

FREE

SPRING 2022 | ISSUE 94

Children's Cancer and Leukaemia Group | the EXPERTS in CHILDHOOD CANCER

# contact

SUPPORTING FAMILIES THROUGH CHILDHOOD CANCER

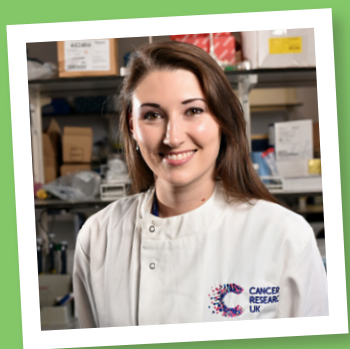
MAGAZINE

## New beginnings

Lee Brennan, lead singer of boy band '911' during the late 1990s, shares how his lymphoma diagnosis as a child influenced his outlook on life.



IMPROVING THE LIVES OF CHILDHOOD CANCER SURVIVORS



**'I DREAM OF HELPING OTHERS LIKE ME'**

Jack Hamilton was seven years old when diagnosed with medulloblastoma in 2010. Now at university, he tells us how he hopes to fulfil his dreams of becoming an oncologist

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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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## KEEP IN TOUCH



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What you had to say...



Here are the results from our Contact reader's survey

Last year, we relaunched Contact with a brand-new design and additional content, so that it was bigger and brighter than ever before. Here's some of the responses we received in our recent reader's survey...

“Informative articles from a broad range of subjects relating to childhood cancer”

“Useful advice”

“Thank you for all you do”

“Good mixture of family and professional stories”

How helpful is Contact's content?



80% extremely and very helpful

How do you rate the variety of articles?

100%

Excellent and very good

On a scale of 1-10, with 10 being the highest, what do you think to Contact's new design?

👍 9/10



Hello!

When one door closes and a new one opens, it's a time of reflection and acceptance as well as the promise of a fresh start and opportunity. After a cancer diagnosis, families are thrown into an unfamiliar and distressing world of hospitals and treatment. It can be hard to close the door on this emotional and often traumatic experience and be able to look ahead. This first issue of Contact for 2022 is on 'New Beginnings' and shows how families and patients can learn to live life again. We hear the inspiring stories of four cancer survivors whose experiences have shaped their chosen career paths. We also learn about the extensive research taking place in long-term follow-up care to make sure all childhood cancer survivors are able to have their new beginnings in life.



Claire [editor@cclg.org.uk](mailto:editor@cclg.org.uk)

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



NEW

## 'Life After Childhood Cancer'

Our new information resource for survivors

### Featuring:

- ✓ Written by clinical experts
- ✓ Information on long-term side effects
- ✓ How to stay healthy throughout life



**FREE to order from our website from April 2022**



## MEDICAL ADVISER

Dr Martin English

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

Every time there is an end there is a new beginning. Some are big, some are small. Some we can choose, some we cannot. Some we can predict, some are unexpected. I regularly meet families and patients who find themselves with an unwanted, unpredictable and unchangeable new beginning when a loved one is diagnosed with a tumour.

I've had the great privilege to look after many of them during their treatment journey and see them after it. And, while there are no quick and easy fixes to make things better, we're fortunate in the UK to have a modern healthcare system that supports patients and families, and the other support networks such as the different charities working to make things better for them. Of course, there's always room for improvement, but things are better than they used to be and without those support networks things would be worse.

I'm coming towards the end of my career and it's good to see how health is improving. Over the past few years, we've seen the start of a revolution in treatment. We now find out more about the genetic make-up of tumours than ever before and this is opening up new avenues of treatment targeting the actual drivers of tumour growth in cells and resetting the immune system. I'm sure we'll continue to see improvements in the second quarter of the 21st century that will be at least as good, and probably better, than those in the first quarter.

So, as we move forward it's helpful to look back at where we've been, and understand what options we do or do not have as we do so. I don't want to give a sermon, but I'm reminded of the writings of two people. Firstly, Reinhold Neibuhr's serenity prayer about being able to accept the things that cannot be changed, and having the courage to change those that can be changed, and the wisdom to know the difference between the two. Secondly, Albert Camus' writings that while we cannot choose to change some things that happen to us, we always have a choice in how to respond to them. This doesn't mean that we can do everything ourselves. However, with family, friends, colleagues, schools and everyone that we interact with and can look to for support in our lives, we can have new beginnings every day.

## NEWS IN BRIEF

### Risk-stratified therapy has positive health impact for survivors of childhood acute lymphoblastic leukaemia (ALL)

Risk-stratified ALL therapy has succeeded in reducing risk for poor general health, functional impairment, and activity limitations among more recent survivors of standard- and high-risk therapy, according to a report from the Childhood Cancer Survivor Study in the USA.

Future research into the relationship between risk-stratified therapy, health status, and late health outcomes may provide new opportunities to further improve late morbidity among survivors.

(Source: American Association of Cancer Research)



### CCLG celebrates 45th anniversary in 2022

In 2022, CCLG celebrates its 45th anniversary. Since forming, many of the key principles of childhood cancer treatment and care have been developed by CCLG and its members, and this year we will be reflecting on our achievements and advances in the treatment and care of children with cancer over the last 45 years.

However, we also know there's so much more to be done. That's why we'll be continuing to drive improvements and influence positive change with investment in pioneering research, professional education and awareness raising, supported by a number of activities, initiatives, campaigns and resources to help change the future for children with cancer.

Follow our social channels for further updates on our 45th anniversary plans and celebrations as the year progresses.

### CCLG funds four innovative projects

We are delighted to announce that we are funding the following important research projects:

- ▶ How cancer-causing genes are switched on or off in children with T-cell acute lymphoblastic leukaemia (Prof Lisa Russell, Newcastle)
- ▶ Does radiotherapy to a child's spleen put them at risk of infections later in life (Dr Henry Mandeville, London)
- ▶ Growing rhabdomyosarcoma tumours in the lab to test new treatments (Prof Janet Shipley, London)
- ▶ Creating a 'living review' of new treatments for rhabdomyosarcoma to keep track of latest updates (Dr Jessica Morgan, Leeds)

Your support helps fund pioneering projects like these – find out more on our website

# “Life is about moments – don’t wait for them, create them”

*Lee Brennan, 48, found fame as the singer of '911' in the late 1990s. He was diagnosed with Hodgkin lymphoma as a 9-year-old, before relapsing aged 15, and he tells us how his cancer experience has influenced a new vocation.*

Having cancer has influenced me in so many ways, from the way I see the world to how I live my life. It made me want to reach for my dreams, to have a ‘feel the fear and do it anyway’ kind of attitude. To seize moments and to be spontaneous.

Lying in a hospital ward when I was really ill taught me many things, not least patience and observance, and about the power of our thoughts and how to use them positively. I’ve always wanted to help people and I think that came from being cared for by doctors, nurses and social workers. I try to uplift others and listen and understand people more. All of this inspired me to study counselling skills at college, to enhance my understanding of ‘helping’ professions. And this spring, I’m launching a nutrition and coaching business, as I feel that everything I’ve experienced and been inspired by will help with my coaching.

**“I live life without being afraid of making mistakes or failing at something!”**

The biggest challenges I faced with cancer were how I saw and felt about myself when going through body changes due to treatment. I became very insular, lacked confidence, and really didn’t like the person staring back at me in the mirror. I hated how I looked and losing my hair was a big thing for me. I used to isolate myself from everyone and it’s something I’m now very aware of as an adult and keep an eye on in case I find myself slipping into that old pattern.

Being patient and kind with myself helped me to understand my emotions and how I saw

myself. Learning to accept what happened to me was such a great thing, as it really set me free from certain feelings that were holding me back in life. Although I can be a quiet person, I’m not unhappy, I’m not too hard on myself anymore and I’m much more comfortable and accepting of myself. Not being able to have children because of cancer treatment was a big emotional hurdle to overcome, but I’ve worked through those emotions with counsellors and learned to accept it and focus on the fact I’m alive, and I have so many good things in my life.

I’m proud I went from the boy who had cancer twice, to the boy in a top selling boyband. But I think what I’m most proud of is how I’ve overcome all the different emotional obstacles that cancer can put in your way. I’m proud of my resilience and strength, how determined I am as a person and how I’ll never give up on myself. I live life without being afraid of making mistakes or failing at something, and I think it’s a positive mindset to have and can open so many doors to a fulfilling life.



Lee during treatment

**“I’m proud of my resilience and strength, how determined I am as a person.”**



Lee Brennan



## “I want to help people in the same situation I was once in”

*Jack Hamilton was diagnosed with a brain tumour in 2010, aged seven. Now at university studying medicine, he explains how he hopes to fulfil his dream of becoming an oncologist.*

The summer of 2010 should have been just another normal summer holiday, and I was looking forward to the added bonus of countless hours of football from the World Cup. However, I spent most of the time lying on the sofa with pounding migraines, and in mid-July I was diagnosed with medulloblastoma following a seizure.

I'd heard of the term 'cancer' but never really understood what it was, nor its potential consequences. Being so young, I was quite naïve to everything that was to come. I believe this was a benefit to myself, as I never really knew what was before me or what I had to face. I was just grateful for the relief from my headaches after my first operation.

Over the next year and a half, each cycle of chemo and radiotherapy seemed to roll into one. There were days where I naïvely felt positive and on the up, only to be demolished the next day as the treatment took effect. It felt never-ending, and something I would seemingly have to live with. It's what 'normal' had begun to feel like to me.

But, as 2011 came, my outreach nurse decided that it was time I tried going back to my primary school, while also arranging a home tutor to help me catch up with missed work. I was

apprehensive that I hadn't seen my classmates in over six months and now had no hair, but I was warmly welcomed by the class who were just happy to see me.

I returned to school slowly by going in for one or two lessons a week, and gradually increased how much I went in. By the end of term, I was nearly back full time, apart from the odd stay in hospital. With the help of my tutor, Liz, I'd quickly caught up with missed work and was ahead of the class by the end of term.

**"Cancer taught me to respect my limits, but at the same time, to challenge and push myself as far as I knew I could."**

In February 2012, I was finally given the all-clear and have thankfully been in remission since. I attended school full time from then on and was nominated as school captain before moving up to high school. Up until this point, everyone in my

school knew what I'd been through and had an understanding of my situation. When I started high school, though, the majority of people didn't know about my cancer diagnosis. They looked upon me as an 'ordinary' pupil just like everyone else, except I'd often be asked what happened to the back of my head, which I'd happily explain. I did find it annoying, however, especially during PE, when I wasn't able to do something as a result of my treatment. I felt as if I was being interrogated by people at times as to why I wasn't taking part. Nevertheless, I knew my limits and wasn't being pressured



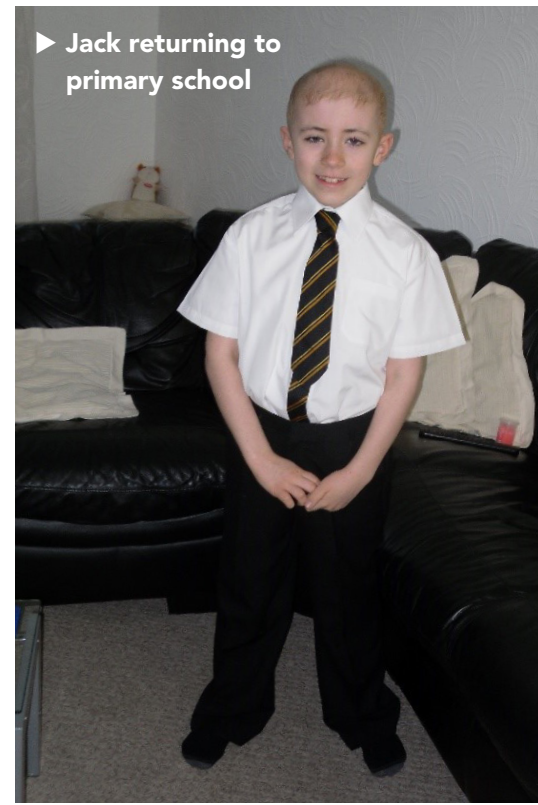
**Jack during his treatment**

into doing something I knew I wasn't comfortable with, or physically capable of. Cancer taught me to respect my limits, but at the same time, to challenge and push myself as far as I knew I could.

Science was a subject I was in love with from the start. I studied physics and chemistry up until S4 when I also picked biology for my exams. I wasn't quite sure what I wanted to study when I left school, though throughout my treatment I'd jokingly mentioned becoming a doctor. At the time, my mum and dad took this with a pinch of salt. They were just delighted that I was healthy. However, having become so enthusiastic about science - and biology in particular - I was determined that studying medicine and becoming a doctor was my calling. After all, I had the experiences that not many others would have. I knew what it was like from a patient's point of view, and I was inspired by those who treated me at the Beatson, Yorkhill, and Southern General Hospitals.

So, in addition to being made school captain again in S6, I was ecstatic to gain the qualifications needed to apply to study medicine, receiving offers from Dundee, Aberdeen and Edinburgh. I also received an offer from Glasgow for the access to medicine course, which I was delighted to accept in the hope of studying medicine at my home university. The course helped me gain essential experience and I made friends with whom I hope to transition into medicine. I'm pleased to say that I passed with distinction and began studying medicine at Glasgow University in September 2021.

I'm now working hard towards my dream of one day becoming an oncologist and emulating those who inspired me during my own treatment. I want to help people in the same situation I was once in, using my experience to treat patients with a greater deal of understanding and empathy. And more than that, I want to provide hope and inspiration to children and families who are going through such challenging times.



▶ Jack returning to primary school



▶ Jack at high school being awarded team captain

I knew what it was like coming from a patient's point of view, and I was inspired by those who treated me at the Beatson, Yorkhill, and Southern General Hospitals.



# ALLTogether-1 trial: Finding more effective leukaemia treatments for children



ALLTogether-1 is an international clinical trial looking at improving treatment for acute lymphoblastic leukaemia (ALL). **Dr John Moppett**, who oversees the trial in the UK, explains more.

The treatment of ALL is a massive success story. In 60 years, we've moved from facing a uniformly fatal condition to one where we can cure more than 90% of children and young adults. Progress has been made through the repeated study of potentially better alternative treatments through clinical trials that are run across the world. Two factors are key to this:

- ▶ **Best use of conventional chemotherapy drugs** – learning what dose and what schedule works best for each drug and in what combinations.
- ▶ **Risk stratification** - treatment of leukaemia is potentially toxic and for many years now we've used multiple factors to work out how likely an individual patient's disease is going to respond to treatment (for example: age, white cell count, genetic mistakes found in the leukaemia cells, response to early treatment). This has been critical in helping us to reduce the toxicity of treatment for many patients, whilst still targeting the most intensive and usually toxic therapies at those with the most difficult-to-treat disease.

## Collaborating with international colleagues

Until recently, the UK has run its own series of ALL clinical trials, that have been very successful in answering questions and improving outcomes. But several years ago, we decided that collaborating with European colleagues was the best way forward, mainly because we need really large numbers of patients to answer our questions.

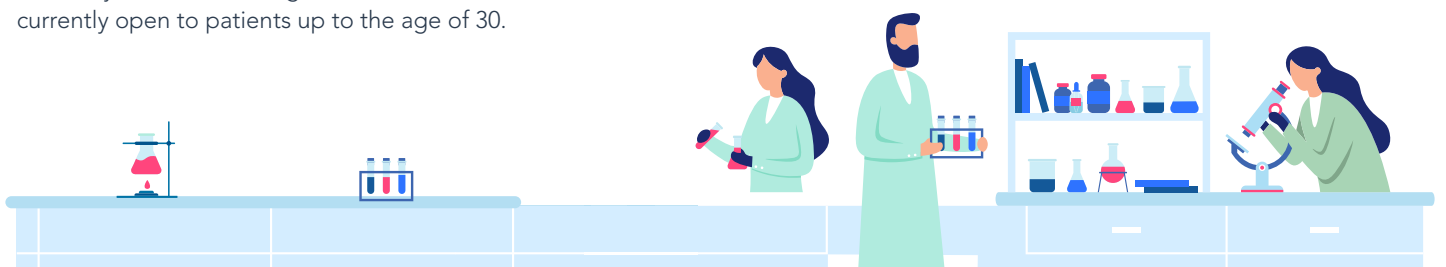
Over several years, meetings were held with other international groups to develop a joint protocol called the ALLTogether-1 study, which is a collaboration between 14 countries and will recruit nearly 8,000 patients over its six-year duration. It opened in 2020 in a few countries, and in limited UK centres in mid-2021. We're now in the process of opening the study across remaining sites here in the UK, where it's currently open to patients up to the age of 30.

## What do we want to know?

- ▶ Many children with ALL have very curable disease and we believe they can still achieve cure with less treatment – which, in turn, should lead to less toxicity from treatment (particularly severe infections but also other specific drug side-effects). For this group (around half of all patients), we're asking whether small reductions in how much chemotherapy they receive can be done safely.
- ▶ There are still some (individually rare) groups of children with ALL who are more challenging to cure, and we want to improve their chance. We're studying targeted immunotherapy drugs such as inotuzumab and blinatumomab, and drugs targeting specific genetic mistakes in the leukaemia cells in some of these children, to see if they reduce the risk of relapse. Some patients with very high-risk disease are directed towards separate studies of cellular immunotherapy.
- ▶ To ask these questions at the same time, it's critical that we know which group an individual patient should be placed in. To do this, we've developed a world-leading stratification system which we believe is the most accurate in the world.

## Helping further studies into ALL

Through leukaemia samples kindly provided by participants, the study presents an amazing opportunity for scientists to learn more about ALL: why it happens and how to treat it more effectively. We're also studying better tests to identify those with a greater risk of relapse and better ways to look after patients during treatment. For example, the closely-related CiproPAL study led by Dr Bob Phillips will look at whether antibiotics to prevent infection in the early stages of treatment are beneficial.





# Understanding late effects to improve the lives of childhood cancer survivors

*Dr Rachel Cox, is a consultant paediatric oncologist and Chair of CCLG's Late Effects Group. She tells us what late effects are, and how the work of the group is helping to improve the quality of life for survivors of childhood cancer.*



Dr Rachel Cox

There are over 35,000 survivors of childhood cancer living in the UK today and this number is growing. Through the shared experiences of survivors and long-running research studies comes the knowledge of the impact of cancer treatment, known as 'late effects'. As more and more young people survive their cancer, this knowledge continues to grow.

## What are late effects?

Late effects can be physical, occurring in any organ or body system, or psychological. They can occur because of the cancer, its treatment, related illness, an underlying condition or because of treatment-related complications. Risks of treatment are discussed with parents at the time of consent and are monitored or screened for when treatment ends. Late effects monitoring for any survivor can be predicted by knowledge of their treatment – 'treatment summary' – and should be planned for according to an individual 'care plan'.

## Who supports patients with late effects?

The role of the late effects or aftercare team is to help hand over information, learnt by the parents at the time of consent for treatment, to teenage and young adult cancer survivors to empower them to look after their future health. They provide a monitoring plan for late effects, promote healthy lifestyle choices and provide a key point of contact for survivors for advice about future problems. Education and signposting for both survivors and other healthcare professionals they may meet throughout life is a particularly crucial role. To deliver survivor support, late effects teams throughout the UK offer flexible methods of contact through email, telephone, and more traditional clinic appointments. The late effects nurse is pivotal in this role.

## About the CCLG Late Effects Group

The CCLG Late Effects Group was formed over 20 years ago to provide a voice for professionals involved in delivering care for or studying the late effects of treatment across the UK. Membership of the group is varied and includes survivors, doctors, nurses, allied healthcare professionals, scientists, and trainees, all of whom have a passion for improving life after childhood cancer.

The group aims to share and promote best practice in the UK, to advocate for and empower survivors of childhood cancer locally, through team members' clinical practice, nationally and internationally through links to PanCare, our European partners, and to assist in development of high-quality international guidance through the International Guideline Harmonization Group.

The group provides high-quality education for healthcare professionals (free to CCLG members) through a lecture programme and promotes research to improve the long-term health outcomes of childhood cancer survivors. A series of virtual talks for survivors is planned for 2023.

Late effects can be physical, occurring in any organ or body system, or psychological.

The impact of cancer treatment on fertility is one of the most common and important concerns raised by adult survivors of childhood cancer and group members have been instrumental, together with experts in fertility preservation, in developing new guidance for treating teams to preserve the fertility where possible of children currently undergoing treatment.

Above all, the group members are stimulated by the experiences of young people and adults under their care. They listen to their achievements, their hopes, dreams and fears and use those experiences to help others. The group would welcome other survivors of childhood cancer who wish to offer their time or experiences in ways that would benefit the community.



For more information please email at [info@cclg.org.uk](mailto:info@cclg.org.uk)



# Preserving fertility in young people with cancer

*Professor Hamish Wallace is a Consultant Paediatric Oncologist at the Royal Hospital for Children & Young People in Edinburgh and honorary professor at The University of Edinburgh. He explains what fertility preservation options are available for young cancer patients.*

For children, young people and their families, a diagnosis of cancer is both devastating and frightening. The future is uncertain and there is so much to quickly learn and understand. Most young people with cancer will start a treatment plan with a combination of chemotherapy, surgery and sometimes radiotherapy. Doctors will explain the nature of their cancer and, if it is a solid tumour, will investigate whether the tumour has spread elsewhere throughout the body. This involves tests, scans and assessments as part of diagnosis which can take time and can be an anxious wait for families. There is lots of information to take in at once and it can be difficult to think ahead to the future when a young person may want to start a family of their own. However, families are asked to consider this possibility before treatment even starts.

## Talking about fertility preservation with families

As we expect most young people with cancer to be successfully treated and go on to lead a healthy life, it is important that a discussion takes place as soon as possible about how the intended treatment might affect their future chances of either fathering a child or having a baby.

While many cancer treatments are unlikely to affect fertility, there are some treatments that can cause long-term or permanent damage to fertility. As such, it is important for all young people with cancer and their families to have the opportunity to discuss their future fertility prospects with their doctors and nurses before treatment begins. This discussion is seen as a positive one

because the doctors and nurses believe it is important to the child or young person's future, and that the opportunity to either father a child or have a baby will matter to them in later life.

## What can be offered to girls and young women to preserve their future fertility?

Fertility preservation means storing one of the following before treatment:

- eggs
- embryos (eggs fertilised with sperm)
- ovarian tissue

If there is a high risk of infertility and premature ovarian insufficiency (POI, or premature menopause), there are both established and experimental options.

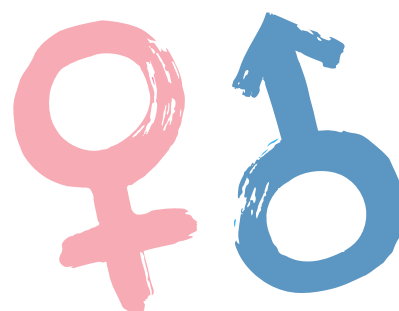
**For older girls who have undergone puberty and have a partner,** they can be referred to an infertility unit to start hormone treatment to mature an egg. This egg can be taken out and fertilised with their partner's sperm to create an embryo which can then be frozen and stored. 'Embryo freezing' is very successful; they can survive for many years, and after thawing placed back inside of the uterus for fertility long after cancer treatment is completed. This fertility option can only happen if enough time is available before treatment starts.

**For older girls who have undergone puberty and do not have a partner** which is more common, there is the option of 'egg freezing'. New egg freezing techniques (vitrification) are improving the chances of a frozen then thawed mature egg of being successfully fertilised to create an embryo, which

can then be placed back in the uterus in the hope of successfully achieving pregnancy. However, there needs to be time to delay the start of the cancer treatment so the patient can receive hormone stimulation and egg collection in the infertility unit. This can take at least two weeks.

**For younger girls who have not started puberty** but are at a high risk of infertility and POI ovarian tissue, 'cryopreservation' can be considered, though this remains experimental. It is an additional keyhole surgery procedure under general anaesthetic. Either samples of ovarian tissue can be taken from one ovary and frozen, or a whole ovary can be removed, and then frozen in the laboratory. Later, when the young woman wishes to start a family, the tissue can be thawed and transplanted under a general anaesthetic into her pelvis.

We don't yet know how successful this procedure will be in preserving fertility for pre-pubertal girls, but there have been several hundred babies born worldwide after the transplantation of frozen thawed ovarian tissue taken from post-pubertal women. This gives us good reason to hope that it is likely to be successful and allows the young woman the chance of a pregnancy, once she is cured of her original cancer.



## What can be offered to boys and young men to preserve their fertility?

For young men with a new diagnosis of cancer who have undergone puberty and are able to masturbate and produce semen before starting their treatment, we offer all patients 'semen cryopreservation', which is established and successful, even if there is a low risk of infertility. The sperm can be safely frozen for many years and once thawed can be used to fertilise an egg using in vitro fertilisation (IVF). Usually, semen samples are provided by masturbation in a private room in the fertility clinic.

Some young men are unable to produce samples by masturbation, but it may be possible for a specialist doctor to collect sperm from the testicle under sedation or a general anaesthetic. It is not recommended to bank sperm after chemotherapy has started.

Freezing sperm is a positive thing to do, but it is not easy having received the news of a cancer diagnosis and that treatment is needed with lots of potential side effects. It can be difficult for young men to go to the infertility unit and produce a semen sample when they feel ill and scared. Hospitals where young men are being treated for cancer offer this service and have appropriate counselling

available to support these young men at a very difficult and challenging time.

**For younger boys who have not started puberty but are at high risk of infertility**, there are currently no established options available. In some hospitals, under the process of a clinical trial, a pre-pubertal testicular biopsy and freezing is being offered. This is carried out by a paediatric surgeon under a general anaesthetic. We do not yet know if this frozen pre-pubertal tissue will preserve future fertility, and this is an important area of active research.

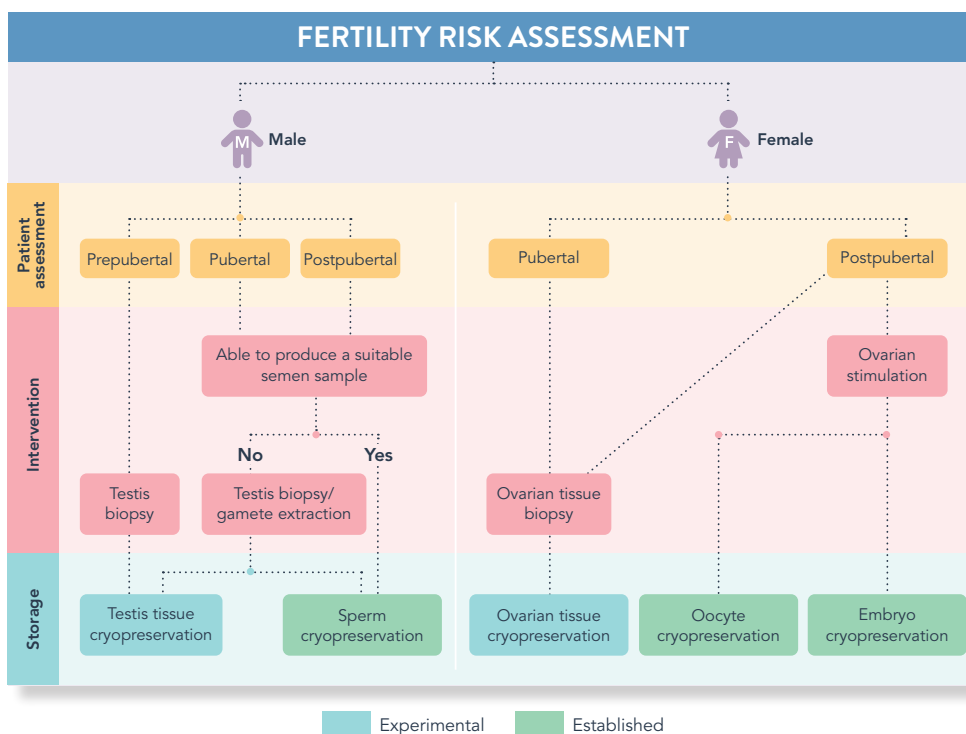


### BOYS

In boys who have not started puberty, testicular biopsy and cryopreservation is an experimental option. In boys and young men who have started or undergone puberty, the ability to produce a sperm sample enables sperm cryopreservation: if this is not possible, testicular biopsy with cryopreservation of sperm or tissue is needed.

### GIRLS

In girls who have not started puberty, ovarian stimulation is inappropriate, so ovarian tissue cryopreservation can be considered but remains experimental. After puberty, egg or embryo cryopreservation is an established option.



### Useful links

[www.tyac.org.uk/fertility](http://www.tyac.org.uk/fertility)

[www.macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/fertility-in-women](http://www.macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/fertility-in-women)

[www.macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/fertility-in-men](http://www.macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/fertility-in-men)

Source: Anderson RA et al. (2015) *Cancer treatment and gonadal function: Experimental and established strategies for fertility preservation in children and young adults. The Lancet Diabetes & Endocrinology*, 3(7): 556-567.

# How my cancer journey led me to a career in research



Dr Catherine Pointer  
Photo credit: Cancer Research UK

*Dr Catherine Pointer was diagnosed with leukaemia in 2006, aged 14. She tells us how her experiences inspired her to become a cancer researcher, working alongside one of the doctors who treated her.*



▲ Catherine in hospital as a teenager

It was on a family holiday in 2006 when I suddenly became ill. I couldn't stand without fainting and lost a huge amount of weight. When we got home, a domino effect of tests and being transferred to different hospital departments began. After several weeks of testing, I was moved to Piam Brown Ward at Southampton General Hospital, and was eventually diagnosed with acute myeloid leukaemia (AML).

In the first weeks of treatment, my consultant noticed my reaction was different to that of other teenagers. While others asked, "Why me?", I was asking, "How me?". How does a healthy 14-year-old with no family history of cancer, get leukaemia? I would sit with my doctors and they would answer my questions as best they could, but there would always come a point in the conversation where the answer would be "no one knows, that's what research is trying to find out". It was in these conversations with doctors and scientists that I realised I could become a scientist myself. But as I realised this, my education was falling by the wayside, and I missed Year 10.

After four cycles of chemotherapy, I went into remission and returned to school. With the help of some awesome teachers, I managed to scrape decent grades in my GCSEs, which was enough to be accepted onto science courses for my A-levels. However, the leukaemia suddenly returned after my first year of A-levels and I had to take a full academic year out to have a bone marrow transplant.

None of my family were a match for me, but when a donor was found I was warned that the transplant would be the hardest treatment yet. Indeed, it was. It was the only time in all my treatments that I ever contemplated giving up. It seems horrifying to say that 12 years on, knowing how well things have turned out now. But at the time I'd been so unwell for so long that it was hard to imagine it would ever end. One of the hardest parts of cancer treatment is just how utterly relentless it is, and it's something few understand unless they've experienced it themselves. It wears the whole family down. But we tried to focus on one day at a time and clung on to the hope that I'd eventually start to improve.

### Looking to the future

When I returned to college, I knew I wanted to study biomedical science at university and even cited my illness as work experience in applications. Though my immediate family were very supportive, sadly many people were of the view that I shouldn't bother and should simply "just go and get a job". School and exams are difficult enough at the best of times.

When cancer strikes, it seems logical to many people that you should cut out anything else which is causing you stress.

It's a major unspoken challenge young cancer patients face, but I found this attitude completely unjust. Having just fought for my life, why should I now limit myself for the rest of it? Cancer presented itself to me as a problem and I wanted to do something about it. And, while I often cursed the stress, it all became worth it the day I finished my PhD.

I did think carefully about whether I wanted to work in cancer research. Did

I really want my career to be all about a disease which had already dominated so much of my life? But during my degree I did work experience in the lab of a consultant who had looked after me, and cancer became the subject which interested me the most. After completing my degree, I did my PhD at Southampton, back in the hospital which I'd once called home.

### My research interests

Since finishing my PhD in 2019, I've stayed at Southampton Hospital, working for the Cancer Research UK Experimental Cancer Medicine Centre, where I am a lead scientist and research fellow for cancer clinical trials. The best thing about my job is that I'm quite literally improving cancer medicine on a regular basis. The treatments I had 12 years ago are much improved now. All of our trials are immunological, using and educating a patient's own immune system to diagnose and treat their own cancer. My favourite trial at the moment is of

a blood test which can diagnose lung cancer up to two years earlier than the current method of a CT scan.

Sharing my experiences with cancer has been important to me since finishing my PhD. I've always wanted to reach out to other people, and show others that even cancer can open new doors. Previously, I didn't personally know anyone else in research who'd also had the disease as a child. But recently we had a new member join our team for a placement year as part of her degree, who was also treated for leukaemia on Piam Brown and now wants to work in research as well.

It's an absolute privilege to be in the position I am in today, supporting others in establishing a career, as well as improving cancer medicine. I'm very grateful to have made the most of the cards I was dealt, and I hope others can see that they can do the same.



▲ Catherine (right) and colleague Macy who was also treated for cancer on the same ward

“Sharing my experiences with cancer has been important to me since finishing my PhD. I've always wanted to reach out to other people, and show others that even cancer can open new doors.”



# Hope after loss

**Gayle Routledge**, mum to Lewis who sadly died of cancer aged two in 2010 and founder of bereavement charity **A Child of Mine**, tells us how his memory inspires all that she does now.



Lewis and Gayle

In 2008, our world was turned upside down when our eight-month-old son Lewis was diagnosed with an aggressive cancer called neuroblastoma. We were thrown into a journey of hospital stays, chemotherapy, scans, and trying to juggle life between treatment and our eldest daughter Georgia, who was five at the time and about to start school.

Lewis's treatment was intense. However, he took it all in his stride, he responded well and always knew how to charm the nurses. Neuroblastoma only affects around 100 children a year, and presents with solid tumours that spread through the nervous system. We knew Lewis's prognosis was poor due to his staging, yet as a family we remained positive, which I think was very much a coping mechanism. We knew only too well the severity of his disease, but being positive helped us deal with his condition. Plus, this was our son. We could never give up.

Almost a year to the day Lewis was diagnosed, we were told that his cancer was back. The relapse hit us harder than his initial diagnosis, as we knew there was no cure for relapsed neuroblastoma. We still remained positive as there were some treatment options available to us. Those treatments didn't work as well as we

would have hoped and in January 2010, we were told that Lewis was palliative. We did have a treatment to try in London which was radiation therapy, but when we were there, we learned the cancer had moved into his brain. I think it was that moment that I actually accepted Lewis was going to die.

Lewis came home from London and was offered external radiation but the cancer was progressing and his little body couldn't take much more. On 3 July 2010, Lewis died peacefully in my arms at Birmingham Children's Hospital.

**"We use his strength and his amazing spirit to inspire us"**

This may be difficult to read but, for us, it was a relief to see him out of pain, he'd endured so much in the two years since his diagnosis and he was now at peace. We strongly felt that we would rather have had Lewis in our lives even for short time, than to never have had him at all. Lewis taught us a lot and as our new life into bereavement started, we tried to remain positive for him, as we believe there's always hope.

After Lewis died, we highlighted an unmet need in support for bereaved parents, and I really wanted to address that gap. In 2013 I founded **A Child of Mine**, a registered charity offering support to bereaved parents who have lost a child at any age and from any circumstance. A charity that gives hope after loss and shows parents that you can learn to smile again and not feel guilty. The charity helps guide parents through their grief and we're very proud to have helped so many families in their darkest times.

I can honestly say that I'm at peace with Lewis's death as I see the incredible legacy that he has left. Of course, life will never be the same without him and we'll never allow him to be forgotten. But we use his strength and his amazing spirit to inspire us to be like him. We have to take hold of life and make the most of what we have. It's not easy but we can learn to enjoy life again.

Find out more about **A Child of Mine** by scanning here:



[achildofmine.org.uk](http://achildofmine.org.uk)



# A parent's view...

## Learning to live again

**Sinead Wood's** son Cillian finished treatment for T-cell lymphoblastic lymphoma last summer. She writes on how it took time for her and her family to adjust to life after treatment, and offers advice to others trying to do the same.

My name is Sinead Wood, mum to two beautiful twin boys Oisín and Cillian. In 2017, at the age of seven, Cillian was diagnosed with T-cell lymphoblastic lymphoma. For the next three-and-a-half years, he would undergo treatment and it was the hardest thing we as a family had ever done, but we did it - he did it!

I say "we" because when your child is diagnosed it truly affects the whole family. I used to feel selfish for feeling down, upset, tired or frustrated, but we as parents take on every bit of our child's pain and it really does have a long-term effect on your own mental health, too.

Eventually, it did become easier and we quickly returned to being a 'normal' family again, but it was tough in the beginning. It really does get better but there is a process.

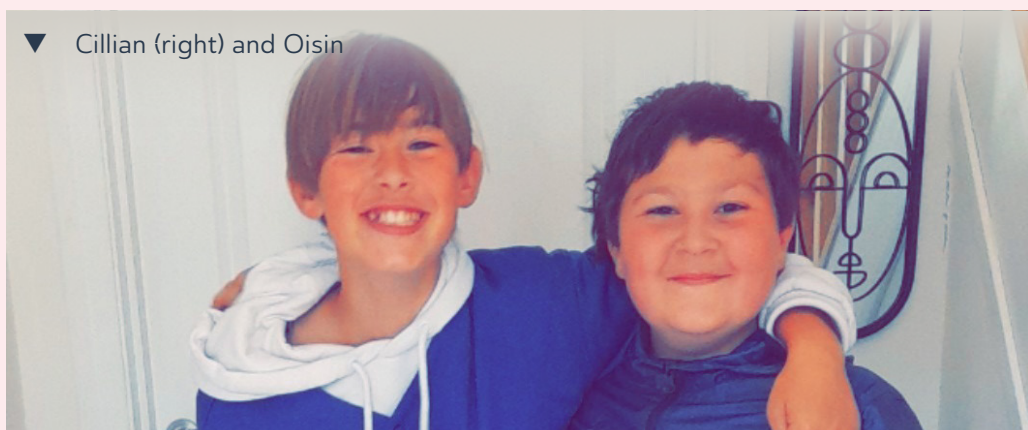
I'd become so anxious by the time Cillian finished treatment in the summer of 2021. During the last few months, I had so many questions and worries running around my head: How will this boy survive without chemo every day? How will I know if it's back? Who am I now, if not a full-time carer with thoughts of hospital appointments and medication times? How can I unlearn everything I've been doing religiously, for the last three years?

I thought it would be the best day ever when Cillian finally got to ring the bell, but when it arrived, it didn't feel like that. We said goodbye to nurses we had built a friendship with, nurses who'd seen

the darkest side of us and knew things we hadn't even told family members. We also said goodbye to other families going through the same journey, wondering if, and hoping, they will one day ring the bell too. And I was still so flooded with anxiety, about what lay ahead.



The first few weeks were awful - every bruise, headache or slight temperature I was straight on the phone to the hospital thinking the cancer was back. They'd explain that this was normal and reassured me that they'll always be there to help. Eventually, it did become easier and we quickly returned to being a 'normal' family again, but it was tough in the beginning. It really does get better but there is a process.



▼ Cillian (right) and Oisín



Sinead Wood

I found helping to spread awareness and giving back to charities really helped me, it gave me a way to focus and to talk, and I knew I was helping in some way.

Being kind to yourself and trying to enjoy life is also so important, as is being proud of all that you've achieved as a family, too. You don't have time to think of how much your life is changing when your child is diagnosed, as you get thrown into it and everything happens so quickly. So, when that comes to end, spend time looking back and reflecting on all you've accomplished.

Cillian has just celebrated his 11th birthday with his first-ever sleepover. He's now also finding his own personality and building a new life for himself, which is lovely to see. And though our kids - and us - will never be the same as before the diagnosis, that's not always a bad thing. They have compassion for others, empathy, and they'll always know that life is so precious.



# Accepting the past and looking to the future

**Cara Smith** was diagnosed with a brain tumour as a toddler. Here, she tells us how the past is helping shape her future.

My name is Cara. I'm 19 years old and was diagnosed with an optic pathway glioma brain tumour at the tender age of 21 months. Growing up hasn't been an easy journey, with many trips to hospital, numerous rounds of chemotherapy, periodic medical interventions, several operations, and more.

Over the years, I've also faced many prejudices and at times my cancer has been something of a stigma. If you're disabled, or have medical conditions, some people form opinions of you. Having not been through a similar situation, they might not understand who you are or what you are capable of and this has been a huge hurdle I've had to overcome. But just because some people may have certain assumptions, it doesn't mean you're less worthy or capable of achieving anything you desire to.

When I was 14, my teachers implied it was highly likely I'd fail my GCSEs because I'm blind and had missed a lot of school because of health complications. This made me feel extremely sad and worthless, and that I was never going to accomplish my dreams and fulfil my aspirations. But me being me, with a burning passion inside, I was determined to prove them wrong!

I moved to a new school for children and young adults with varying degrees of visual impairments. It was a place where

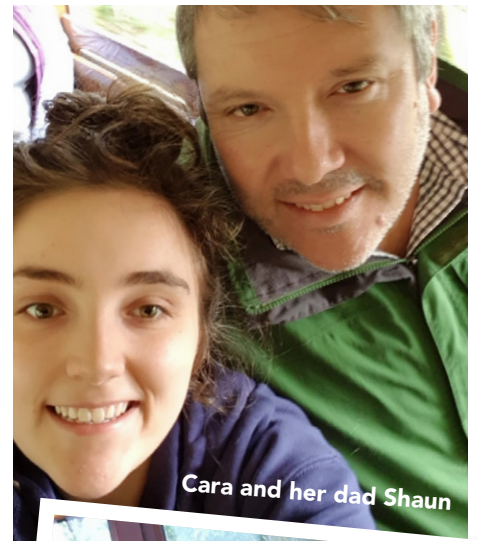
teachers helped you strive to do and be anything you dream of and, more importantly, to believe in yourself. I'm proud to say that with their support, I passed every exam! From then on, I started to believe in myself more and realised there was hope for the future. It was a fresh chapter, and the new and exciting beginning I'd been craving.

I'd be lying if I said my journey hasn't been a challenge, but I strongly believe my tenacious personality and optimistic outlook on life from an early age has helped me through. Sure, I've felt isolated from the world and often wondered what it would've been like to have been young and free as a child, instead of being so 'different' to others my age. But that's my journey and it's made me stronger and hopefully much more understanding as a person.

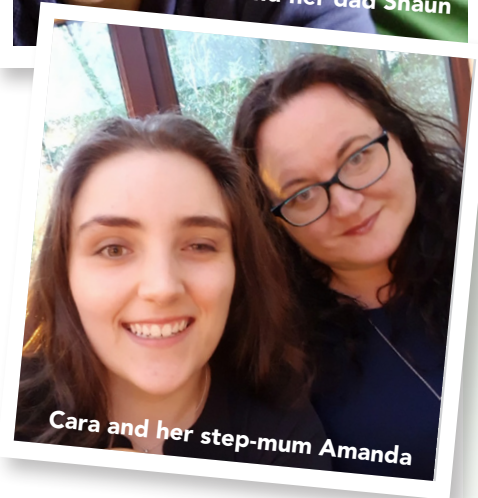
I'd be lying if I said my journey hasn't been a challenge, but I strongly believe my tenacious personality and optimistic outlook on life from an early age has helped me through.

It's taught me a lot, too, not least that it's crucially important to live every day as if it's your last. By that, I mean not wasting precious time and energy worrying about things we can't change or control. Equally so, we shouldn't be worrying about what may or may not be in store for us.

I've also learnt it's important to accept the past for what it is and move on. I try to live my dreams and be the best person I can be and, despite some of the hardships I've faced, I try not to



Cara and her dad Shaun



Cara and her step-mum Amanda

be bitter, as it can eat you up inside. Instead, I focus on the future, taking small and steady steps to make it a brighter and happier place for everyone.

My advice to others is to enter into new things with a fresh outlook and an open heart. Try and wish everyone well, even those who've made you feel angry and upset. Give and accept love and have respect for yourself and others. Once you grasp the art of doing this, in my opinion, you're halfway there.

And just remember: you are loved, you are strong, you are brave and you will get there - wherever there may be!



▼ Cara in hospital





# Understanding the challenges of growing up with treatment-related hearing loss

Our research projects cover the whole cancer journey from learning about how cancer cells grow to improving everyday life for patients and survivors.



## Living with treatment-related hearing loss: Experiences of survivors of childhood brain cancer

- ▶ **LEAD INVESTIGATOR:** Dr Carmen Soto (pictured left)
- ▶ **INSTITUTION:** Great Ormond Street Hospital (GOSH)
- ▶ **AMOUNT AWARDED:** Approx £14,600 (funded by CCLG's Late Effects Project Grant)

Hearing loss is a recognised side effect of some cancer treatments, like chemotherapy and radiotherapy, and children and young people who are treated for brain tumours are at particular risk of developing hearing loss, because of both the disease and the treatments that are used. Treatment-related hearing loss can develop during the treatment or afterwards – sometimes after many years.

Research has shown that hearing loss in childhood is linked to a number of problems including language, school performance, social interactions, emotional difficulties and quality of life. Children learn to live with their hearing loss in different ways, supported by family, schools, and healthcare workers, who help them to overcome some of the problems linked to it in childhood.

We understand a little about the effect of hearing loss on children who have been treated for a brain tumour, like how they seem to have the same difficulties as other children with hearing loss. We know hearing problems during childhood can make some things harder – such as developing language skills, managing at school, or making friends. But we don't really know what it's like to live with this hearing loss if

you're also dealing with growing up after brain tumour treatment. This is really important because having a brain tumour in childhood can lead to lots of other complications or challenges, like problems at school, or poor eyesight. Children and families also have to deal with managing 'normal' life after cancer, and coping with other late effects of treatment.

This research study is hoping to find out what it's really like by speaking to children, young people and their families about their experiences and the challenges they face in everyday life – and also the solutions that they've found. We know that they are experts in finding ways of making everyday life work for them, even when things get really tricky, and we think this is true for those children and young people living with treatment-related hearing loss as well.

We want to learn from their experiences so that this expertise can be shared with other families in a similar situation – rather than them having to work everything out themselves. We can also make suggestions for how things could work better, based on real experiences.

### Interested in learning more?

If you're interested in learning more or in taking part in the study, please email [carmen.soto@nhs.net](mailto:carmen.soto@nhs.net) for more information (participants have to be <19 years old and have finished treatment five years ago).



[www.cclg.org.uk/  
our-research-projects](http://www.cclg.org.uk/our-research-projects)



# 60 SECONDS WITH Professor Kathy Pritchard-Jones



The President of International Society of Paediatric Oncology (SIOP)  
and long-standing CCLG member, talks to us about her work.

## Q: Tell us a little about your career...

**A:** My interest in childhood cancer was kindled as a junior doctor in Newcastle, working with Professors Alan Craft and Andy Pearson. Moving to Edinburgh, I undertook a PhD on Wilms tumour genes. This combined my interests in paediatrics and molecular biology and cemented my lifelong commitment to understanding why children develop cancers and how to treat them more effectively. I established a research group at The Institute of Cancer Research, finishing my clinical training in paediatric oncology at the Royal Marsden with Professor Ross Pinkerton.

In 2010, I moved to a new role to provide clinical leadership for transformation of cancer services for patients of all ages, uniting 11 Trusts in north London. My experience of international collaborative networking came in very useful, keeping the focus on improving whole pathways of care and outcomes that matter most to patients and families.

## Q: How far have things come for childhood cancer treatment and care, and where do you see things going?

**A:** Survival rates have improved hugely over the last 20 years from 70% to nearly 85%. This is driven by more sophisticated use of existing treatments based on a child's individual risk and stronger multi-disciplinary team working and international collaboration. The introduction of molecular biology into diagnosis, choice of treatment (type and strength) and the assessment of how well a child responds to their treatment have all had a big impact.

The identification of specific molecular drivers that enable the discovery of drugs with clearly defined targets has had - and will continue to have - a major impact on treatment options for different sub-types of childhood cancers. This should result in safer, kinder and more effective therapies for all cancers.

Early diagnosis is key to improving outcomes. Raising public and healthcare professional awareness and providing clear and quick routes for assessment of potential cancer cases are key to this. I expect that even prevention of certain childhood cancers may become possible in the next decade, with increasing knowledge of molecular drivers and their control pathways.

## Q: What area of your work excites you most?

**A:** Measuring outcomes that matter to patients and understanding the reasons for variation. Data might not sound exciting but it underpins all the evidence on which we base our decisions. My current focus is on maximising what can be learned from reusing the existing information gathered from clinical trial databases for international benchmarking, and on collaborative work between population-based cancer registries (which collect information from people diagnosed with cancer who live within a defined geographic location). Around the world there are large differences in survival chances - some reasons are well understood while other variations are more subtle which need evaluating further.

I'm also excited by the potential to bring together data and information collected from cancer registries in the UK, Europe and beyond. It should become possible to evaluate children's

outcomes across their whole life, to discover if the treatment choices we recommend on their behalf today are the best ones for their adult life.

**“Early diagnosis is key to improving outcomes. Raising public and healthcare professional awareness and providing clear routes for timely confirmation or exclusion of cancer are key to this”**

## Q: What is the proudest moment of your career?

**A:** I was incredibly humbled to be elected President of the International Society of Paediatric Oncology (SIOP) in October 2019, enabling me to represent the global paediatric haematology-oncology community in dialogue with the World Health Organisation (WHO) and many others, especially in response to the COVID-19 pandemic.



# ASK THE Expert



**Nicky Webb**, Clinical Nurse Specialist for the long-term follow-up of survivors of childhood cancer and joint Chair of the Children's After Cure Nurses UK Group.

## What are long-term follow-up clinics?

Long-term follow-up clinics, beginning approximately five years post-treatment, help detect and manage any problems caused by a young person's cancer or its treatment, to ensure the best possible quality of life for patients.

### Why do we have long-term follow-up clinics?

As children and young people reach around five years on from the end of active treatment, the focus moves from monitoring the risk of recurrence to observing late effects of cancer and/or its treatment. Attending long-term follow-up clinics helps families move forwards as the appointments focus on growth, educational needs and reaching developmental milestones, like puberty.

Families have a key worker allocated who they can contact to help with the transition from off treatment follow-up, plus ongoing psychological support is in place as patients move through adolescence into adulthood. Links to other services can be made and there's a huge emphasis on the importance of educating patients in relation to maintaining a healthy lifestyle to help reduce risks of developing second cancers and other health-related problems.

### What can patients expect?

Your consultant will talk to you about moving care across into long-term follow-up (with either another consultant or, for many patients, within a nurse-led service). Visits tend to focus on any late side effects of treatment so they can be spotted early and treated quickly. This can be daunting, but it's important that all children and young people are given this information and supported as they move towards their own independence, and transition back to their GP.

Growth measurements will usually be recorded until the patient turns 18. Blood tests and scans will also be repeated occasionally. Every patient receives a detailed care plan which lists all future surveillance and other healthcare needs. This information will be discussed, together with why they're important in ensuring ongoing good health. Services also provide support with education, benefit reviews and psychological needs.

Appointments are usually just once a year and can be slightly longer than previous clinic times.

### Why are they important?

As children and young people approach independence and start taking control of their own personal life choices, it's hugely important that they're given information surrounding their diagnosis and treatment so they can make informed choices. Monitoring late effects ensures early detection of potential problems and intervention, if necessary. Some centres will accommodate appointments around key times in education to avoid further disruption and, if possible, see young people during holidays.

### What happens when children become adults?

Not all patients need to continue attending regular hospital appointments, many can have their follow-up with their GP. This will be discussed very early on, so everyone, including GPs, is aware of future transition plans and long-term requirements. Many centres now offer 'patient-initiated follow-up', so even after transitioning back to your GP you can re-engage at any time.

There are a group of patients that, due to the complexity of their treatment or consequences of surgery, require ongoing consultant follow-up. They'll be made aware of future transition plans into a specialist adult service or an adult long-term follow-up service for survivors of childhood cancer.

*Have a question to ask one of our experts?*

Please get in touch by emailing [info@cclg.org.uk](mailto:info@cclg.org.uk) or via DM on our social channels. We may feature your question in a future 'Ask the Expert' to help other families and patients who have the same question.



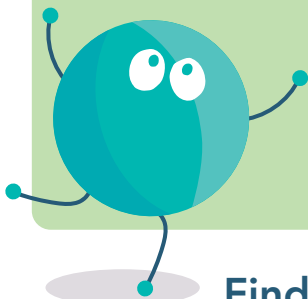


## Get involved today!

Organise your Big Play Date<sup>®</sup> this March to raise funds for CCLG!

From hula-hooping and balloon keepie-uppies, to colouring competitions and garden Olympics, there's lots of activities you can do!

Register to take part in our **Big Play Date – Hop, Skip & Jump** on Facebook, and receive a limited-edition Big Play Date t-shirt! All children (or adults) have to do is hop, skip or jump 45 times a day for seven days and collect sponsorship.



Buy or sell our cute pin badges and keyrings!



Find out more at [www.cclg.org.uk/bigplaydate](http://www.cclg.org.uk/bigplaydate) or email [fundraising@cclg.org.uk](mailto:fundraising@cclg.org.uk)



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