

FREE

AUTUMN 2021 | ISSUE 92



Children's Cancer and Leukaemia Group

the EXPERTS in CHILDHOOD CANCER

contact

SUPPORTING FAMILIES THROUGH CHILDHOOD CANCER

MAGAZINE

Normality and childhood cancer



SEPTEMBER IS CHILDHOOD CANCER AWARENESS MONTH

A day in the life... what does a normal working day look like for professionals involved in childhood cancer care?



LIFE AFTER TREATMENT



RE-ADAPTING TO NORMAL LIFE



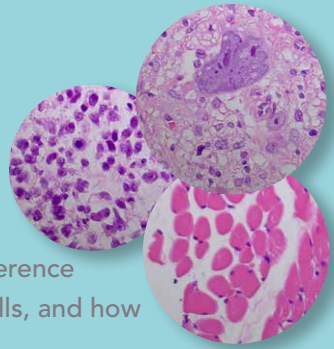
Parent's view

Sarah McDonald, mum to Summer and Kya, writes on how normality changes for siblings after a childhood cancer diagnosis in the family

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ALL GOOD THINGS ARE WILD AND FREE

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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...

"It's really full of interesting things to read and visually fantastic."

"Really great magazine, so professional."



Every achievement is that little sweeter

"I can so relate to this. I want everyone to realise what children in treatment go through, and how tough it really is. Every achievement is that little sweeter and more admirable."



Read the full article on our website.



Go-to resource

"An article on the importance of school in a child's cancer journey and benefits of communication and support between all parties. CCLG's Contact magazine is always my go-to resource!"



CCLG's updated COVID-19 guidance, including answers to vaccine FAQs and the lifting of restrictions

"Thank you for continuously providing reliable and up-to-date advice in a timely way, our team have found it so incredibly helpful to signpost families to the answers you're providing."



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

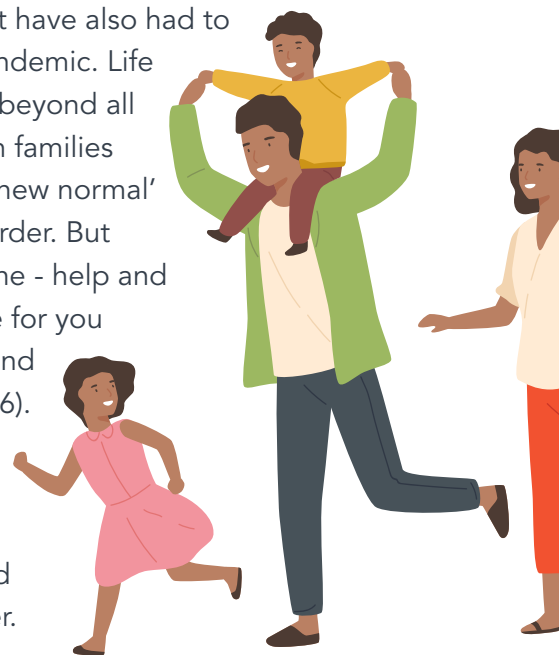


Hello!

Nothing about the last 18 months has been 'normal'. We have lived through an extraordinary global event which has left its mark on all of us in some way.

It's unimaginable to know that families have not only had to face the devastation of being told their child has cancer but have also had to live through the pandemic. Life really has changed beyond all recognition for such families and adapting to a 'new normal' must seem even harder. But families are not alone - help and support is still there for you despite lockdown and restrictions (see p.16).

Read this issue to find out more on how normality is affected by childhood cancer.



Claire editor@cclg.org.uk

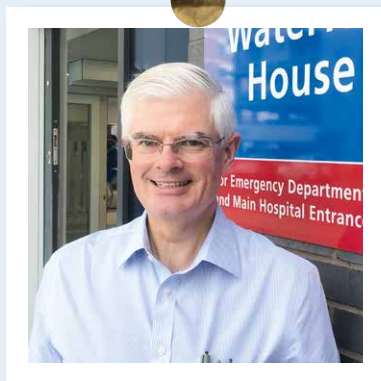
September is Childhood Cancer Awareness Month (CCAM)

To donate **£5** text **GOLD** to **70460**

Texts cost £5 plus one standard rate message.

www.cclg.org.uk/ccam





MEDICAL ADVISER

Dr Martin English

Consultant Paediatric Oncologist at Birmingham Children's Hospital and CCLG member

"Is this 'normal', Doctor?" This was one of the first questions I was asked when I started in paediatrics, and I suspect it's the same for most of my colleagues. It's a frequent question from new parents with a first baby who worry about what is and isn't expected. So, too, do most new paediatricians who are also on a steep learning curve!

Of course, normal life isn't the same after a new baby or any other major change. When we talk about getting back to normal, what we often really mean is that we want to return to how things were. If a family member has an illness such as cancer, routines and priorities all change. It's not just getting the family up, dressed and breakfasted before school and work. It's also about taking medicines on time, coordinating appointments with community nurses doing blood tests and dressings, scans at the hospital, admissions for treatment, reviews in clinic and so much more. Take your pick, the list seems endless.

In this 'new normal', it feels as though you are spinning a lot of plates at the same time. More plates are then added, and some plates can only spin slowly and some must go faster. I think the best way to cope is to take help when it's offered - and ask for it if it isn't. It's a bit like climbing a mountain: you need to follow a map to get you to your goal at the top, but on the way, keep looking everywhere else so you don't trip and fall.

Big changes are always hard. On that first day at school, there were probably a lot of butterflies in the stomach, possibly some tears, or maybe some excitement. Before long, going to school every day became normal, or to be more accurate 'routine'. Then one day it's secondary school and there are more changes. Coming off treatment and moving to follow-up can feel a bit like that, too. The comfort blanket of contact through things like clinics, line flushes and dressing changes goes and families can feel a little adrift after treatment finishes. Even though it is great to be back in a non-cancer routine, it isn't always the same as it was before and it sometimes does not feel normal.

What is normal are the emotions we feel, such as the worries, anxieties, fear and uncertainties following a new diagnosis or an unexpected scan result. Reaching out to give or receive help is the best thing we can do when normality changes.

NEWS IN BRIEF

Virtual appointments in long-term follow-up care: Patient and professional satisfaction

Childhood cancer survivors and providers were very satisfied with video-conferencing for long-term follow-up during the COVID-19 pandemic, according to an American report. Except for physical examinations, virtual appointments met the provider's objectives for long-term follow-up, while most survivors considered virtual appointments as helpful as face-to-face and want them to remain as an option post-pandemic. (Source: *Pediatric Blood & Cancer*).

Greater mental health needs for parents of childhood cancer patients

Researchers have found that parents of childhood cancer patients have significantly higher needs for mental health care compared to the general parent population. They emphasise the importance of future interventions towards targeted mental health counselling and supportive strategies for vulnerable parent groups, such as mothers and those caring for children undergoing more complex treatment plans. (Source: *Journal of Clinical Oncology*)

Genetic discovery could guide treatment for aggressive childhood cancer

Scientists have found that specific genetic changes in tumours are linked to how aggressive rhabdomyosarcoma will be, which could pave the way for new, tailored treatments. Findings from the study could lead to some children being offered more intensive treatment, while sparing others of aggressive interventions. By looking at the genetic features of different tumours, patients can be divided into different risk groups to help guide their treatment. (Source: *Cancer Research UK*).

IS YOUR CHILD AGED 4-15 YEARS OLD?

Do they currently have or have they had cancer in the past? If yes, we need your help! We want to know what is important to them by asking them to take part in a short online survey so that we can improve research priorities for our young patients. The survey

is anonymous and brothers and sisters can also take part.



◀ Scan the QR code to take part

“Your life may not be what you once envisioned, but you can find a new path”

Chloe Hunt was diagnosed with neuroblastoma in 2010. She describes the challenges she faced adapting to a ‘new normal’ both during and after treatment, and how she overcame them.



Being diagnosed with cancer at 15 brought so many challenges. My normality was suddenly ripped away and replaced with grueling treatments. I felt completely robbed of my precious time as a teenager. Everything in my life was dictated by hospital appointments, tests and treatment.

Instead of worrying about usual teenage things like exams, relationships and finding out who I wanted to be, I was worried about even having a future. I often saw people of a similar age out enjoying life, whereas I just felt like the ‘girl with cancer’, who didn’t fit in anymore when doing ‘normal’ things.

To maintain some normality during treatment, I enrolled to do my A-levels. This gave me something to focus on and I treasured these little things like being able to study, even part time. Other things I’d previously taken for granted also became so important, like spending quality time with family, rare outings with friends and simply being out of hospital.

I thought after treatment I would just slip back into normal life, but I found it extremely challenging. I’d changed, and the world looked very different. After being so focused on treatment and trying to quite literally survive, I’d forgotten how to live a normal life. Most of the time during treatment I had my mum by my side and I’d lost most of my independence at the age I should have been gaining it. So, going out into the world and going it alone was terrifying.

During treatment I was too scared to look ahead to the future, so I didn’t really know what I wanted in life, apart from health and happiness. I found that I had to push myself out of my comfort zone to move forwards, while also setting realistic aims, beginning with little ones and progressing to bigger goals. Achieving things most people do as a young person, like passing my driving test, filled me with satisfaction, giving me that motivation to push forwards and shape my future.



I realised my path in life would be to pursue a career in children’s nursing. I had first-hand experience of the positive impact nurses can have on patients and families. I felt like I’d a lot to give to the profession and I guess it was also my way of giving back. I qualified as a children’s nurse in 2016 with a first-class degree, receiving awards both as a student and when qualified.

This year I published my own book: ‘Beyond Fear Is Hope’. It’s all about my cancer story and the rollercoaster of emotions, which I began writing as a way to process what I went through. Finishing treatment, I felt like all the emotions I

experienced were the ‘wrong’ way to feel, which I now know isn’t the case. I felt like the only person struggling, and this pressure to carry on like cancer didn’t happen. I experienced trauma symptoms many years after, having gone full steam ahead to reclaim my life, not giving myself time to heal or even breathe. This gave me the idea for the book, to help other young people with cancer and those trying to move on.

Although I’ve faced many difficulties, I now realise that it’s enhanced my best traits and I’m a better version of myself. Finishing treatment is all about rediscovery - your life may not be what you once envisioned, but you can find a new path. To all those who have finished treatment and feel lost, just remember to reach for your dreams and anything is possible.

▼ Chloe’s published book





▲ Helen

All good things are wild and free

Helen Ball's daughter **Emily** has recently finished treatment for acute lymphoblastic leukaemia (ALL). Helen tells us about what life has looked like for her family since Emily's diagnosis, and how nature and the outdoors has helped them.

The Henry David Thoreau quote "All good things are wild and free" has always resonated with me - I even have it framed as a picture on our kitchen mantelpiece. And it's something I found myself coming back to more often when our youngest daughter, Emily, was diagnosed with ALL at the age of two.

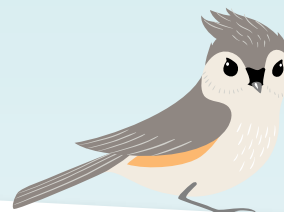
Up until that point our lives were 'normal', if there is such a thing. Our normal involved my husband Paul and I both working full time, with our eldest daughter, Bryony, at primary school and Emily attending our lovely local nursery. I guess we were settled in the sense that each of us had our roles in family life, as well as our own hobbies and interests, and things generally all slotted together.

But Emily having cancer changed all that. When she became too poorly to attend nursery, Paul gave up his job to care for her full time, while I continued working to keep us afloat financially. And Bryony just tried her best to deal with it all. It felt like a tsunami had hit our little household while the rest of the world carried on regardless.

After the initial shock and distress of front-line treatment - worsened by a dreadful flare-up of chicken pox and extended hospital stays - we began to find a 'new normal', each taking on our changed roles as best we could. It wasn't easy, but we had wonderful help and support from some utterly generous family and friends. We were also supported by the Childhood Cancer Parents Alliance (CCPA), who offered the opportunity of regular social meet-ups and events for families affected by childhood cancer.

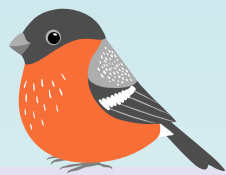
And then, coronavirus appeared, followed shortly by the first national lockdown. We went from one tsunami into another and, perhaps worse, this one came with greater isolation.

I had to dig deep to find the inner strength to stay positive and carry on. I did so by focusing on the small things in life. At first, the most basic: one more hour of cancer treatment



▲ Emily (middle) with her sister, Bryony, and Dad, Paul.

"It felt like a tsunami had hit our little household while the rest of the world carried on regardless."



"I found myself smiling when Emily smiled."



finished, one more medicine taken, one more lumbar puncture done, one more meal eaten. Then, with small steps, I found myself smiling when Emily smiled, inhaling with pleasure the scent from her little fuzzy head, now bereft of her golden locks. I took joy from the daftness of the girls making hats from cardboard hospital bedpans, from hearing the squeals of laughter when Bryony and Emily played together, or from lying snuggled in bed at home with them fast asleep next to me.

With growing appreciation of the things I had to be thankful for, cancer's grip began to loosen. We began family outings – car picnics when cold and raining, outdoor picnics when warm. These became our regular weekend fixture. Sometimes we would do them locally, even in the garden, while other times we might drive a few miles away to a favoured spot. This was usually one that was quiet, with few people about. Often, it was out in the wilds of the Peak District moors.

I found I could breathe again by being able to feel the cool upland breeze on my face, the hush of the wind blowing through trees, the gentle sound of bird song and hum of bees. And, in winter, the shock of cold, hard hailstones hitting my face. As an ecologist by profession and a naturalist at heart, nature and the outdoors are fundamental to my existence – to everyone's existence, in fact. And I've taught Emily and Bryony to develop a love for it.

Emily's mobility suffered tremendously during treatment and still hasn't fully returned. I dug out the toddler backpack and strapped her to me and we went for short walks, either from home or further afield. The girls collected leaves, feathers and pinecones. They made dens and climbed trees (well, Paul generally lifted and held Emily on the lowest branch, while Bryony scrambled higher) and they loved it. They stained their fingers and lips purple by gathering and eating blueberries and blackberries.

If all this sounds idyllic, it isn't meant to. We constantly fretted about Emily keeping her hands and central line

clean, needing regular medicines, not eating, getting uncomfortable in the carrier, and wanting to stay warm in the car while Bryony pleaded for her to get out and play. But it meant we were getting out of the house and away from the monotony of treatment, just for a few hours, sometimes even for less than an hour. But that was enough.

I was trying my best to shield our family by homeworking as much as I could, so I began to run a moth-trap in our garden, something I'd fallen out of the habit of doing. It doesn't harm the moths – they're attracted to its light and become captured in the collecting box below, settling to rest in the egg cartons provided before being released safely in the morning. The girls loved it, especially Emily who quickly learnt the names of many of the different moths as well as coming up with a few of her own: Snowy, Custard, Pinkie Pie.

Emily has recently finished treatment. More changes are ahead as we try to adapt to, and cope with, yet another 'new normal', both as a family and as individuals. The fear of relapse is ever present, the long-term monitoring of Emily's health will continue and life for our family has been altered forever. All of us are dealing with the fallout of the past two years, with Paul and Bryony both struggling with, and being treated for, anxiety. But with each small step and with an appreciation for the here and now and the small things in life - the little things wild and free - my hope is that we can each find our inner peace.

"More changes are ahead as we try to adapt to, and cope with, yet another 'new normal'."



Let the adventure continue!

A new 'new normal': Ward life during COVID

Steph Hall is a senior children's cancer nurse at Leeds Children's Hospital (LCH). She tells us what life looked like on a children's cancer ward before COVID, what it's looked like during the pandemic, and what it's looking like now.

As children's nurses, we're taught throughout our training the importance of family-centred care and the positive impact this has on patient experience and the wellbeing of the whole family. These principles are really important to us at LCH, particularly in paediatric oncology and haematology, where patients often have long in-patient stays.

Except for only allowing one parent to stay overnight due to space and safety, visiting our wards was open from breakfast until bedtime. We would see immediate family, grandparents, aunts, uncles, cousins and for the teenagers, boyfriends, girlfriends and friends coming in to support them while they were having chemotherapy. We supported patients to maintain normal relationships and as normal a life as possible, albeit one that involved having to live in hospital some of the time.

As nurses we knew all the important people in each patient's life, and it was lovely to chat to them and hear stories of their lives before hospital. We often had the pleasure of joining in with family birthday parties that had to take place on the ward due to unexpected temperatures that meant they could not celebrate at home.

Then came COVID. Quickly this idea of normality went for us all, but even more so for those families having to come into hospital for cancer treatment. Family visiting was restricted as everyone worked so hard to keep each other safe. In the early days of the pandemic, visiting was restricted to one parent being able to be on the ward for two weeks. That's two weeks of the child or young person not being able to see their other parent or siblings, and the resident parent not being able to see their other children.

“...we're taught throughout our training the importance of family-centred care and the positive impact this has on patient experience”

Of all the impacts that COVID has had on nurses (the PPE, hand washing, staffing challenges, moving staff to support our adult nursing colleagues and vaccination centres) this has been the hardest thing. Telling parents that they're

not able to come on to the ward to see their child having chemotherapy has been absolutely heartbreaking.

Since the early days, visiting policy has developed and we no longer have to restrict visiting to one parent for as long as two weeks. At LCH, one parent can now visit for five days, then parents are allowed to swap every 24 hours. We're still only able to permit one parent at the bedside, which we know can be so hard for these families.

As difficult as this is for all involved, keeping our patients, families and staff safe will remain our priority. I want to say a huge thank you to all of our families for their understanding and patience during this challenging time. We, as nurses, are looking forward to the time when we can see a patient's whole family - in person, in the same room, and not just on a screen.

“Telling parents that they're not able to come on to the ward to see their child having chemotherapy has been absolutely heartbreaking”



Looking back: Life through a different lens



Louise Campbell, 30, remembers how her parents tried to maintain some normality during her leukaemia treatment. As an expectant mother, she also explains how she now finds herself looking back on her own childhood with a different perspective.

I've no recollection of being diagnosed with acute lymphoblastic leukaemia (ALL) when I was three years old. However, I do remember a lot that followed: a mixture of difficult times, feeling poorly and - strangely - happy memories, too. I remember making friends on the children's ward of Addenbrookes in Cambridge, where there was Amanda, the fabulous nurse, and what seemed like an endless supply of toys and teddies to play with.

For my parents, it was so important to them to try and keep as much normality as possible for me. I still went to playgroup and school, doing all the normal things a child my age would. For my brother Tom, who was six when I was diagnosed, it was a worrying, scary time. When I was first in hospital, he asked Mum if I was going to die. She explained to him that although I was poorly and would need a lot of medicine, and it would take a long time, the doctors said I'd get better.

I think that's exactly how they tried to approach my treatment, too. They acknowledged there would be tough times but would strive for some normality for me, while of course still taking extra precautions and care, particularly when I was at risk of infection. Mum says that so much normality was maintained for me partly due to me being such a 'spirited' child, who wouldn't let anyone overprotect me.

The past few years feel like they've been a whirlwind. I married my soulmate, Jake, in August 2019 and we're expecting our first baby. Now, as I prepare to become a mother, I've started to fully realise just how different my childhood years were. Normality to me was something very different to what other children experienced, despite my parents doing a fabulous job of maintaining the status quo.

I've always been in awe of my parents and how they helped me, my brother and wider family through the challenging years of chemotherapy, but as I wait to welcome my baby into the world, I have a new profound admiration of how they coped. When I was born, my mum was told I had a hole in my heart (a VSD), and recently we found out our baby will have the same. Although it's not necessarily anything to worry about, I suddenly found myself looking back on my childhood. I realised just how challenging my diagnosis and treatment must have been for my parents and found myself worrying that my baby will face the same illnesses that I did. I know that this has no medical bearing, but it was a thought I couldn't shake.

Looking to ease my worries, we've had additional checks. All is okay, but I just can't wait for my baby to arrive now. I've taken the time to look back on my childhood, from diagnosis 27 years ago, through to a secondary cancer and major surgery in my

teenage years. I find myself hoping that my little one doesn't go through the same - and I suppose that's any parent's natural instinct. Yet at the same time, I remind myself that my experiences have had no negative bearing on who I am today.



Louise, expecting her first baby

I'm happy, surrounded by wonderful people, successful (having completed school, sixth form and university), and looking forward to so many more wonderful experiences to come. That makes me feel incredibly grateful, for the support of incredible doctors, medical researchers, hospital staff and, of course, my family, throughout all the challenging moments but the many positive experiences, too.





What is cancer?

Dr Ed Cheeseman, Consultant Paediatric Pathologist and Chair of CCLG's Biological Studies Steering Group, explains the difference between 'normal' cells and cancer cells, how the latter develop, and what they do to the body.

What do normal cells look like and what do they do?

The human body is made up of many trillions of cells that together, form the various organs and tissues of the body, as well as circulating blood cells. The brain, for example, is made up of neurons (which transmit nerve signals), glial cells (which support the neurons) and other supporting cells such as the cells that form the blood vessels. Almost all cells contain a nucleus, which stores most of the cell's DNA. DNA stores all of the genetic information that's required for our development, function and reproduction. The DNA is almost exactly the same in every single cell, but the way it's expressed varies between different cell types. Genes are made up of a specific length of DNA, and each gene codes for a particular protein. Proteins are the building blocks of our organs and tissues.

How do normal cells develop over time?

Normal cells go through a life cycle of being formed by division of a parent cell, growth, function (depending on the particular organ), division (to form new cells) and, finally, death, to be replaced by younger cells. The body has many ways of controlling this life cycle of cells, to ensure that the cells do not deviate from this normal pathway.

Unfortunately, things sometimes go wrong for various reasons, and then some cells escape from the body's normal control mechanisms. These cells have the potential to become cancer cells.

What do cancer cells do and how does treatment target them?

Cancer cells have the ability to ignore the body's signals that tell them to

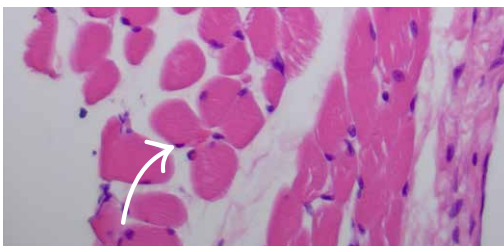
stop dividing, so that they can divide uncontrollably, forming a 'lump' of cancer cells. Instead of growing to a particular size, individual cells can again ignore the body, and become much bigger than normal cells.

“Unfortunately, things sometimes go wrong for various reasons, and then some cells escape from the body's normal control mechanisms. These cells have the potential to become cancer cells.”

Unlike normal cells that are kept safely where they belong, cancer cells have the ability to escape and move to different parts of the body. This is called 'metastasis', and is one of the defining

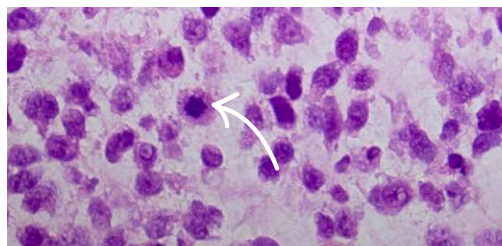
🔍 What cancer looks like under the microscope...

Normal muscle cell



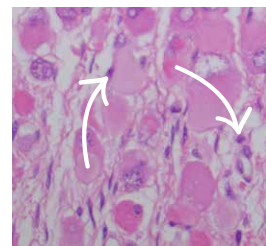
Nucleus

Early cancer cell



Dividing nucleus of a rhabdomyosarcoma cell

Enlarged tumour cells



Abnormal size and shape of nuclei

*Anaplasia - this is a key feature of cancer cells. If present, it means that the cell is distorted and undifferentiated so has lost the appearance and function of a normal cell. As a rule, the more undifferentiated or 'anaplastic' the cancer cells are, the more quickly the tumour may be expected to grow and spread.

features of cancer. Some cancer cells develop the ability to trick the body. For example, they can promote the growth of small blood vessels to feed them, and this allows them to grow even further. Or, they can bypass the body's protective immune system that normally kills cancerous cells.

Oncologists can take advantage of these mechanisms, with some cancer drugs preventing the formation of new blood vessels, thereby starving the cancer cells of vital nutrients. Other cancer drugs target the cells of the immune system, so that they become reactivated against the cancer cells.

How do cells become cancerous?

There are several ways in which a normal cell can become a cancer cell. One of the more common ways is through damage to the DNA within the cell, often as a result of exposure to damaging environmental agents such as cigarette smoke or radiation. This often requires prolonged exposure to the damaging agent over a number of years, and therefore cancers that develop in this way tend to be more common in adults. Alternatively - and more common in children - cancer cells can develop due to random faults that occur in the DNA when cells divide, or due to faults in the DNA that have been inherited from one or both parents. All these changes in the DNA are called mutations.

Mutations in genes that regulate the normal life cycle of the cell can result in uncontrolled cell division. Similarly, mutations in genes that normally prevent the growth of cancerous cells, can also result in growth and division of cancer cells. There's a group of genes that are responsible for editing mistakes that occur in our DNA, and if a mutation occurs in one of these genes, then the body loses its ability to fix or remove erroneous DNA, and cells with this abnormal DNA can continue to divide in an uncontrolled manner.

What are the commonalities and differences between cancers, and what does that mean for treatments?

Cancer is not one disease. In fact, there are hundreds of types of cancer, depending on what cell type the cancer has arisen in. Despite this diversity, there are some common features that most cancers share, such as uncontrolled cell division and growth, evasion of the immune system, and the potential to metastasise, or spread to different parts of the body. These common features form the basis for many cancer treatments.

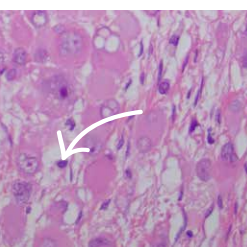
Each individual's cancer is unique to them, and this has led to more advanced treatments that are targeted to the individual, and based on the molecular

characteristics of that person's tumour cells. This is a new and exciting area in oncology, which has become known as 'precision medicine'.

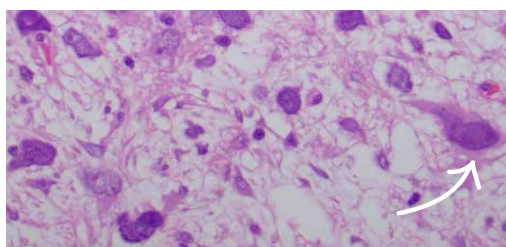
Why are cancers named what they are?

Cancers are usually named based on the organ or tissue in which they develop. The most common cancers in adults are carcinomas, and they arise in organs like the breast, prostate or lung, and they are called breast carcinoma, prostate carcinoma or lung carcinoma (although subtypes occur even within each organ). In children, cancers more commonly arise in the brain or spinal cord, the blood (leukaemia), and bone and soft tissues (sarcomas: for example, osteosarcoma and rhabdomyosarcoma). Other common childhood tumours include Wilms' tumours that arise in the kidney, and neuroblastoma that arises in nerve cells. In some rare cancers, we don't know for certain which cell type or tissue the tumour has arisen from, such as Ewing sarcoma.

Unlike normal cells that are kept safely where they belong, cancer cells have the ability to escape and move to different parts of the body. This is called 'metastasis', and is one of the defining features of cancer.

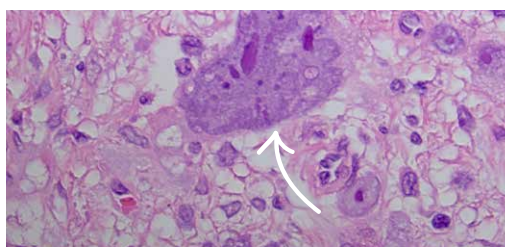


Abnormal tumour cell



Abnormal anaplastic* nucleus

Very large tumour cell



Large abnormal nucleus of a rhabdomyosarcoma cell with anaplasia*

A day in the life...

Have you ever wondered what everyday life is like for your consultant or ward nurse? Though no two days are the same, three paediatric healthcare professionals offer us an insight into what a normal working day for them might entail.

...of a paediatric oncologist and childhood cancer researcher

Sam Behjati divides his time between clinical work at Addenbrookes Hospital in Cambridge and research at the nearby Wellcome Sanger Institute. He writes:



As an academic paediatric oncologist, I probably don't ever have a 'normal' day as I'm constantly juggling clinical work, research and family life.

However, the highlights of my week are my clinics on Fridays, when I roll up my sleeves to look after children and their families, and Tuesdays, when I meet with my lab group to discuss science. The other days are mainly filled with meetings, meetings and more meetings, and responding to emails. Although I try to keep research and clinical time separate, I catch up with my patients every morning remotely through emails, phone conversations and check what is happening on the ward. Occasionally, I get the luxury of a few hours of uninterrupted writing and thinking time which, far too often, tends to be on Sunday mornings. As is the norm for a paediatric oncologist, my days start early and finish late, interspersed with family time and household chores.

My research focuses on studying the origin of childhood cancer using the genetic information that is contained in cancer and normal cells.

Sanger offers cutting-edge equipment and laboratory pipelines that enable me to generate vast amounts of data. More importantly, the Institute is full of highly gifted researchers from diverse backgrounds that bring together incredible expertise about all things genetics. My own group comprises mathematicians, biologists, clinicians and even an astronomer, all from different corners of the world. We're not focused on any particular disease. Instead, we study the development of a range of cancers (and sometimes of normal tissues, such as the placenta).

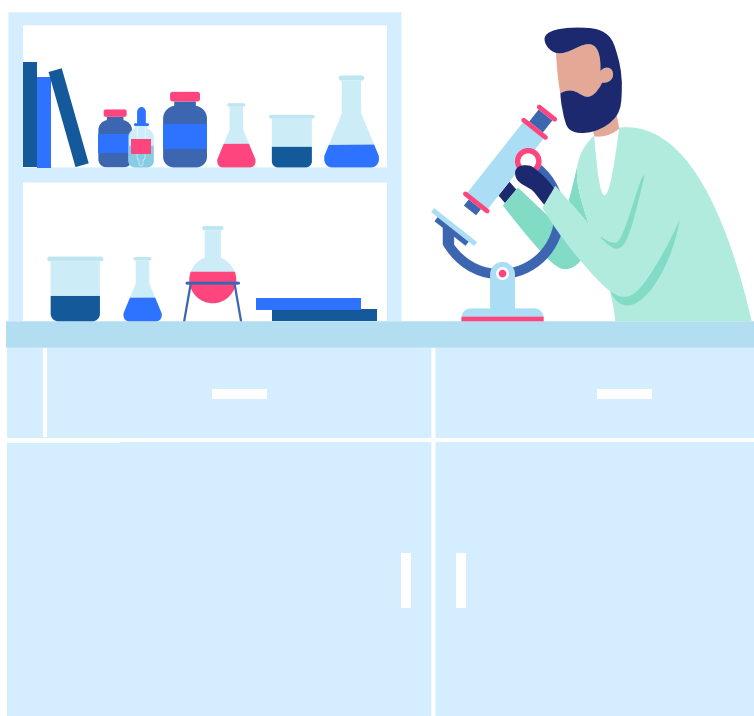
Questions about the origin of childhood cancer are, at their heart, considered 'basic' science. Nevertheless, our findings often have clinical implications. For example, we've found specific genetic changes (mutations) that are diagnostic of certain tumour types, and this knowledge is now routinely used in clinical practice. Usually, however, the clinical implications of our research findings are less tangible and mostly point to future directions and possibilities.

When studying the origin of the kidney cancer Wilms' tumour, for instance, we found that in many cases there was a pre-existing cancer root in regions of normal-looking kidney tissue. Based on this discovery, we can now begin to ask the question whether it might be possible

to identify children at risk of developing Wilms' tumour through screening for the root. Although this idea remains fantasy at present, it's exciting that our discovery allows us to think along such lines without sounding ridiculous.

My scientific expertise is becoming increasingly more helpful in my clinical work, as genetic information about cancers is entering clinical practice. In England, the NHS is now offering whole genome sequencing (WGS) to all children diagnosed with cancer. This rather fancy test provides a readout of the entire genetic code of tumours, which often contains useful information for clinical management. At Addenbrookes we hold a weekly 'molecular MDT' meeting, where we discuss the genetic data, which primarily allows us to assess whether we can tailor treatment for each child.

Although life is very busy juggling being a father, a clinician and a group leader, I feel indebted to the children and the families that I have cared for, who continue to drive me to understand - and ultimately, better treat - childhood cancer.





...of a play specialist



Catrin Bayliss is a health play specialist at Cardiff and Vale UHB. She writes:

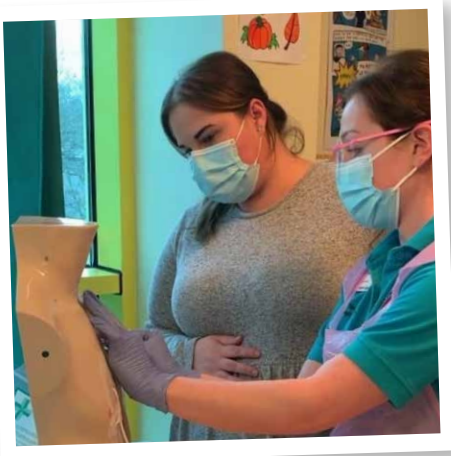
As a registered health play specialist working full time on an oncology ward, my role is extremely varied, which is the thing I love most about it. No two days are the same, and the 'plan' is never as you'd think when you start work in the morning. A 'normal' day may include working with babies just a few months old, facilitating developmental play sessions in the morning, and creating a giant train track with a three-year-old. It could also mean distracting an anxious 10-year-old while they have an NG tube and then being asked to speak to a teen about hair loss or them feeling low due to all their friends posting their 'normal' life on Instagram. And this is all before lunchtime!

can be overwhelming for them. It's my job to help them process what will happen at each stage of their treatment by communicating it in a way they can understand. This is often vital to how they react to procedures.

This past 18 months, we've faced the added pressure of COVID and only one parent or carer being allowed to stay with the patient at any time. This has meant my role has been more demanding, in terms of the day-to-day preparation, distraction and the need to provide a lot more reassurance and emotional support to both parents and patients. It's also been very important during this time to ensure families are equipped to explain things to siblings. We've made sure they have the tools we'd normally use - such as books, chemo ducks, Olly The Brave Lion, and tips to support talking about their brother or sister's hospital stay - to take home. It's been so hard for both patients and their siblings, not being able to see each other.

It's also been really tough for the patients in that they've not been able to mix in playrooms and be a support to one another as they would normally pre-COVID. And it's been a new and different challenge for us - adapting play sessions to the bedside, having to book patients into the playroom for one-to-one sessions and cleaning in between. However, it now feels normal, and the patients and their parents or carers have been hugely grateful for this time. For children and young people to have a space to relax and have some control and choice has been essential through COVID.

Hopefully, we'll get back to having a playroom full of people making slime and having film and pizza days one day soon.



The role can be demanding, and good time management is essential, but this highlights the necessity of the role. But when you work with such a supportive, caring team like I do, days run so much smoother. Being integrated within the multi-disciplinary team helps us to achieve our goals together. We want to give the patient the best opportunities and help them to reach their full potential, even if they're on the ward for a long period of time, which a lot of our patients are.

I am ward based, which means I meet the child or young person as soon as they arrive. I reassure patients and parents and let them know that I'm there to help them understand what's going on, and keep them busy while they are waiting around a lot of the time. Building up this rapport and relationship in the beginning sets the foundations for the trust needed to be able to prepare patients for their lines, anaesthetics, talking about their treatment and side effects such as hairloss.

Being an advocate for the patient is something I'm very passionate about. Things happen very quickly for a child or young person when they first arrive to us, and it



...of a paediatric oncology clinical nurse specialist



Valerie Tomlin is a children's cancer nurse at Addenbrookes Hospital in Cambridge. She writes:

While every day on the unit is different - and all are unpredictable and varied - Monday morning starts with the ward round (an update of the patients on the ward from over the weekend) and a clinic handover to discuss the children attending clinic that day. The paediatric day unit (PDU) can see up to 30-40 children in a day, including children attending for treatments or scans, bloods/reviews, or long-term follow-up.

The rest of my morning is usually spent in the clinic seeing patients with the consultant, then following their care through the rest of the day - giving chemotherapy, discussing protocols and planning future appointments with them. Education is key - I spend a lot of time teaching parents how to give medication and chemotherapy at home and helping them to understand the protocols.

Four mornings a week, children attend for bone marrow aspirations or lumbar punctures under general anaesthetic which are carried out on the unit (up to six children a day). We have a small treatment room where the procedures are performed, rather than attending theatre, led by a paediatric anaesthetist, an operating department practitioner (ODP), registrar, and either myself or one of the other clinic nurses.

My first task of the afternoon is attending an MDT (multi-disciplinary team: Consultants, radiologists, pathologists etc.) meeting to discuss results and future care planning. Post-MDT I call the parents with the results and follow-up plans, then book/request all future scans for reassessments.

Addenbrookes as a Principal Treatment Centre (PTC) covers the whole of East Anglia, and we work with 11 shared care centres. Much of my afternoon involves liaising with these shared care centres and local community teams. It mostly consists of coordinating care at home, or supportive care at their local hospitals.

The communication between centres is paramount in ensuring continuity of care, and also supporting our patients in transitioning from hospital to home.

Essentially, my role is to provide specialist support to the families, by coordinating their care and offering education and advice. I act as their advocate and keyworker throughout their treatment programme and into early follow-up. From the first moment I meet them on the ward, I aim to earn their trust and alleviate their initial fears. I'm their first point of contact during the patient pathway, so it's important to build these relationships early on. Actually, my role is never-ending. At some point, I may even have time for a coffee - and there's always cake on the ward!

Caring for children with cancer and their families can be challenging, but while it's emotional, it's also incredibly rewarding. These children - and their parents - are inspirational, and every day working with them is filled with fun and laughter.

“The communication between centres is paramount in ensuring continuity of care, and also supporting our patients in transitioning from hospital to home.”

“From the first moment I meet them on the ward, I aim to earn their trust and alleviate their initial fears.”



A parent's view...

Childhood cancer and siblings... Sarah McDonald's daughter Summer was diagnosed with leukaemia in 2012. She writes on what life looked like for Summer's sister, Kya, during treatment.

My daughter Summer was diagnosed with lymphoblastic leukaemia (ALL) as a five-year-old in November 2012. I was a single parent who also had another daughter, Kya, who was two at the time.

After a childhood cancer diagnosis, you soon realise that nothing is ever 'normal' again, not as you knew it before. When Summer was diagnosed, everything changed in an instant, not just for her, but for Kya, too. The calm, fun, normal life Kya knew was now anything but. Suddenly, out of nowhere, her sister - her best friend - was suffering from this horrible illness. She could no longer go near Summer due to the fear of hurting her 'wiggles' (central lines coming from her chest) and had to sit and watch her being pumped full of chemo or hear her screaming as doctors poked her with needles and watched as her hair fell on to her dinner plate.

What's more, Kya was staying with my parents during all the hospital admissions and illness and could only visit Mummy and her sister at the hospital. Despite this upheaval and the trauma of seeing her sister in pain, Kya was always so good and took everything in her stride. She accepted that people came to visit Summer and bought her gifts,

and that our life was now hospital visits, play workers, and seeing or listening to her sister being sick or in pain.

Kya didn't complain once, which we took at the time to mean that she was fine and coping really well with it all. It was only later, as she neared her fifth birthday, that it began to dawn on me how much things had affected her. The morning of her birthday came, and I was so excited for her to wake up. But when she did, she was withdrawn and silent.



She opened her presents very quietly and spent the day playing with Summer. Later, we lit the candles on her cake and that's when the tears started to flow.

She was so scared. She truly didn't want to blow out her candles due to the thought of turning five. She thought that she'd also get cancer, because of how many children she knew from our oncology family that had been diagnosed as a five-year-old. She was so convinced that it was her turn now she'd reached this age and it took me weeks and weeks to persuade her that this isn't what happens. From then on, I tried to protect her, vowing never to take her along to things like hospital visits. I didn't want her to have to see the horrendous things her sister had to face again.



Sarah McDonald

Childhood cancer is so cruel and really does affect the whole family, siblings included. Thankfully, almost nine years later, Summer, now 14, and Kya, 11, are both doing well. Kya does sometimes struggle, and worries about people being ill, but is coping. She moves up to secondary school this year, while Summer is a typical teenager and spends most of the time in her room! She likes to express herself through drawing, and is very good at art, taking this as a GCSE.

They've been joined by five-year-old Madison and, being totally different ages and personalities, they do bicker and argue. But they love each other and are still always there to support each other. Still best friends.

Our booklet and animation 'My brother or sister has cancer' have been produced especially to support siblings understand what is happening to their poorly brother or sister. Download or order your free booklet or watch the video by scanning the QR code.



What to expect emotionally during your child's treatment



Dr Rob Jobe is a clinical psychologist at Health in Mind, Birmingham Children's Hospital. He spoke to parents about some of the emotions they experienced during their child's cancer journey and offers advice on managing such feelings.

Firstly, I'd like to thank the parents who have shared their experiences and emotions with me – all of which are completely normal to feel – to support other families. The first mother I spoke to said: "At first everything is scary and strange, but you'll soon learn the jargon, the levels, the protocols, chatting over tea about what anti-sickness is best

and what food cupboard to try, whether that be in the parent's kitchen, by the bed of your child or online, you'll soon become the 'mumcologist'." Another parent described treatment as "like being in a river, up to my neck in the water, occasionally it goes over my head, and I cling to the rocks on the side while the current is pulling at me".

The experience of a child's treatment is often moment by moment, "like an emotional rollercoaster with scary stomach-churning moments and then huge highs", one parent said. Another said: "Your plans can change with the beep of a thermometer." I also repeatedly heard from families that change will happen and it alters your perspective. All the families recommended "not fighting those changes but accepting them".

Managing your emotions and support

When I ask parents how they are looking after themselves, typically - and understandably - the answer is: "I am just focused on putting my child first." Caring for a child with cancer is incredibly

draining, but in order to be in the best position to support your child, your own wellbeing needs to be focused on. This might simply start with thinking about small ways to improve your hydration, sleep, diet and fitness, all of which are incredibly important for your emotional wellbeing, while the below advice and resources may also help.

Connect with others

Many families told me that connecting with others going through the same journey can be a real boost. CCLG's Parents and Carers Facebook group allows families to support and interact with each other, sharing experiences and advice.



Scan the QR code to take you directly to our Facebook support group.

Be open and honest with your child about your emotions

I often hear parents say, "I don't want to worry them" or "I don't want them to see me upset." In my experience, children are incredibly perceptive and will pick up on tensions and anxieties in adults anyway. So, without acknowledging this, things can become even scarier for children and can also model them to hide, rather than express, their emotions. Children are likely to be more contained when emotions and feelings are acknowledged. Try this with your child: "I sometimes feel upset and scared and that's ok."

Relationships can change

Relationships are placed under huge strain during cancer treatment. In partnership with Macmillan, Relate (www.relate.org.uk) provides free relationship counselling to

anyone affected by or living with cancer. Relate can help with issues such as:

- ▶ How to express your experience(s) with your friends and family
- ▶ How to talk to children, or parents and other relatives about cancer
- ▶ Challenges in getting 'back to normal' once treatment has ended

SIGNS YOU MIGHT NEED MORE SUPPORT

Parenting a child through their cancer journey is hugely traumatic and emotional, and we often see huge fluctuations in mood for both children and parents in short spaces of time. If, however, the types of changes listed below persist for several weeks, this might be a sign that you could benefit from additional support:

- You're feeling sad all the time, crying a lot and can't be comforted by others
- You can't concentrate, even without distractions
- You're less interested and taking less pleasure in things you used to enjoy
- You're having severe mood swings
- You often feel irritable, upset and angry
- You're having trouble sleeping

If you have any questions or need further support to help with how you're feeling, please contact your hospital's clinical psychology team.



Children, teenagers and young adults UK cancer statistics report 2021

This year, a new cancer statistics report for children, teenagers and young adults was published. This is the first report for almost a decade covering the whole of the UK and the first that covers both children's and teenage and young adult cancers. With input from CCLG professional members, the report was shared at our Winter Meeting in February, and will help us to understand progress in the management of these cancers. Here are some key figures from the report:



EVERY DAY IN THE UK 10 CHILDREN OR YOUNG PEOPLE ARE DIAGNOSED WITH CANCER

There are around 3,755 young people diagnosed with cancer each year in the UK: That's 1,645 in children (aged 0-14 years) and 2,110 in teenagers and young adults (aged 15-24 years).

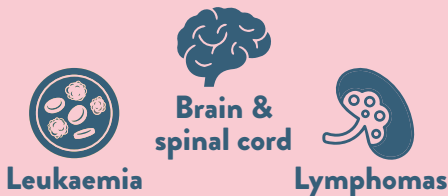


developed cancer compared to one in 490 girls. For young people aged 15-24, it was one in every 360 for males and one in 380 for females.



CHILDREN (0-14 YEAR OLDS)

MOST COMMON TYPES OF CHILDHOOD CANCER ARE:



OF ALL CANCERS DIAGNOSED IN CHILDREN

LEUKAEMIA

is the most commonly diagnosed cancer in children.

TEENAGERS AND YOUNG ADULTS (15-24 YEAR OLDS)

MOST COMMON TYPES OF CHILDHOOD CANCERS DIAGNOSED IN TEENAGERS AND YOUNG ADULTS ARE:



LYMPHOMAS

are the most common cancers in young people.



Cancer in children, teenagers and young adults accounts for

0.3% OF ALL CANCER DEATHS IN THE UK

In 2018 there were around 260 childhood cancer deaths, accounting for 7% of all childhood deaths (0-14 year olds).

For teenagers and young adults (15-24) there were nearly 290 cancer deaths, accounting for 11% of all TYA deaths.

SURVIVAL RATES

MORE THAN
8/10
(86%)

young people diagnosed with cancer survive at least five years, and many of these are cured.

READ THE FULL REPORT HERE:
(Cancer in children, teenagers and young adults ncin.org.uk)



60 SECONDS WITH Dr Shaarna Shanmugavadivel



Research Fellow at the University of Nottingham
and CCLG member, talks to us about her work

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

A: This August marked my seventh year out of the clinical training programme, having graduated from the University of Nottingham in 2009 and starting my paediatric training in the East Midlands in 2011. I've an interest in childhood cancer diagnosis, paediatric emergency medicine, public health and medical education

From 2015, I spent three years as the HeadSmart Fellow working on the award-winning HeadSmart (brain tumour) awareness campaign, which sparked my interest in the early diagnosis of other cancers. I'm currently an NIHR (National Institute for Health Research) Doctoral Research Fellow at the University of Nottingham, undertaking a PhD in childhood cancer diagnosis. I also dabble clinically in the Children's Emergency Department and am completing a diploma in public health.

We're collecting data on all new diagnoses of childhood cancer over a two-year period across the UK in order to understand referral routes and the time it takes for diagnosis.

healthcare professionals for suspected bone and abdominal tumours, and the third part is understanding the public perception of childhood cancer through a series of focus groups.

Q: What inspired you into research?

A: Two incredibly important people. The first is Dr Damian Wood, a paediatrician with whom I did a special study module in my fifth year at medical school. He taught me that much can be learnt through pure observation and that completing the research cycle is important in order to make real change. And, of course, Professor David Walker, whose work has made such an impact on children with brain tumours, especially through translational research and awareness. He's taught me to never give up, and that collaboration is the key to success.

Q: What do you enjoy most about your work?

A: Working with children is such a privilege. They always put a smile on my face and that's why I do what I do!

Q: What part of your work's potential impact are you most excited about?

A: I'm really excited to see the results of the CCD Study and to finally have a national picture of how and where children and young people are diagnosed across the country. Data drives change, and so once we understand this, we can target areas

that need to be improved through whatever means we need to. We know that the earliest possible diagnoses have the best outcomes, and so the impact of making national policy changes to ensure early diagnoses, is the most exciting for me.

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

A: The proudest moment so far was probably securing my current fellowship. Hearing that the NIHR panel agreed that this was a crucial piece of work to fund was a big step forward for childhood cancer research.

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

A: I'm so sorry that you're having to go through this, but every single one of you inspire me daily with your positivity, courage and strength. I know that those involved with childhood cancer research will not stop trying to understand this illness, to ensure other children and young people will have better experiences going forward.



Scan here
to find out more about
the CCD Study.



ASK THE Expert



Dr Amandeep Samrai & Dr Rachel Marfleet

Clinical Psychologists in Paediatric Oncology at Queens Medical Centre, Nottingham

What is life like after treatment has finished?

Adapting to life after treatment can be difficult, and patients and their families may experience a range of different emotions as a result.

Q: While I'm so happy and relieved my child has finished treatment, I'm also sometimes sad, anxious and overwhelmed. Is this normal?

A: Lots of young people and their parents talk about experiencing a complicated range of feelings at the end of treatment - so this sounds completely normal! There's happiness and relief that treatment is over and a hope that life will get better. However, there's also lots of uncertainty with unanswered questions and "what ifs?". For example, parents can feel anxious about fewer hospital appointments and feel sad that the safety net of the medical team is less available. You might also feel anxious about what the future holds, or about scans and your child returning to school. There are a lot of changes that happen in a short timeframe, so feeling overwhelmed is understandable.

Q: Why am I finding life difficult now that my child's treatment has finished?

A: Although the cancer diagnosis and treatment would have been especially difficult and challenging at the start, families tell us that treatment and medical appointments provide structure and something to focus on. The goal is to finish treatment, but sometimes when treatment stops it can feel like a bit of an anti-climax. This might be because you hoped things would go 'back to normal' when treatment finished.

You may also notice that the emotional experience starts to catch up with you when treatment ends and what you've been through really starts to sink in. We hear parents talk about coming off the "rollercoaster" or "treadmill" of treatment, disorientated about what life will now be like. You might have questions about what is possible to do in terms of activities and whether things have changed for you as a family, or if life will be the same again.

Q: How can I overcome any negative emotions and what support can I get to readapt to normal life?

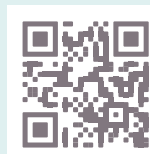
A: We often talk to families about the 'new normal' after treatment. It's a chance to reconnect to people, activities and routines that weren't possible during treatment. The experience of cancer may have led to you reevaluating who, or what's, important. You might feel disconnected from things that used to be normal or from people that don't understand what you've been through. It can be a challenging transition and initially you might draw heavily on the support of the hospital team and as life settles you might notice you turn to family, friends and your community more.

We know this is a difficult time that brings up complex emotions. If you think you or your family would benefit from speaking to a clinical psychologist - someone who can listen independently and draw on their knowledge and experience of adjusting to change - then speak to your team about a referral.



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.



September is Childhood Cancer Awareness Month (CCAM)

Spotting cancer in children and young people can be difficult. Please help us to raise awareness of the common signs and symptoms of cancer in children by sharing our social media posts



Twitter



Facebook



Instagram



LinkedIn

Thank you for your help and support during September ♥

What are the common signs of childhood cancer?



Feeling very tired and/or pale skin



Persistent infections such as ear, throat and chest



Flu-like symptoms that don't go away



Blood in urine, poo or when being sick



Bruising easily or a rash of small red spots



Sweating or fever especially at night



Aches and pains that don't go away, especially in the bones, joints, back or legs, and may be worse at night



Unexplained new limp or leg weakness



Changes when going for a poo such as constipation, diarrhoea, pain or feeling of not having finished



Feeling a lump, swelling or unusual firmness anywhere on the body



Eye changes such as a white glow in the eye (usually seen in photos)



Weight loss or slow growth



Changes in moles in size or colour



Persistent crying and screaming in young children



Brain tumours can cause a number of different symptoms including persistent headaches, dizziness, seizures, clumsiness, off balance and being sick, particularly when waking up in the morning.



www.cclg.org.uk/spotchildcancer



Children's Cancer and Leukaemia Group

the EXPERTS in CHILDHOOD CANCER

www.cclg.org.uk ChildrensCLG CCLG_UK

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