured in the booklets and within the designs in our centre.

I also wrote a book which helps children understand hair loss caused by cancer treatments, published by CCLG. 'Anna loses her hair' was highly commended and shortlisted in the Children Award category at The British Medical Association Patient Information Awards, and CCLG has created an animation based on the book, too.

I'm also proud of obtaining a Master of Science in Contemporary Health Care – Cancer Care from Coventry University. This gave me a wealth of theoretical knowledge and a deeper understanding of the complexities in cancer care for teenagers and young adults, which has enhanced my work with our patients.

Being away from home with an unwell child can cause significant stress for parents and carers. We offer holistic care that focuses on the child and their family.

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

A: Helping children and young people understand their clinical procedures and working with them to alleviate their fears and anxieties. I love to empower them, and I'll always do my best to ensure they receive age-appropriate information, and a tailored support plan that meets their needs. I feel particularly skilled in supporting families through their treatment pathways in a sensitive and caring way and when I see families become more settled, happy and confident, I know the team's done a good job.

Q: What does your job mean to you?

A: Being a health play specialist is more than a job – it's my vocation. I'm so passionate about the profession and love every aspect of my role. It's a huge part of my life as I am a practicing HPS but also, as vice-chair of the Society of Health Play Specialists, a lot of my time is spent in this world!

I've never known such a varied role that offers so many opportunities to work alongside other health professionals to achieve the best outcomes for children and young people.

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

A: Get to know your healthcare team (especially the HPS team) and take every bit of support you can. Being in hospital and healthcare settings can be very isolating and lonely without the right support in place. I'd also encourage you to be kind to yourselves and take each day as it comes.



ASK THE **Expert**



Dr Sarah Evans, Head of Research at CCLG.

What is patient and public involvement (PPI) in research?

PPI is about researchers and those who fund research teaming up with people who have personal experience with a health condition. This collaboration helps make sure that research focuses on what really matters to the people it's meant to help, like patients and their families. Researchers might come up with great scientific ideas, but without knowing how these ideas affect families in real life, they might not work out as well as hoped. PPI makes sure research is not just scientifically strong but also practical, patient-friendly, and truly helpful in improving lives. It helps us focus on research that directly benefits patients and makes a real difference in their quality of life.

How are families involved in CCLG's research?

Families play a crucial role in CCLG's research activities. We have an amazing team of volunteer parents, carers and survivors in the CCLG Patient and Public Involvement group. Whenever researchers apply for money from CCLG or our Special Named Funds for their research projects, our PPI group helps us assess their applications. They each bring unique perspectives and lived experiences, providing invaluable feedback to researchers. Their input helps ensure that our research addresses real-world challenges and priorities that matter most to those affected by children and young people's cancers. This collaborative approach helps us focus on practical solutions that improve patient care and outcomes, while also helping our researchers develop their engagement skills.

Who can get involved?

We welcome anyone with experience of children's and young people's cancers. This includes parents, carers, family members and those who have personally had cancer themselves, either during childhood, as a teenager, or as a young adult. You don't need any scientific knowledge or background, because the researchers are bringing the science. We need PPI volunteers for their unique perspectives and insight into whether research proposals chime with real-life experiences. Every experience of childhood cancer is different, and you never know when a research project may speak to your personal experience – whether it's about treatment decision making or follow-up care and 'scanxiety'. We

provide all the necessary support and guidance to help people participate effectively, and it's very much a two-way street in that we want to learn how to support them better, too.

What are the benefits for families getting involved in PPI?

Some of our PPI group members recently told us that they find it very rewarding, even healing, at times. They get insight into how research happens and see first-hand the progress being made, which can be reassuring. It also provides a sense of empowerment, knowing their experiences and opinions are directly contributing to improving care and outcomes for future patients. We plan to further develop the PPI group, which is currently small, into a larger, supportive community where people with lived experience can connect with others who understand what they've been through. Through having a larger group, there'll be more opportunities for those with lived experience to get involved with shaping a wider range of CCLG's research activities.



HOW TO GET INVOLVED

To get involved with the CCLG Patients and Public Involvement group, please email research@cclg.org.uk or register your interest by scanning the QR code.



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