

FREE

WINTER 2021 | ISSUE 93



Children's
Cancer and
Leukaemia
Group

the EXPERTS
in CHILDHOOD
CANCER

contact

SUPPORTING FAMILIES THROUGH CHILDHOOD CANCER

MAGAZINE

Digital

Prof Louis Chesler tells us about some of the exciting innovations being developed for childhood cancer treatment



TEENAGERS AND YOUNG ADULTS WITH CANCER (TYAC) - FIND OUT MORE ABOUT ITS AMBITIOUS NEW PLANS



SIXTY SECONDS WITH TYAC CHAIR JAMIE CARGILL



FINDING MY VOICE

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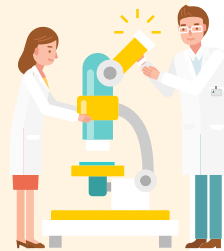
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Contact

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

Contact aims to reduce the sense of isolation many families feel following a diagnosis of childhood 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.



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Your messages...



More on Contact's new look and content...

"The magazine is full of inspiring and interesting messages. Thank you for such a wonderful read."

"There's a really good breadth of people who contributed from different professional groups."



On CCLG's information resources

"If childhood cancer has knocked at your door, CCLG is a lifeline of practical information! It can be tempting to Google. Don't! Go to the website and find what you need."



"Your publications have really helped us and we are so grateful to have these excellent resources available to us."

Download or order our publications here ►



On the 2021 Childhood Cancer Conference

"Eternally grateful as a childhood cancer parent and researcher for your dedication to researching #childhoodcancer and its effects. Brilliant conference. Thank you, all!"

You can watch all the talks from the 2021 Childhood Cancer Conference here ►



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!

Living in the digital age has its pros and cons. The pace of technology is ever-growing with technologies such as artificial intelligence (AI), big data and cloud tech so we can transfer more and more information quickly and easily. For many of us, it means our world is becoming ever more complex as we try to keep up and adapt to these changes in our daily lives. But today's children are digital natives and they will look to this space first to help them make sense of their cancer experience. This issue celebrates how we can embrace the opportunities and challenges that the digital age has to offer in medicine, research and patient care.

Claire editor@cclg.org.uk



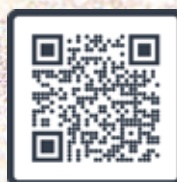
There's still time to get your digital charity Christmas cards...

Stay in touch with friends and loved ones with our paperless Christmas cards.

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MEDICAL ADVISER

Dr Bob Phillips

Senior Academic Consultant at University of York, Consultant Paediatric Oncologist at Leeds Children's Hospital and CCLG member

The digital world once stood very much apart from the real. E-mail was laboriously opened in chunks like the post that arrived twice daily. Computer games took longer to load up from cassette tapes than a cup of tea takes to make. Databases were physically located on banks of CD drives in libraries, and it was only special people who had access to health data.

Things moved on, sped up, and became more accessible. Many households gained a computer and transitioned online. Internet usage switched from occasional to always. Mobiles evolved to include smartphones, and soon it was possible to be on the train keeping on top of your mail. Things keep evolving, and digital now pervades.

The pandemic pushed us even more. Before it, only very occasionally would we have a remote meeting. Now I find myself asking - slightly excitedly still - "Can that be face to face?". Digital evolution has opened up the world of electronic-only notes and allowed easy access to investigation results and complex guidelines. It's brought the rapid transfer of images, prescriptions, pictures - across the hospital, region or globe - and we can network with parents from across the country for a psychological support intervention.

What do I think we have lost from the world? Well, I still prefer a child's drawing in crayon and glitter than pixels and PNG. I miss the gossip over bad coffee and pastries. Expecting instant information troubles me, and I personally need to learn how to manage the deluge of possibility better!

But when colleagues from across the region can be brought together remotely to discuss a case, or academic collaborators from around the world can chat through a study or we're able to catch up with patients who don't need to spend an hour driving each way, all of this is I can forgive.

NEWS IN BRIEF

A step towards better precision in treatment for neuroblastoma

A new international risk classification system has been developed for children with neuroblastoma in North America, that could benefit children with the disease around the world. Experts have updated and validated a new classification system, to now incorporate genetic information and surgical staging that have become available since the adoption of the previous version approximately 20 years ago. Neuroblastoma's variable nature demands a personalised approach. Together with other steps, this will substantially improve the accuracy of classifying neuroblastoma tumours and will result in treatment being precisely tailored to each child's needs.

(Source: Neuroblastoma UK)

Study illuminates genetic understanding of aggressive childhood leukaemias

New research reports how two separate DNA changes appear to predict aggressive childhood leukaemias when they occur in combination. Researchers found that patients with these changes - a 'double deletion' - had worst outcomes in childhood leukaemia and in some cases had almost twice the risk of relapse. They hope their findings can give new insights into treatment by providing a useful clinical prognostic marker.

(Source: JAMA Oncology)

We need your thoughts

Take our reader survey to tell us your views on Contact magazine...

Our reader survey is now open until the new year! We'd love to hear your thoughts on Contact to help us to shape the future content, design and direction of the magazine, making it the best it can be in supporting families affected by childhood cancer.

Scan here to take the survey or visit www.cclg.uk/contact-survey





Transforming the way we treat children with cancer

Prof Louis Chesler leads the Paediatric Oncology Experimental Medicine (POEM) Centre at the Institute of Cancer Research (ICR). He tells us about some of the exciting digital innovations that have the potential to transform childhood cancer treatment.

At the POEM Centre, we have two core goals: to deliver transformative research direct to hospitals so that best practice improves, and to educate the next generation of young academic clinicians with the same goal.

There has never been a more promising time for what can potentially be achieved using the complex tools now available. Many of these advances have been inspiring and will transform the way we treat cancer in children. Finding funding for technology-driven clinical research is a challenge and we're grateful for the charities, organisations and patient advocates who help us.

Using multi-gene testing and liquid biopsies

Technology allows us to probe a small amount of tumour tissue or blood in better detail, showing us the structure and function of DNA and other cells. We potentially can now analyse blood droplets within hours and generate both point-of-care test results for doctors as well as research data. This means we could perform these tests and report results at the same clinic visit.



These results give a detailed view – at the molecular level – of how the cancer is responding to treatment, including anything that may be stopping the treatment from working, as well as alerting doctors to any disease that has spread but can't yet be picked up by scans. We're keen to roll out this technology in all children's cancer hospitals.

We can now rapidly sequence tumour tissue in better detail and return test data back to doctors in time for them to select molecularly-guided drugs for children who relapse with cancer.

This sequencing programme was a collaborative success and delivered four molecular-based tests to the NHS. The NHS will use this knowledge to expand whole-genome and high-depth sequencing across the UK, a major success for children with cancer.

Digital pathology and artificial intelligence (AI)

Technology is also transforming the work of pathologists. In the past, pathologists looked at the shape and appearance of normal cells and cancer cells using stained slides, and then added more 'stains' to detect specific markers of cancer type. They can now reconstruct the data digitally, integrate it with clinical scans done on the same tumour tissue, and even train a computer to recognise patterns and cancer signatures, or identify drug targets via AI algorithms.

This gives pathologists a visual and functional 3D 'Google map' of the cancer material at the level of individual cells.

Integrating these systems so that we can almost instantaneously diagnose and quickly start treatment for children with newly-diagnosed cancers is on the horizon.

Assigning mechanistically-guided treatment using AI

Google DeepMind recently announced AlphaFold, an AI algorithm that accurately predicts the 3D structures of proteins.

Proteins are the target molecules that cancer hijacks in normal cells making them turn into cancerous cells. Targeting them using small-molecule 'next-generation' cancer drugs, which bind to proteins and silences them, represents perhaps the most significant advance in cancer treatment in the past 25 years. This has led to longer and better quality of life for adult cancer patients and, increasingly, children with cancer. The significant task of manually examining each protein structure to identify docking sites for drugs used to take months or years in the past, but now takes just hours.

Using AI for data sharing, collaboration and learning models

Organising, sharing and analysing data emerging from these technological advances is now even more important. It's essential that anonymised clinical data on patient outcomes and characteristics is studied together with research data, results of clinical tests and procedures and is shared across all areas to generate the most benefit to patients. It's still an aspiration that AI could potentially synthesise all this data to identify treatment approaches for individual patients, but it probably isn't far off!



Team Ellie



Finding my voice – how digital platforms helped me advocate for childhood cancer



Ellie Waters

SUBSCRIBE

Ellie Waters, 20, is a digital content creator who was diagnosed with rhabdomyosarcoma, aged 14. She tells us how she began creating digital content to share her experiences and help raise awareness of childhood cancer and its effects.

I began creating content after my mum noticed that I was becoming gradually more anxious and distressed, with the weight of my cancer diagnosis beginning to bring me down. I felt as if I had all these pent-up emotions that were desperate to be freed. So, she suggested I start a blog. I was a bit dubious at first, having always been reserved when it came to showing my emotions, but I knew that nothing would get better if I didn't try something. Plus, it would give me something to occupy my mind during the lonely days stuck in my hospital bed.

My first few blog posts were very therapeutic as I could push all my thoughts, feelings and emotions on to a virtual piece of paper. But, once I had vented all that I could, I realised I needed something else to write. That's when I had a lightbulb moment. I could spend the rest of my treatment feeling sorry for myself and venting online, or rather, use that energy to help others going through the same experiences as me. So, I chose the latter. I decided I was going to start writing cancer advice blogs.

The first one I wrote was titled 'How to cope with losing your hair', which received a lot of positive comments. From then on, I became passionate about helping others in the same situation as me, so I continued writing blog posts about many different aspects of cancer. I kept writing the blog for a few months, but it began to feel too impersonal. Plus, as I was becoming more and more exhausted from radiotherapy, I was finding it difficult to concentrate on writing. So, taking inspiration from Talia Joy, a cancer YouTuber, I decided that I was going to start my own YouTube channel to create cancer advice videos.



▲ Ellie's YouTube set-up

My first video, called 'My Cancer Story', had 396,000 views, and my videos soon started becoming popular in the childhood cancer community. This led to great opportunities, such as appearing on ITV News and collaborating with charities, like Sarcoma UK. It felt amazing that I could reach so many people using my YouTube channel. At a time when I felt powerless to cancer, having the power to be a voice for other cancer kids made me feel like the most powerful person in the world. It was like I had a superpower!

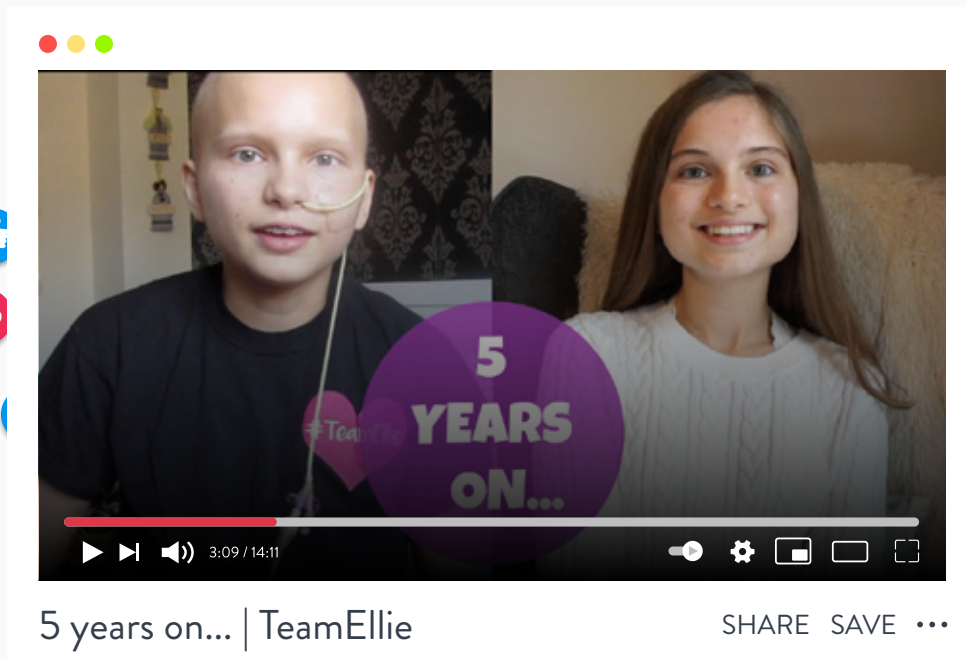


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But the best part of it all, and what kept me motivated to keep producing videos, was the messages I'd receive from fellow cancer patients. Hearing them say that my videos had helped them, it made me feel like I had a purpose at a time when my life had stopped.

YouTube also fuelled my passion for childhood cancer advocacy. Seeing how my platform could reach so many people, I knew I had to use it to spread the word about childhood cancer. My favourite video shows me approaching random members of the public, asking them if they knew that childhood cancer receives so little funding. It took a lot of guts to randomly approach members of the public - I must have asked over 50 people, but only five would agree to be in my video. But ultimately, I achieved my goal of spreading awareness of childhood cancers, so I was happy.

"At a time when I felt powerless to cancer, having the power to be a voice for other cancer kids made me feel the most powerful person in the world."

Nowadays, I've slowed down the digital content a lot, as life has taken over. I'm now nearly five years post-treatment and currently studying medicine at Keele University. However, I still keep my Instagram account, with 14,700 followers, active. I feel like on social media you can hear the bad stories of cancer and success stories can be sometimes hard to find. So, I make sure I

keep my Instagram updated, to give others who are undergoing, or have finished, treatment hope that there's life after cancer.

Recently, as well as continuing to advocate for childhood cancers, I've been directing my focus on informing people about the late effects of cancer treatment. Most notably, the menopause. I was diagnosed at 15 with menopausal symptoms and finding information online was very difficult, which made me feel isolated and hopeless. So, I'm very passionate about informing other young women about early menopause and advising them on how to best look after themselves, and how to get the help they deserve. From this, I've co-written a digital booklet with Dr Louise Newson, called 'A young woman's guide to menopause after treatment for cancer'. This is one of my proudest achievements and has helped a lot of other young women.

Being able to use digital platforms to share my story and amplify my voice, helped me mentally during and after cancer treatment. It helped me reach out to others going through the same thing, and it gave me a sense of purpose at a time when my life felt futile.



FOLLOW



Ellie on Instagram
@teamellie_blog

Using tech to tackle loneliness

Brad Gudger, diagnosed with leukaemia as a 19-year-old, tells us how he has used his own experiences to establish a charity and launch an app for cancer patients aged 18+.

It seems such an obvious thing to say, but cancer completely changed my life. In 2013, I was diagnosed with chronic myeloid leukaemia, which eventually required me to have a bone marrow transplant in 2018. When I got my diagnosis, it felt like I'd been hit by a train, had the rug pulled from under my feet, and the world had stopped, all at once. It sounds dramatic, but there's no easy way to explain that experience.

The shock at my diagnosis mostly came from the fact that I didn't really know anything about leukaemia. As cancer wasn't spoken about in school, or in conversations with friends or family, I'd no idea that some of the symptoms I was experiencing - including fatigue, night sweats, random bruises and rapid weight loss - should have worried me.

The loneliness of cancer treatment

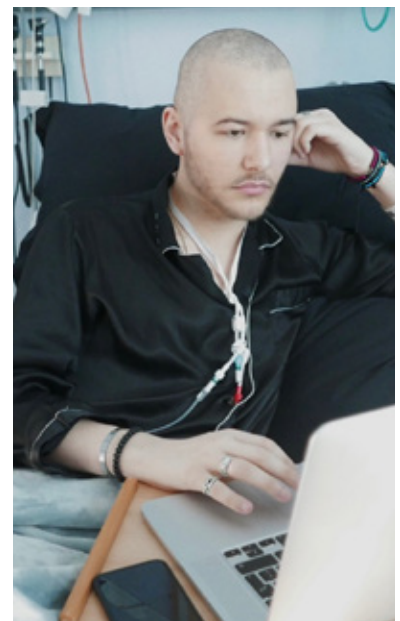
I had chemotherapy, and was on the road to recovery when, in 2017,

the cancer relapsed. Leaving my life in London behind and returning to Yorkshire to stay with my parents, I remember feeling really angry about how unfair it was. After rebuilding my life, I had to go through it all again: the harsh treatment and the loneliness.

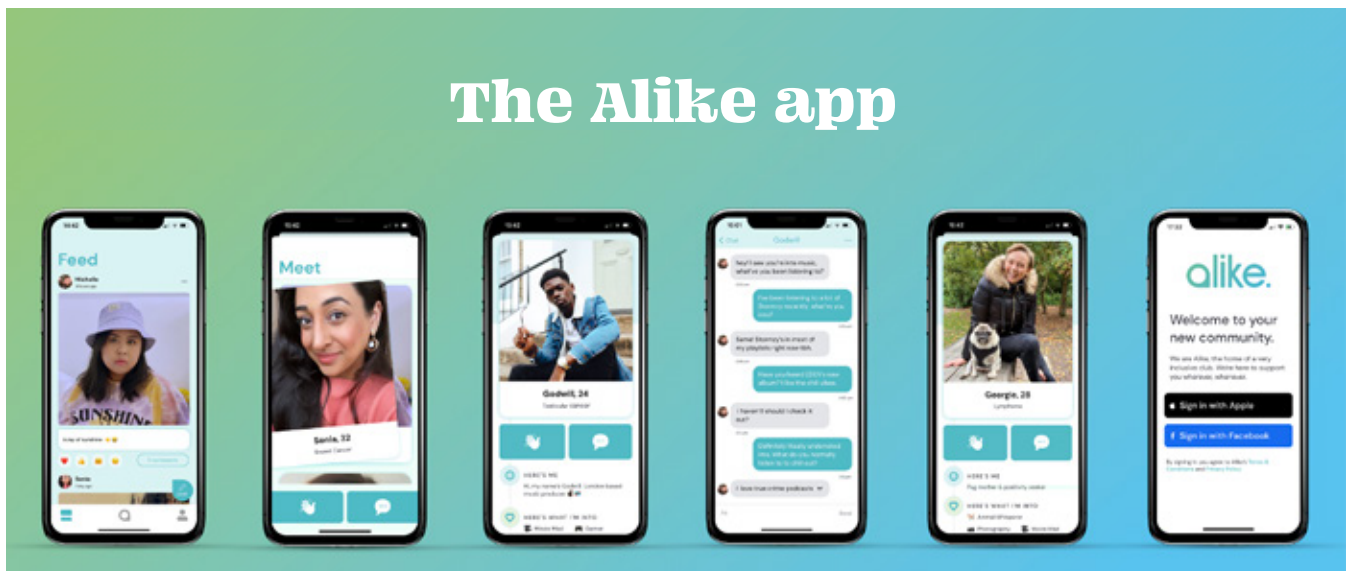
As a cancer patient, loneliness was something I was all too aware of. When I originally went through treatment, I felt lonely being in the rural North Yorkshire village I grew up in. Later, I felt just as lonely in the heart of central London, where I worked.

The story of **Alike** is rooted in my own diagnosis. Before I thought of creating an app, I always knew I wanted to create a youth-led charity that provided dedicated peer support for people impacted by cancer. I've been fortunate to build a group of friends who have experienced cancer and share their experiences, but I only found this group when I'd finished my second round of treatment. I know what it's like to be stuck in a room, feeling

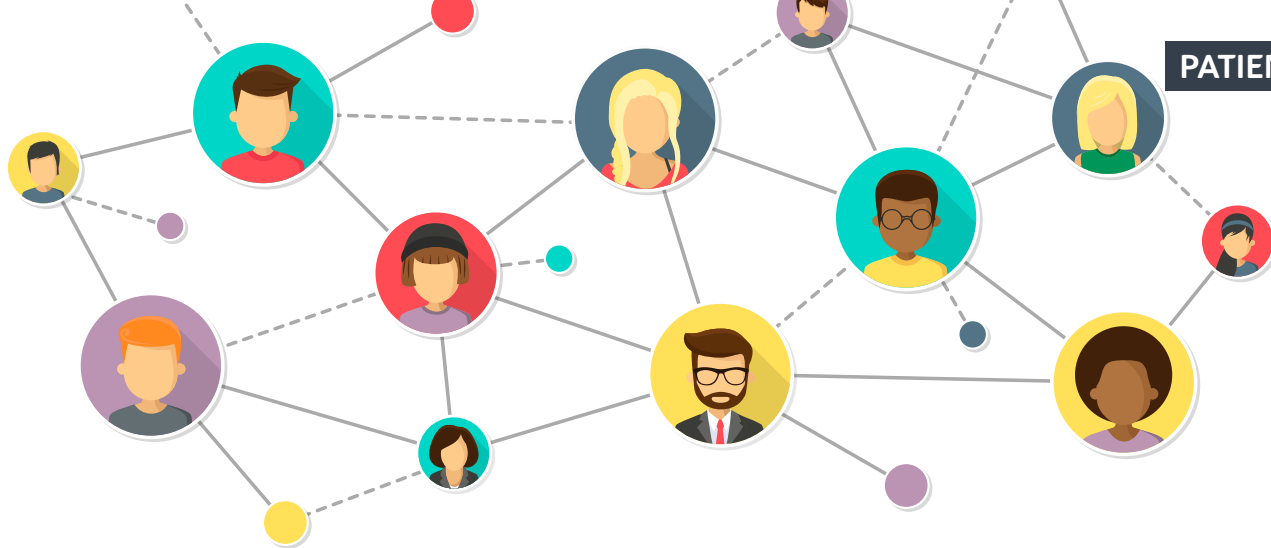
the worst you've ever felt, and having no one to talk to who understands.



Brad in hospital during treatment



The Alike app



The idea

Not wanting anyone else to feel like I'd felt, I started by talking to friends who had survived cancer, to validate that it wasn't just me who felt this way.

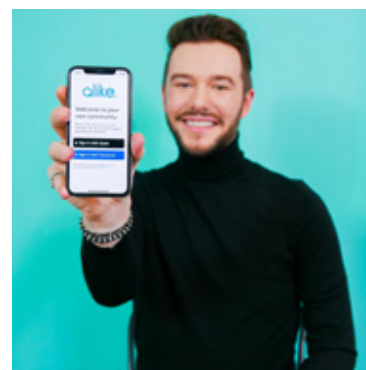
The overwhelming response was that everyone agreed with me, we only knew each other because we'd gone to the right events at the right time. And what's extraordinary is that despite 83% of young people diagnosed with cancer experiencing loneliness during and after treatment – something exacerbated by the COVID-19 pandemic - and nearly four in five wanting to interact online with other young people in similar situations, there's no digital network to connect them.

For me, speaking to other young people with cancer was essential, empowering and life-saving. So, I wanted to offer that opportunity to others who were going through a similar experience to the one I had. Our app is about stopping the loneliness that all too often accompanies a cancer diagnosis, and giving people the space to talk about what they're going through with others who understand.

There are some great organisations that help our community, but if you're in a rural area, or less mobile, or facing life after treatment, it can be much harder to make those connections. I'm not an expert in developing apps or charities, but I am an expert in lived experience. When I don't have skills

in certain areas, I reach out to experts in the field. This is what makes **Alike** special.

Alike isn't my charity - it's by and for everyone in the community. We called it Alike because it's not about cancer, it's about finding what brings us together as a community. We're all individuals, different but the same - we're all alike.



Brad using the Alike app

About Alike

Alike is designed to be a companion throughout diagnosis and treatment. Users connect based on a mixture of diagnosis, stories and interest, providing individuals with a group of patients and survivors they can interact with on their own terms. It's also a hub that provides information on a young person's level and showcases user-generated content. Recent statistics from the app's monitoring shows that users are most active in the evenings on weeknights and weekends. Cancer patients are seeking continued support into the nights where their cancer treatments and in-person appointments have finished for the day. Data from the app has shown us that:

- 86% of users on the Alike app are active within a three-day period, meaning they are engaging right away
- This shows the community on Alike is there, with app users wanting to join in conversations, be it voicing their day-to-day life and questions about treatment and conditions, or raising concerns for peers to reassure them
- 58% of the users are most active during the evenings after 5:30pm, as well as weekends after 3pm, meaning people who have or have had cancer may show that they are seeking extra support, distraction and advice they can't get as easily outside of working hours



◀ **Alike is available to download on the App store and Google Play. You can find out more about it by scanning here.**

Childhood cancer scans

Dr Annmarie Jeanes, Consultant Paediatric Radiologist at Leeds Children's Hospital, explains the different types of imaging your child may experience at the time of diagnosis, during treatment and follow-up

Huge advances in medical scans and imaging have taken place over the last two decades with significant improvements in both the quality of images and how quickly we can access the scans. As a result, complex and time-intensive imaging, such as magnetic resonance imaging (MRI), have become much more accessible for children.

These advances, together with better access to specialist children's cancer imaging services, have played an important role in improving the quality of cancer care in children. Medical imaging plays a part in confirming your child's cancer diagnosis, finding out where it is, whether it's spread, planning the best treatment for it and assessing response to treatment.

A broad range of imaging types are now routinely used in children. This will depend upon their symptoms, the type of cancer they have and specific imaging recommendations of any clinical trials they may be enrolled in. Not all children will require the same imaging and some children will require more scans than others.

Some scans such as MRI, CT and some nuclear medicine examinations will require your child to remain very still. This can be difficult for some children and where required, infants or young children can be given a sedative or a general anaesthetic.

X-rays

'X-rays' are digital images formed by using small amounts of radiation which passes through the body. They are performed by a radiographer and are mostly used to examine bones, joints and the chest. They are quick, painless and readily available and usually completed within 15 minutes.

The chest and, less commonly, abdominal X-rays are the most common types performed in children with cancer. They are most useful if your child is unwell with acute symptoms.

Bone scans

This is a type of nuclear medicine scan which is used to look at your child's bones and to look for spread of childhood cancer to the bones eg. rhabdomyosarcoma and certain bone tumours.

A small amount of radioactive material (isotope) is injected into your child's vein and will accumulate in their bones. More radioactive isotope will collect in areas of active bone growth such as at the ends of long bones (legs), and in any tumour areas.

After the isotope is injected, your child will lie on a table under a camera called a gamma camera. The gamma camera detects radioactivity and creates pictures of the bones. The detectors are shaped like a box and lie above and below your child. They move from your child's head to toes during the scan, taking pictures of the whole body.

Ultrasound scans

Ultrasound uses high-frequency sound waves to create pictures of the inside of your child's body. A probe with a camera is placed on your child's skin, together with some gel to make it move more easily. Ultrasounds aren't painful or uncomfortable, but the gel may feel cold and sticky.

Ultrasounds are used to image the abdomen and soft tissues of the neck or limbs. They are usually performed by radiologists (doctors who specialise in imaging) or sonographers (radiographers trained in ultrasound).

Ultrasound is quick, readily available and highly accurate, and is likely to be the first type of imaging test your child will have. It's well tolerated by children and has the advantage of being highly portable so can be performed on the ward if your child's unwell or isolating.

It's also commonly used to find out the best site for biopsy at diagnosis. After your child's treatment has started, ultrasound can be used with CT or MRI to assess your child's response of the cancer to chemotherapy, or treatment related to symptoms.



CT scans

CT uses X-ray technology to create detailed images of the inside of the body in places such as the head, neck, chest, abdomen and pelvis. It uses ionising radiation and all children's scan departments will have protocols in place to make sure lower doses of radiation are used for children and adolescents.



CT scanners are large, doughnut-shaped machines, with a short tunnel in their centre, through which a table slides. Your child will need to lie on the table, which will move through the tunnel, during the scan.

They are used to image tumours of the brain, abdomen and pelvis, and are first choice to image the lungs, with its main role being to look for cancer nodules, which are too small to see on a chest X-ray.

CT is fast and readily available compared to MRI and most children won't require a general anaesthetic. Therefore, it's often performed at the time of initial diagnosis, where MRI isn't available.

PET-CT scans

Positron emission tomography (PET-CT) is a nuclear medicine scan, which involves using a radiotracer combined with CT. Cancer cells usually function at a faster rate and, as a result, use more glucose (sugar) than normal cells. The cancer cells show up on PET scans as 'hot spots' which can be localised more accurately by combining the scan with the CT. PET-CT can also help assess how well treatment is working.

PET-CT is used routinely in children and adolescents with Hodgkin's lymphoma, at diagnosis and in assessing response to treatment. It's also recommended, where available, for seeing the spread of rhabdomyosarcoma, Ewing's tumour and MIBG negative neuroblastoma within the child's body.

MIBG scans

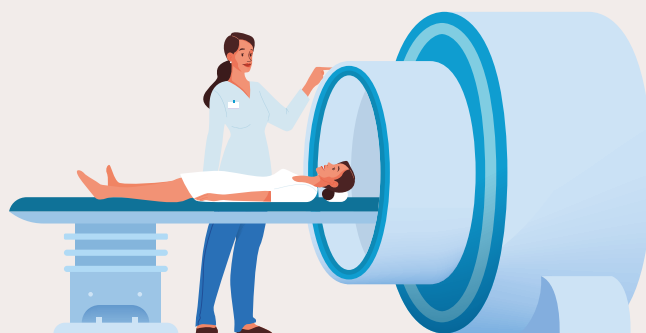
An MIBG scan is a nuclear medicine scan that uses 'metaiodobenzylguanidine', a radioactive iodine (an isotope). MIBG is a molecule that is absorbed by certain cancers such as neuroblastoma in children.

MIBG scans help confirm the diagnosis of these tumours and can detect disease which has spread to bones or other organs. It's also used to assess whether the cancer is responding to chemotherapy.

MIBG scans take place over two days. On the first, your child will receive an injection of MIBG and a radioactive isotope which will accumulate in any neuroblastoma cells. On the second day, the scan will take place using a gamma camera.

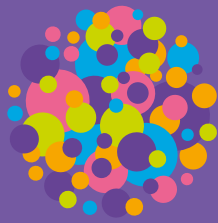
MRI scans

Similar to CT scans, MRI scanners are also large doughnut-shaped machines, with a short tunnel in the centre, which a table slides through. MRI uses radiowaves and a strong magnetic field to produce detailed pictures of the inside of your child's body.



MRI gives more detailed images of the soft tissues and organs compared to CT scans and doesn't involve the use of ionising radiation. MRI is therefore usually used in preference to CT to image the brain and spine, abdomen, pelvis and tumours of the soft tissues or skeleton.

Unlike CT scans, MRI technology is more complex and takes more time to produce an image resulting in much longer scanning times. Infants and young children (under the age of six) and claustrophobic or anxious older children, will usually need to have a general anaesthetic. MRI scans can be noisy due to the magnet and radiowaves. Headphones will be given to help mask the noise so children can listen to music, audiobooks or videos during the scan.



Teenagers and Young Adults with Cancer



Ashley Ball-Gamble

BRIDGING THE GAP FOR TEENAGERS AND YOUNG ADULTS WITH CANCER

With the COVID-19 pandemic delaying many of its plans, Teenagers and Young Adults with Cancer (TYAC), CCLG's sister organisation, has revisited its ambitious 2020-2025 strategic plan. **Ashley Ball-Gamble**, CEO of TYAC and CCLG, explains more.

Something we often say when talking about children with cancer is that "children are not just small adults!". What we mean is that cancer in children is different to cancer in adults – they get different types of cancer, need different treatments and need specialist care in expert hospitals. Even where a cancer occurs in all age groups – such as acute lymphoblastic leukaemia (ALL) – it's treated differently to children than it is in adults, and has different outcomes.

It might not surprise you, then, that we believe that teenagers and young adults (aged 13-24) with cancer also have specific needs – both psychological and physical – that differ from children and older adults. Teenagers and Young Adults with Cancer, or TYAC, is a sister organisation to Children's Cancer and Leukaemia Group (CCLG), founded in 2004. Like CCLG, TYAC started out as a small, like-minded group of professionals that recognised the specific needs of this age group. Over the last 17 years, TYAC's grown alongside the field of TYA cancer care, which has seen the development of specialist principal treatment centres (PTCs) for 16-24 year olds with cancer, and the TYA multi-disciplinary teams first recognised in the 2005 NICE Improving Outcomes Guidance.

In 2018, TYAC merged with CCLG, to provide a stable platform for the further growth and development of TYAC as the country's only professional membership body of its kind. It would benefit from CCLG's infrastructure, size and reach to support its membership and enable them to direct their energies to TYAC's mission – which is working to achieve the best possible care for teenagers and young adults with cancer. Since its inception, TYAC has been supported financially by Young Lives vs Cancer (formerly CLIC Sargent) and Teenage Cancer Trust, and we're grateful for their continued support.

In 2019, TYAC launched a new strategy, clearly setting out four key goals:

01

To build a membership community for all professionals working with TYA cancer patients

02

To be a strong professional voice for teenagers and young adults with cancer and their need for specialist care

03

To educate for impact, to improve the cancer experience for young patients

04

To lead and fund world-class research dedicated to teenage and young adult cancer research

These goals represented an ambitious expansion of activities for TYAC, responding to key gaps in TYA cancer where TYAC and CCLG's combined expertise could provide more impact for young people with cancer.

And then, along came COVID-19. With many of our planned activities curtailed by the impact of the pandemic, as well as the huge impact on our members working on the frontline of

the NHS, TYAC's plans had to be put on hold. Now, some two years on, we've been working hard behind the scenes preparing to relaunch TYAC, now more ambitious than ever, to ensure all young people with cancer receive the best possible treatment and care...

INFORMATION AND SUPPORT

We have launched a new-look TYAC website, featuring a wealth of comprehensive health information for young people with cancer, covering a wide range of areas. This includes help and advice for patients, friends and family, and expert information on different types of cancer, living with cancer and specialist resources and support.

We're also working to increase the amount of information resources, including good practice guidance and educational content, for our professional members. Ultimately, this will help to improve the care given to young cancer patients.



Cancer information for teenagers and young adults



TYAC's research strategy

RESEARCH

In 2019, the TYA Cancer Research Priority Setting Partnership (PSP) published the top 10 research priorities in teenage and young adult cancer, as agreed by young patients and survivors, their families, and the professionals treating and caring for them. This pivotal work suggested that future research should focus on holistic and psychosocial care delivery as well as traditional treatment research. In response, TYAC has formed a Research Advisory Group and published its first research strategy, setting out our ambition to become a major funder of specialist research, while focusing on the top 10 priorities identified by the PSP.

We want to bridge the gap between the children's and adult oncology research worlds. TYAC is taking the lead on building a new focus on research that's dedicated to the specific needs of TYA cancer treatment and care, to improve outcomes for young people with cancer.

We're also committing to supporting and developing the TYA research community, through our 'TYAC Research Academy'. This will offer training and mentoring to early career researchers looking to build a career in TYA cancer research, ensuring that research in this field is sustainable.

#FUNDTHEANSWERS

To enable these important areas of research to be undertaken, and to answer the questions identified by the PSP, we have developed a new, dedicated fundraising campaign for TYAC called #FundTheAnswers.

There isn't a major national funder of solely teenage and young adult cancer research. That's where TYAC comes in! CCLG has had a huge impact on children's cancer research directly and through our partnerships, and we're in a position to do the same for TYA cancer research through TYAC.

We know the research questions, but research takes money – and that's why we're asking our supporters to help us #FundTheAnswers. Whether running, cycling, skydiving or taking part in one of our special events, there's lots of ways to get involved, while at the same time having fun.



Get involved and help #FundTheAnswers

Find out more at www.tyac.org.uk



Connecting with the childhood cancer community

+ Follow

Message

More



Sheila Cartwright, one of the first CCLG members and retired paediatric radiation oncologist, reflects on her career, and explains how LinkedIn allows her to keep up with developments in childhood cancer and reconnect with former patients.

I trained as a doctor at University College Hospital London, where I commenced my studies in 1963. At University College Hospital the radiotherapists had marvellous, compassionate careers and inspired me. I had an elective period at Great Ormond Street Hospital (GOSH) for six weeks and then spent six weeks in my hometown Leeds at Cookridge Hospital, the treatment centre for radiotherapy in Yorkshire. After qualifying as a doctor and working in a couple of hospitals, I returned to Leeds in 1971.

I made swift progress up the medical ladder, passing the Fellow of the Royal College of Radiologists (FRCR) exam and being appointed as a consultant radiotherapist in 1974, with responsibilities for paediatric oncology and breast cancer. None of us knew how to treat children and my consultant colleagues quickly passed their patients to me. Work needed to be done to change this, to gather information and better knowledge of children's cancers.

people, the ward sister and I raised considerable funds to build the unit. We were made Leeds Citizens of the Year in 1977, and I had the honour of showing Princess Diana around the unit.

LinkedIn

Now in my 70s, I'm updated with modern precision guided radiotherapy and take an interest in immunotherapy and webinars, thanks to LinkedIn.

I'm in contact with over 200 radiation oncologists worldwide and work to promote international protocols for solid tumour patients.

Also through LinkedIn, I've been contacted by surviving childhood cancer patients. Recently I wished a Wilms' tumour patient greetings on his 50th Birthday, which was so gratifying.

I'm in awe of today's brilliant oncologists, their accomplishments and complex treatment protocols. Cancer medicine is undergoing a revolution, and now more than four out of five children with cancer survive. I'm so fortunate to be an honorary member of CCLG and see all its wonderful work, including Contact magazine.

“I'm updated with modern precision guided radiotherapy and take an interest in immunotherapy and webinars, thanks to LinkedIn.”



Progress

Some colleagues and I soon formed a multi-disciplinary team - the Yorkshire Paediatric Oncology Team. We quickly linked up with the Christie Hospital in Manchester, then Newcastle, Liverpool, and Birmingham. The next step was to reach out to GOSH and The Royal Marsden, to form the United Kingdom Children's Cancer Study

Group (UKCCSG) - the forerunner to today's CCLG. Soon, national guidelines for ependymoma, Ewing's sarcoma and neuroblastoma were developed. We were aware of SIOP, the international children's cancer group, becoming members, and together with a colleague I travelled to many international meetings.

I became concerned with how chemotherapy drugs were being prepared on the wards and so promoted their labelling and the use of a laminar flow cabinet to store them. Bone marrow transplantation for acute lymphoblastic leukaemia (ALL) became a possibility, with total body irradiation (TBI) a challenge for the physics team and myself. It was necessary to build a unit for the children receiving radiotherapy and, thanks to the Yorkshire Post and generosity of Yorkshire



Sheila showing Princess Diana around Cookridge Hospital's new radiotherapy unit

A parent's view...

Childhood cancer at Christmas

Rachel Corbett's daughter, **Suki**, was diagnosed with acute lymphoblastic leukaemia (ALL) in January 2017, aged four. Rachel writes about spending Christmas in hospital and how the experience has changed how her and her family think of it.

Christmas is usually seen as a magical time and one that often carries so many special memories, particularly of happy childhood days. But it can also be strange and difficult, full of such mixed emotions. On Christmas Eve 2016, we returned from another inconclusive GP appointment. Sick with worry, knowing there was something so wrong with our daughter, my husband Pete and I quietly uttered the words "leukaemia" to each other, a moment I'll never forget. Suki spent that Christmas desperately poorly, too ill to get involved with the festivities. It was to be another few weeks before we got confirmation of the diagnosis we'd been dreading.

The following year Suki had already been admitted to hospital, having picked up a virus and with her temperature soaring. As the Salvation Army band played carols in the corridor outside our room, our daughter looked on, hooked up to drips and machines. Tears quietly rolled down my cheeks. It felt like a dream. She bedded herself down for yet another night in isolation, and sobbed when she soon realised we'd be in hospital on Christmas Day.

Having a two-year-old daughter and husband at home, we had to come up with a manic plan of action as to how best to work through the logistics of the next few days, and still in some way make sure Christmas was special for our girls. Laying out stockings at home on Christmas Eve, the reality really sunk in, knowing Suki was lying in a hospital bed nearly an hour's drive away.

Spending Christmas in hospital isn't something anyone ever wishes for, but all four of us had such a truly special day. Suki herself was starting to respond well to treatment, which gave everyone a boost.

The staff were simply amazing, going above and beyond in all that they did. So much thought was put into everything. Christmas dinner, eaten in shifts, balanced on laps, crackers, and donated gifts.



A senior doctor dressed up as Father Christmas and was grilled by our youngest, Betsie... questioning his choice of footwear, where he'd parked his sleigh, and even his beard! Another doctor performed a hilarious routine with his pet (puppet) singing turkey on his shoulder, apparently something of legend on the paediatric ward! Knowing so many special people were giving up time with their own families to look after our poorly daughter made it an incredibly emotional and heart-warming time, and one we now look back on with such fond memories.



Rachel Corbett and daughter Suki

For three years our lives were dominated by childhood cancer.

We lived on tenterhooks, fully aware of how quickly things could change. To live with the constant worry of a possible hospital admission hanging over us for years on end, it's hard to put into words just how draining that becomes. Last year, with all the restrictions in place across the country, we spent Christmas at home, just the four of us - quiet and simple. To have no real worries, no anticipated hospital trips, or temperature spikes, made us appreciate the simplicity so much more.

Our lives are far richer from the experiences of recent years. Knowing others facing so much more uncertainty, pain, hardship, and heartache, it's certainly made us look at Christmas - and life - in a very different way. It's truly made us realise how lucky we are to have each other and really that's all that matters.



▶ Rachel, Suki, Betsie and Pete

A focus on functional imaging and artificial intelligence



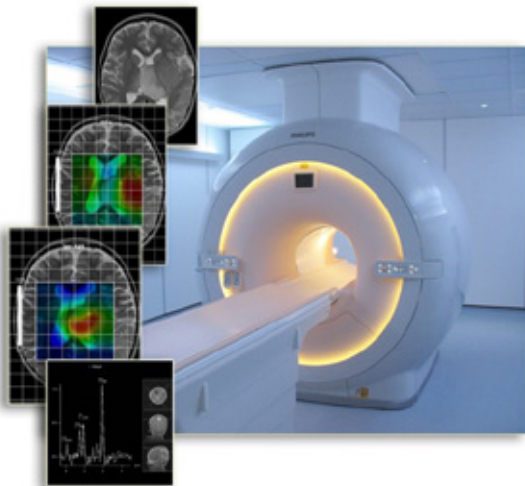
▲ Professor Andrew Peet

Imaging is central to diagnosing and monitoring solid cancers and scans are a key part of the patient and family journey. Different types of scans such as CT, MRI and PET, have all become commonplace in hospitals throughout the UK and children benefit from the accurate high-quality images they produce. Patients and families want to know what the tumour is, how it will be treated and what the outcome will be and want this information as quickly as possible. Imaging is increasingly meeting these challenges and the use of computers with artificial intelligence (AI) promises dramatic improvements in speed and reliability in the future.

Leading the way in imaging research

The UK has a long history of excellence in imaging research, with the discovery and development of both CT and MRI being perhaps the biggest contributions this country has made to cancer care worldwide. Ensuring that children with cancer are at the forefront of this innovation is essential.

Imaging is often thought of as purely producing pictures of the inside of the body. However, there has been a shift towards using imaging to provide information on the properties of tumours, such as the blood flow in them or their chemical make-up. MRI scans can be readily adapted to acquire a whole range of information on tumour properties, giving us a better idea of what type of tumour the child has, and how aggressive it is going to be. These methods together are sometimes called 'functional imaging', since they aim to investigate how the tumour is functioning.



“ In 2004, we set up the Functional Imaging of Tumours study with CCLG and our network of hospitals. We built our own computerised database to store the images and made it available to researchers on the internet.

From the outset, we used computers and early artificial intelligence to analyse the images. Success came quickly and we achieved impressive accuracy in diagnosing the main childhood brain tumour types.

”

Professor Andrew Peet,
of the University of Birmingham

Seventeen years later, the CCLG functional imaging database has more than 1,500 cases with scans collected from 10 centres and is at the forefront of the international effort to develop imaging and AI. The Functional Imaging of Tumours study is still open and recruiting patients, and underpins a number of important research studies through its database of scans.

Here are two of these projects, funded by the Little Princess Trust (LPT) in partnership with CCLG, which demonstrate recent successes.

Improving the diagnosis of children's brain tumours by functional radiomics

Institution: University of Birmingham

Amount Awarded: approx. £100,000

Undertaken by early career researcher Dr James Grist, who won the Sir Peter Mansfield Prize for Innovation in MRI for the work, this project focuses on predicting survival for an individual child. Some tumours don't behave as doctors would expect, and usual treatments don't work. Unfortunately, it can take a long time to know whether a treatment is working, sometimes too long when tumours are not responding to treatment.

“We're using AI to help analyse the images coming off the MRI scanner before they have started treatment to predict whether a child will be okay with normal treatments, or if they would need to be considered for new therapies to treat their tumour.

We're going to be taking this discovery forward to test it at sites around the UK, bringing hope to children with a brain tumour around the country.

What's exciting about this discovery is that we're using information gathered from the moment the child comes to hospital, and not having to wait a long time to see if our treatments are working.”



Dr James Grist

Moving artificial intelligence of functional imaging for children's tumours into a multi-centre environment through a clinical decision support system

Institution: University of Birmingham

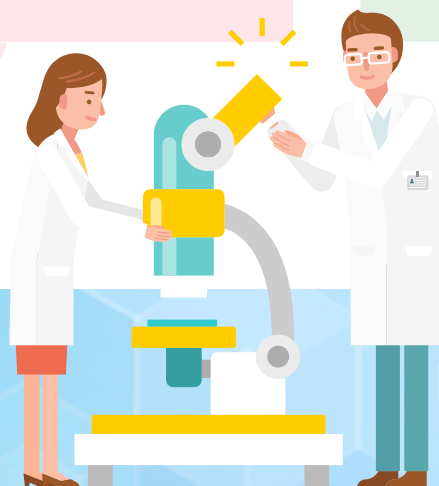
Amount Awarded: approx. £100,000

While functional imaging is becoming widely available, interpreting new scans can be challenging for doctors and this is being addressed in this research study. Undertaken by early career researcher Dr Heather Rose, who won the prize for best research poster at the 2021 CCLG Winter Meeting, the team have designed an app that allows hospitals to use these advanced scans to help diagnose their patients.

“This app presents results in comparison to scans in our database which allows doctors to assess a patient's scan against scans where we already know the type of tumour present. AI uses mathematics and the scan results to predict the type of tumour and feed this information back to doctors.

This app will be made available for testing by staff in hospitals to gather feedback and make further improvements. It's fantastic to think that these amazing methods are going to be available to doctors within the hospital.”

Dr Heather Rose



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



60 SECONDS WITH

Jamie Cargill



The clinical lead nurse at Bristol Haematology and Oncology Centre and Chair of TYAC talks to us about his career, plans and interests.

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

A: I'm a registered children's nurse and teacher and have spent the majority of my career working with children, teenagers and young people with cancer. Since starting my nursing career I've worked in many clinical roles, but also in research and education. Latterly, I led the development of a teenage and young adult regional service in the South West, and established the first Teenage Cancer Trust-funded unit in Bristol alongside a number of significant service development initiatives. Currently, I'm the clinical lead nurse for the Bristol Haematology and Oncology Centre.

Q: Tell us about your role as Chair with TYAC?

A: Well, so far, it's certainly been a challenge! As a consequence of the pandemic, TYAC, alongside many other organisations, was hugely affected and in many ways was forced into prolonged hibernation during most of 2020.

Many of the initiatives and outputs we had planned were put on hold as we recognised the significant efforts and focus of all our members committed to ensuring cancer care and delivery was sustained. As we slowly - and cautiously - start to look forward, TYAC and myself as Chair

remain aware of these challenges, yet committed to relaunching our 2020-2025 strategy to ensure TYAC is the leading national platform in influencing and progressing teenage and young adult cancer treatment and care.

Q: What plans do you have?

A: TYAC's always been proud of our commitment to delivering first-class education, and developing best practice guidelines for service development and expert information guidance for patients and families. We'll continue to build and enhance these, but we have ambitions to broaden our output as detailed in the 2020-2025 strategy. This will include a focus on world-class research dedicated to TYA cancer and to further support and engage with our members by growing our special interest groups and online communities.

Q: What is your proudest career moment?

A: There's been many to date but most notable are the occasions when either you or your team have been able to make a profound difference to a young person or their family. Even the simplest gesture at a time of crisis can make a profound difference, and it's these moments that I cherish and keep me focused on what's important and why we do what we do.

Q: What does your job mean to you?

A: This is a hard one, particularly as the last 18 months have placed enormous strains on our teams, services and sadly, our patients and families. But I still believe what we do is a privilege despite

all the challenges, and I'm enormously proud to be a nurse and to work with the most remarkable colleagues and teams.

Q: What are your interests, professionally and personally?

A: Professionally, I'm about to start a coaching course which I have interests in developing further. Personally, I'm often busy transporting two teenagers around to various clubs and activities so there's little time for much else - although I am training for an Ironman in Ireland next August!

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

A: Be kind to yourself, use the people around you and take each day at a time.

“Be kind to yourself, use the people around you and take each day at a time.”



ASK THE Expert



Naomi Shefford-Thomas, CCLG Information Executive and mum to Phoebe, who underwent almost four years of treatment for neuroblastoma, answers your questions.

Searching for information and support online



A childhood cancer diagnosis can leave you feeling shocked, scared and confused, with many questions running through your mind. Searching the internet is often the first place to start for quick and easy answers, but with a huge amount of information – some trustworthy and some not so – at a person's fingertips, it can be overwhelming, and sometimes conflicting, causing even more worry and stress. Therefore, it's important to make sure that health information is filtered and gathered from reliable, easy-to-understand sources.

Should I search online?

There's no right or wrong answer to how parents might feel. Some parents want to avoid looking online for many different reasons. They may not want to be distracted or worried by information that doesn't apply to their child or may not trust everything they read and are reassured that their child's hospital team provides all the information needed. Other parents want further background and context to the information they already have and want to look for online support. It can, among other things, help them to:

- ▶ Feel more in control and better equipped to play an active part in their child's treatment and care at home
- ▶ Gain knowledge and advice not only about childhood cancer, but also about living and coping with cancer at home
- ▶ Feel less lonely and isolated by reading other patient and family experiences
- ▶ Feel more confident in talking to doctors by asking the questions that they want to know the answers to

What are the dangers of searching online and what should I do?

It's sometimes tempting to constantly search online about your child's cancer, but this can become very consuming and distracting, and may add more worry and anxiety. Taking a break from going online for a day or two from time to time can be beneficial and many parents suggest that taking each hour and day as it comes rather than racing ahead is helpful. If you find yourself becoming overloaded, it's a good idea to talk to your child's doctor or nurse who will go through the information with you to make things clearer in your mind and more relevant to your child.

What should I keep in mind?

Things I watched out for were how recent the information is, whether the site was UK based and whether it was a trusted, well-known source. If I couldn't tell I would try to avoid it. If you do find yourself down an internet rabbit hole, though, please try to speak to someone in your team to talk through what you've seen. In my experience, this has often helped to clear my mind and reassure me of the facts. Don't be scared to ask questions rather than allowing doubts and worries to take over.

Scan to download CCLG's publication
'Searching for information and support online'.



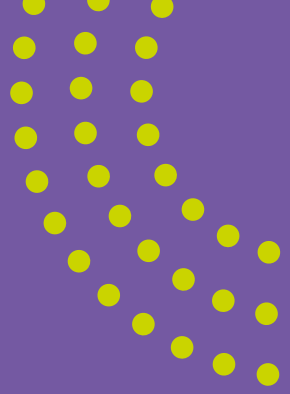
Do you have a question to ask one of our experts?

Please get in touch by emailing info@cclg.org.uk or via DM on our social channels. We may feature your question on a future 'Ask the Expert' page to help other families and patients who have the same question. Parents and carers who would like to join our private Facebook group, scan the code to visit.





Teenagers and
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