

FREE

SPRING 2021 | ISSUE 90



Children's  
Cancer and  
Leukaemia  
Group

the EXPERTS  
in CHILDHOOD  
CANCER

# contact

SUPPORTING FAMILIES THROUGH CHILDHOOD CANCER

MAGAZINE

## Choices

The clear and not so clear... how clinical decisions are made in children's cancer care, and how it can feel when the choices aren't so obvious



THE PSYCHOLOGY OF DECISION MAKING



CHOICES FAMILIES HAVE TO MAKE THROUGHOUT THEIR TREATMENT JOURNEY



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2021

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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



**Contact Letters,**  
CCLG, Century House, 24 De Montfort Street, Leicester LE1 7GB



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



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## Your messages...



### Leading the way

"Thank you! As usual CCLG leading the way in providing much needed clear guidance and advice for parents of children with cancer. I think I knew (most/all) of this anyway, but to have it all in one place and from CCLG is very reassuring."



### Truly inspiring

"I thought the story from Debbi Rowley in your last issue was truly inspiring. It is so reassuring to learn about the work that is being done."



Read the full article on our website.



### #InternationalChildhoodCancerDay

"Many of our researchers use tissue from @CCLGTissueBank generously donated by children or young people and their families. We're also proud to work with @CCLG\_UK as the professional body for paediatric oncology in the UK and a key funder of research." CRUK Cambridge Centre @CRUKCamPaeds



### CCLG's coronavirus guidance for families of children and young people with cancer

"I felt cancer patients, especially children, were ignored by the government. I'm thankful to CCLG for interpreting the information and relaying it to parents."

"CCLG has been fantastic. The discussion on the CCLG Facebook group, especially CCLG replying to messages so quickly and clearly has been extremely helpful."



Search online for 'CCLG COVID Guidance' or scan the QR code to read the latest updates

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)



## Hello!

So, what's new for Contact this year? Maybe something looks a bit different? Yes, it's our fresh new look for 2021 and we love it! But not only that ... the good news is that it's

bigger too! Contact is now 20 pages full of interesting features, thoughts, ideas and information for all those affected by childhood cancer. We hope you like it too.

Our first issue covers the theme of 'Choices'. Our lives are made up of an infinite amount of choices that we make every day. Most will be really small like what you might eat for tea today, but it is the big decisions - the ones that can change your life forever - that are tough to make. Making a choice with confidence based on the options we have at the time is the only sensible thing we can do and sometimes there is no right or wrong, just different.

In this issue, we look at the choices faced by families and professionals while caring for and treating a child with cancer.

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

## NEW Challenge Child Cancer and become a **CHILD CANCER HERO**

### FUNDRAISE FOR CCLG WITH OUR NEW 2021 **VIRTUAL CHALLENGES**



### What's your challenge?

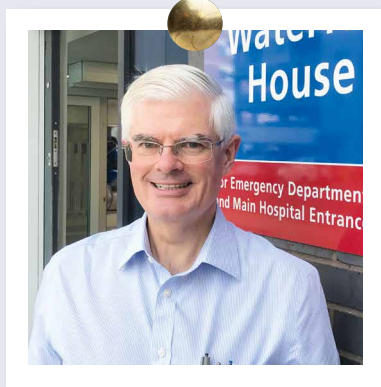
On your own or as part of a team? Each challenge will give you the opportunity to earn an amazing, exclusive CCLG medal and achieve Child Cancer Hero status!

**CLIMB FOR 9:** 8 in 10 children survive childhood cancer. We want a future where 10 out of 10 survive, but first we must reach 9. Join our new 'Climb for 9' challenge! Climb your staircase for nine minutes a day over 10 days and raise money for children with cancer.

**PEDAL 76:** Achieve your Child Cancer Hero status this summer! Pedal for your medal by completing our 76-minute cycling challenge throughout May.

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





## MEDICAL ADVISER

Dr Martin English

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

When I agreed to write this column in this edition of Contact, themed on 'Choices', I thought it would be easy. But it wasn't – just like the choices that families have to make.

When you're in a situation of stress, your mind jumps to emergency mode and your decision-making ability alters. That's good if you're in the jungle and have to instantly decide whether to hide from, run away from or fight the wild animal you've just spotted. But it's not so good if you need to assemble facts, consider all the options, view the situation widely and factor in other unknowns in the future.

Hobson's choice – take it or leave it – is annoying. However, too much choice can be paralysing. The choices that families have to make are often a balance between two competing things and the dilemma – between a rock and a hard place – is painful. For example, treatment 'X' may increase the chance of cure but at a likely cost of more permanent side effects than treatment 'Y'.

The compromise – something has to give – means that you may need to be prepared to sacrifice something else to achieve what you feel is most important. If we want treatment 'Y', we may need to travel to another city and that will cost us in lost wages. Our other children will need to be looked after and need us, too. If we stay and have treatment here, will there be definite consequences in terms of cure or in terms of side effects or is it just a possibility?

So, how do I help people choose? I have to summarise the information that we have about the condition, the treatment and the outcomes. I need to frame these for families so that they can understand them. In an emergency, like a cardiac arrest, the clinician chooses for the patient. Occasionally, in a non-emergency situation, a menu of choices is offered and it is all left to the patient or family. That is less common in complex ongoing conditions such as the treatment of cancer. Usually, the clinician finds out what outcomes are most important to the patient and family and recommends one treatment over another, explaining why.

As always, if you find you are unsure on something, please ask questions. Write them down, and don't be afraid to ask for help if you need it.

## NEWS IN BRIEF

### Digital care plans may help promote survivorship self-management

A study has found that teenage and young adult survivors of cancer are willing and able to self-manage their survivorship care plan digitally or through an app, which may also help promote health-related knowledge. (Source: Pediatric Blood & Cancer)

### Genetic sequencing recommended for rhabdomyosarcoma patients

Genetic sequencing of nearly 400 rhabdomyosarcoma (RMS) patients has identified some gene variants which could be useful for scientists developing gene-specific therapies and surveillance guidelines. Researchers have recommended that RMS patients should have genetic sequencing. (Source: Cancer Genetics)

### Improving patient participation in research

Childhood cancer survivors and parents who receive a video invitation to take part in a research study are more likely to return a questionnaire than those who only receive a letter, a recent study found. This gives researchers a cost-effective way to reach a more diverse audience and improve research quality. (Source: International Journal of Cancer)

### Hepatitis B revaccination should be a priority for acute lymphoblastic leukaemia (ALL) survivors

Research has found that many acute lymphoblastic leukaemia (ALL) patients have lost antibodies that immunise against hepatitis B during treatment. Researchers have emphasised the importance of revaccinating ALL survivors after chemotherapy. (Source: Clinical and Experimental Immunology)

### Biomarker identified which indicates increased risk of infection

Scientists have found that levels of citrulline (an amino acid) in blood plasma of leukaemia patients may help identify those who have an increased risk of infection during treatment. (Source: Pediatric Blood & Cancer)

### CCLG awarded top accreditation for provision of health information

CCLG has been awarded the PIF TICK accreditation, the new UK-wide quality mark for health information, which will appear on all CCLG publications and information resources. For any resource displaying the logo, readers can be assured that the information it provides is clear and easy to understand and based on reliable, up-to-date evidence.

# One family's choices throughout the treatment journey...

**Emily Zobel Marshall** describes some of the choices her family made after her daughter, **Rose**, was diagnosed with leukaemia in March 2018



► Rose in first weeks of treatment

I was on Komodo, a remote Indonesian island, when my husband Tom told me in a quiet, far-off voice: "They think Rose might have leukaemia." I made the long journey home to be with her, the news confirmed when I landed. Rose, 5, had been diagnosed with acute lymphoblastic leukaemia (ALL).

We got used to living with a daily sense of dread and it was so hard to watch her lose her hair in clumps and the steroids puff up her face. But our nurse at Leeds General Infirmary helped us navigate the trauma of those long, strange, dream-like days, as did parents and close friends. We'd all camp out in Rose's room, lightening the atmosphere and entertaining her as she had her various treatments.

She actually has really fond memories of the hospital. She loved the nurses and playworkers, and the affection and interest she received from everyone on the oncology units. They made the ordeal bearable, enveloping us with love, care and support.

We quickly said yes to having a portocath implanted as she hated having canulas. I remember signing the agreement in a complete daze, but it was an excellent decision. The administering of medicines became much more straightforward and relatively painless, and Rose even became quite proud of her port.

After much deliberation, we decided against the treatment trial. We looked at every possible combination of the treatment journey she could experience through the trial, tying ourselves in knots over the options. I was keen for Rose's treatment to be as light as possible and in one possible outcome of the randomised trial, she would have had to spend the first part of her intensive treatment in hospital. However, Tom was keen she didn't have too few drugs – one of the random arms of the trial was one with

family and didn't want Rose to be treated – or perceive herself – as a sickly child. We encouraged her to cycle, run, climb trees, swim and take physical risks. I was quite strict about not giving her too many sweet treats and fatty foods during her steroids. I didn't want her learning bad habits that would affect her food choices long after treatment ended.

We tried to keep Rose's life as normal as possible, not making too much of a fuss or spoiling her. Ensuring she was active really paid off, and she was given a bike from Cyclists Fighting Cancer and one for her brother, so we went on lots of family rides. We felt being active would counter the effects of some of the chemotherapy and I think it really did help.

Eight months off treatment, Rose is a very lively, happy child, top in her PE class and on her school football team. As a family, we now try and squeeze all the joy we can from life, because we now know it's a fragile gift.

**"We quickly said yes to having a portocath implanted as she hated having canulas. I remember signing the form in a complete daze, but it was an excellent decision."**

no steroids after the intensive phase.

I've still no idea if we made the right decision but Rose responded well to her standard treatment, so we've never looked back.

As home filled up with medicines and papers detailing Rose's treatment plan, it was all-encompassing. For me, steroids were the worst part of her treatment. I hated how they made her sad and moody, so at odds with her cheerful spirit. We changed them halfway through her treatment, affecting her mood less.

We still wanted to have fun as a



► Rose enjoying her new bike



# An overview of the decision-making process

*Dr Vikki Langford, Clinical Psychologist at Birmingham Children's Hospital, explains some of the factors involved in making decisions and offers advice and guidance on the process.*

We each make thousands of choices every day, often without even being aware that we're doing so. The vast majority of them are trivial, though on occasions we're faced with much more important, sometimes life-changing decisions. There are often no quick, easy or straightforward answers and we may be left pondering the 'best' way of reaching a conclusion.

Some decisions that we make in life are instinctive, while others require a significant amount of time, effort, research and energy before we feel able to make a final choice. The bigger decisions in life are often accompanied by a degree of risk, ambiguity or uncertainty which make the choice even harder to make.

## What can influence our decisions?

Decision making is unique to each of us. It's a psychological process underpinned by our own values and life experiences. How we approach decision making is often influenced by:

- ▶ How much time we have available to make the decision
- ▶ What information is available to us regarding the different options
- ▶ Our own assessment of the risks involved
- ▶ An ability to weigh up the above knowledge and reach a conclusion that suits us best

In many ways, it may be easier to reach a conclusion if the outcome of the decision affected only ourselves, though the older we get, the less this is likely to be the case. We may need to consider the implications of our decision making on our partner,

children or wider family members. Perhaps we may even be making decisions on behalf of someone else who is incapable of making their own choice, due to their age, maturity or cognitive ability.

## How can we help ourselves to make these difficult decisions in life?

Often, we choose to seek the advice of others, whether this is a trusted friend or a person of authority in the area. It can be helpful to get a different perspective and many people find the views of others useful, particularly when the topic being debated is something they've limited knowledge of. Experts can come in many forms; a specialist in their field, someone in a position of status such as a faith leader or perhaps an 'expert by experience' - someone who's been in your position before.

## The information age: a blessing and a curse

In the modern age, we have a wealth of information at our fingertips. Who hasn't consulted Google at least once this week?! But while availability of knowledge can be very useful in gathering information to help us make decisions, it can also lead to information overload. We can't possibly seek to learn everything there is to know about important topics in life, there will always be an element of the unknown.

## Looking after yourself when making difficult decisions

Whatever tool you choose to use, it's important to look after your emotional

## WHAT TOOLS MAY HELP US IN OUR DECISION MAKING?

Many people find the following ideas helpful in guiding their thinking:

- **Decisional balance sheet:** pros and cons list
- **Cost/benefit analysis:** what do I stand to win vs what do I stand to lose?
- **Emotional forecasting:** if I chose 'X', how would I feel?
- **Consideration of permanency:** is this decision final or could I change my mind later?
- **Advise yourself as if you were a friend:** what would Dave do?
- **Visualising** each of the different options and outcomes

wellbeing while making tough choices. Some people find externalising their thoughts and feelings to be helpful, writing them down, drawing diagrams or being creative. Allow yourself dedicated 'thinking space', along with times when you are consciously switching off the thought process and allowing yourself to rest. Spend time with the people who are most important to you and get some fresh air if at all possible - being surrounded by nature can be an incredibly grounding experience.

Availability of **too much information** can lead to '**analysis paralysis**', a phenomenon that can occur when someone's unable to reach a decision due to information overload. They may get stuck going over the same material over and over, unable to reach a conclusion.

## Involving young patients in the decision-making process

When the decisions being made - as is often the case in childhood cancer care - are on behalf of children, this can be a tricky path to navigate. How much should they be told? How much influence should they have over the final decision? Should they be told that there's a choice to be made at all?

As in all aspects of their care, psychologists would advise that children should be given honest, developmentally appropriate explanations of what's going on. A little information at first, with opportunities to ask questions if they choose to, at any point. Sometimes they will have questions to which there may not be an easy answer and honesty here is also important: "I don't know, but we could ask Dr Smith" or "I don't know that there's an answer to that." Where appropriate, children's views should of course be considered, though children are far less likely than adults to be able to see beyond short-term consequences of their choices. Be clear with your children when asking them for their opinion, if ultimately the final decision will not be theirs to make.

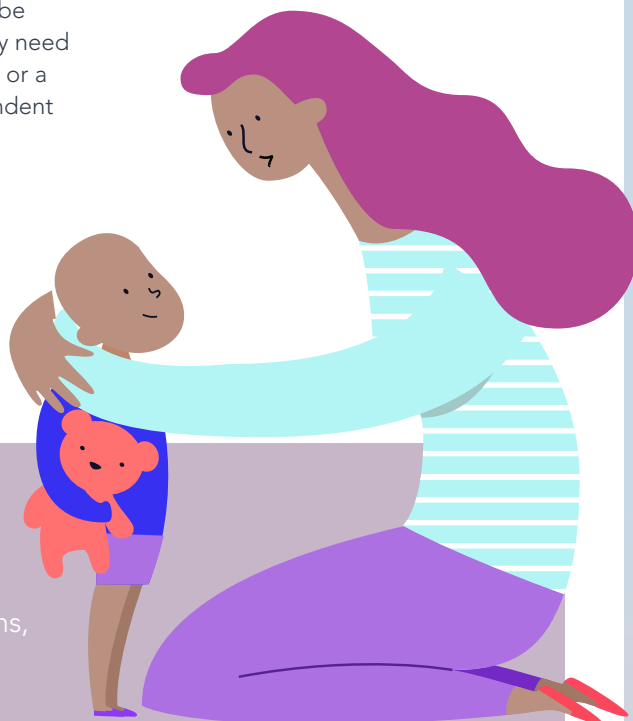
Teenagers are perhaps more likely to wish to be involved in any decisions which impact upon them and they're more likely to be able to weigh up the pros and cons than their younger counterparts. In medical care, young people, even those under the age of 16, have a right to be involved in conversations regarding their care and to make decisions that impact them. Clinicians will always give consideration to young people's ability to understand and weigh up the options available to them, along with their ability to explain how and why they have reached any given decision.

## Support from psychologists

When supporting children and young people to reach their own decision or be a part of the decision-making process, all of the suggestions above may be equally as useful, though they may need support to structure their thinking or a safe space with someone independent in which to explore their feelings.

Clinical psychologists form a part of all paediatric cancer care teams and are happy to provide a space to think about important choices.

“Where appropriate, children's views should of course be considered, though children are far less likely than adults to be able to see beyond short-term consequences of their choices. Be clear with your children when asking them for their opinion, if ultimately the final decision will not be theirs to make.”



## REMEMBER:

Whatever method we choose to make decisions, we can ultimately only make them based upon the information that we have available to us at the time. There may be scope for research, seeking out the opinions of others, or weighing up the pros and cons, but when push comes to shove, the final decision is ours and ours alone.

There's no right or wrong choice, each decision is a judgement call based upon our own individual life experiences and the set of unique values by which we choose to live our lives. And while we all have a tendency to reflect on the 'What if' after the event, none of us can predict the future.

We're all doing the best we can in the circumstances in which we find ourselves.



# Clinical choices:

## The clear and not so clear

As clinicians, we know that from the moment we receive a referral right the way through treatment there will be choices to make - some of them straightforward, some of them complex. In fact, the teams looking after children with cancer have to make hundreds of choices every day.

But how do we make them? Well, we rarely make choices about recommending treatments alone.

When we have to make a decision, we do that by getting as much information as possible. For example, nearly all the diagnoses we manage have a solid grounding in high-quality clinical research - as the more we do and study something, the more chance we have of knowing what's going to happen and our estimates being within a certain degree of accuracy.

In turn, this research is translated into guidelines through CCLG to clearly lay out the best options for 90% of patients. These guidelines often form the basis of our discussions in 'MDTs' - the multi-professional, multi-disciplinary team meetings where the diagnostic materials including biopsies and imaging are discussed and input is received. Together, we mull over the questions, and the information available, and make decisions.

For the one in 10 where the path isn't clear, we have a national - and sometimes international - network of experts to guide and support us.



**Dr Bob Phillips** describes how decisions are made in children's cancer care, and how it can feel when the choices aren't so obvious

What do we do if we need to know how to manage a child whose brain went a bit foggy after methotrexate? We might ring Chris. What if we're unsure if the kidney tumour can be treated with nephron-sparing surgery? We look for when the next CCLG-organised national advisory panel is... we can get input from there. And if we want to find out what's the current third-line therapy for soft tissue sarcoma and what trials might be available? We'll perhaps ask Julia, or Lindlay.

It's almost never that we have a question which can't be aided by input from our colleagues, locally, within CCLG, or further away with our global connections. I often find that the really difficult choices are when they aren't clear, and the views on which is correct, clashes.

Decisions about treatments, or not undertaking treatments, are in collaboration with families and patients, too. There are times when the experts in a field talk of huge uncertainties, and recommend different actions. There are harder times, when parents and young people disagree on what might be the right things to do. It's our job to be able to help facilitate those conversations, and it's hard to stop our own preferences from falling accidentally from our mouths and swaying things unfairly. Some of us see a new drug full of promise, others see an untested therapy with unknown harms.

And then there are the times we've had those conversations where, knowing it's the honest decision of the family, believing their conclusions were reached with fair thinking and clear reasoning, where you wouldn't have made that choice. Or when a perfectly understandable choice is made but is one which makes your heart ache.

As professionals, many of us know these aches and feelings. But we should remember that the stressful conversations and difficult decisions that must be made in caring for unwell children all amount to achieving the one goal. And that's to get those children better.

**Dr Bob Phillips** is a consultant paediatric oncologist at Leeds Children's Hospital and CCLG member.

"It's almost never that we have a question which can't be aided by input from our colleagues locally or with our global connections."





▶ Harry with his family at ITV Studios

## “We decided to take something positive from this horrendous situation”

*Karen and Andrew Phillips were inspired to establish their own charity after their son Harry was helped through his treatment for leukaemia by a special aid. Here, Karen tells us more.*

For us, the date 13 November 2012 and the days leading up to it won't ever be forgotten. This was when Harry, our seven-year-old son, was diagnosed with acute lymphoblastic leukaemia (ALL).

Yes, life for our family, changed forever. Flu symptoms and dry skin on his back very quickly changed to a temperature over 40°. Harry was referred to our local hospital and, after hours of waiting, we heard the words no one wants to hear: “Your child has leukaemia.”

That moment, our world fell apart, as it did for Harry's brother and sister, Luke and Hannah.

We were immediately transferred by ambulance to Leeds General Infirmary. We'll never forget Harry's admission to Ward 31, at 7:50pm. Tests started immediately and this was the start of three years and three months of chemotherapy. The care Harry received there and the support we got was second to none.

During his treatment, Harry was promised a Chemo Duck - a soft, cuddly friend that would help him cope with the challenges ahead. They're fitted with the same medical lines and ports to mirror those of the child, and are used through play therapy to prepare children for every cancer treatment they have to endure.

At that time, it was difficult to source a Chemo Duck. However, Andrew was able

to contact Lu Sipos, who created Chemo Duck in the States to help her son Gabe, and she sent us one. Harry's eyes lit up when he received it and it was a constant companion throughout his journey. In addition, Luke and Hannah received a Huggable Hope, a special friend of Chemo Duck, to help support them.

**“No one wants to hear ‘Your child has leukaemia’. Our world fell apart.”**

Trying to explain procedures and treatment to a child can make them scared, upset and anxious, and Harry's duck really helped him. In turn, this helped make the process less upsetting and stressful for us as parents, too.

So, we decided to take something positive from this horrendous situation. Seeing the difference Chemo Duck and Huggable Hope made to our family, we wanted to offer these resources to every child in the UK. With Lu's support and permission, we founded The Give A Duck Foundation in 2015 and have received positive feedback from

healthcare professionals and families alike about how we're helping children cope with the anxieties of treatment.

Harry has finished all his treatment and his five-year aftercare plan and is doing really well. He enjoys gaming and helps us raise money for the Foundation. Another spin off from Harry's illness is how he developed a passion for magic during treatment, which is another source of fundraising income when he amazes people in restaurants with his tricks! He even won Youngster of the Year 2014 at the Yorkshire Young Achievers Awards for fundraising.

### The Give A Duck Foundation

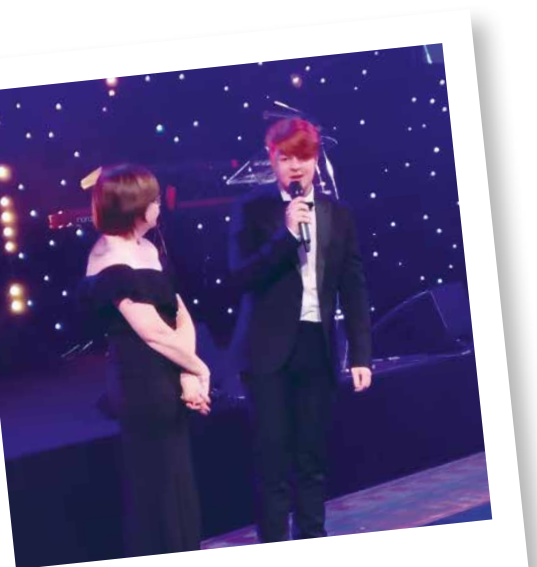
From our initial work with the play team at Leeds General Infirmary we now supply 25 hospitals, children's specialist cancer treatment centres and charities, throughout the UK. Each child names their duck and we work with Blue Light Babies (a network of over 3,800 volunteers who connect via a Facebook group) who create outfits for them.

For further information, please visit [www.giveaduck.org.uk](http://www.giveaduck.org.uk) or email [info@giveaduck.org.uk](mailto:info@giveaduck.org.uk)

# “Now, unlike before, I control my future, not my cancer”



Josh during treatment with his mum, Lynda



Josh speaking about his cancer experience

*Josh Hill was diagnosed with acute lymphoblastic leukaemia (ALL) in September 2004. Now 21, he tells us how he chooses to allow his experiences to drive what he does, rather than control him.*

When I was a five-year-old, being diagnosed with cancer, I had no idea what that even meant. But as I grew older, I realised how ill I was and that is what I struggled with. You see, the reality is, that once my treatment was completed, the cancer still had a hold on me. I have the scars on my body that are a constant reminder. The physical and mental strain was overwhelming.

I've always said the 'What if' mindset has been the hardest fight for me... What if I never had the diagnosis, where would I be today? Instead of scraping through at school and college, would I have been an A\* student with a choice of educational pathways?

This mindset is not a healthy one. It made my life harder. I was constantly wanting a life that I would never be able to have, because I cannot change the past.

ALL is a type of blood cancer. Due to medication, I put on weight which led me to struggle with physical activity. I hated that I was weaker and slower than everyone else. I missed so much school due to frequent hospital visits and fell behind. Once again, my cancer had

limited me - this time not physically, but mentally. In primary school, where my classmates were enjoying PE and ICT, I was doing extra English alone to catch up. In high school, my classmates were doing just fine, but I needed a teaching assistant to help me understand.

However, my life changed one day when I was 16. I was provided a personal trainer by The Joshua Tree charity. I was shown that if I wanted to - if I really wanted to - I could better myself and not let the past define me now, or in the future. I built up confidence that cancer had taken from me and I liked myself again.

Since then, I've chosen to talk about my experiences and use them to drive me, not control me. One feature about myself is that I have ginger hair. For most of my life it's been long and during the times it was 'short', it wasn't for long! I decided to raise money for The Joshua Tree, the charity my mum and dad set up after my diagnosis, by shaving my hair off. At the same time, though, I also wanted to finally let go of the hold that my past had on me. I spoke in front of what felt like loads of people and shared my story.

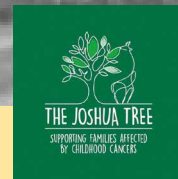
I shared my story on live radio, which was an emotional but amazing experience and one I will never forget! From there, I was invited to the Global Awards where once again, my story was told.

I went on to fundraise further, for Global's 'Make Some Noise' charity, a Heart Radio fundraiser of which The Joshua Tree was a beneficiary. We completed the Three Peaks Challenge in three days. I shared my story on live radio, which was an emotional but amazing experience and one I will never forget! From there, I was invited to the Global Awards where once again, my story was told.

I went on to university where I gained my physical activity and health degree to become a personal trainer. I'm currently working to build my own personal training business, Full HP. The name is inspired by my love of gaming that I got into due to my cancer diagnosis.

For me, Full HP represents that feeling of really loving yourself, for you. Yes, my cancer has played a massive part in my decisions in life, but now - unlike before - I control my future, not my cancer.

► Josh with his brother Adam and sister, Bethan



## The Joshua Tree

Josh's parents, Lynda and David, founded The Joshua Tree children's cancer charity after his diagnosis. The impact it had on their family was life-changing and they decided to set up the Cheshire-based charity to support other families going through the same experience.

Today, it offers a free family support service to children undergoing treatment, siblings, parents, grandparents and the wider family – providing emotional, practical and therapeutic help to families across the North West and North Wales.

[www.thejoshuatree.org.uk](http://www.thejoshuatree.org.uk)

# RED SOCKS OR GREEN?

Even the smallest choices can matter to children with cancer

**Sarah Turner and J'nae Christopher** are assistant psychologists within Health in Mind at Birmingham Children's Hospital. They explain that for a child going through treatment, to be given choice and control over even seemingly small things, can be of real value.

During your child's cancer journey, you're faced with a lot of information, and sometimes you and your child may have no control over what happens: treatment, outcomes and side effects, hospital stays, and more. So, it's important that, where possible, your child is provided with opportunities to make their own age-appropriate choices, to feel included and empowered in their care.

Choices may allow children to build independence at a time when they have to rely on others for support. They can also encourage them to build relationships with their medical team and feel comfortable asking questions. Having a sense of control can help to manage feelings of fear and worry that arise in uncertain situations. It's the little things that matter and make us feel valued by others.

## How can we offer choice?

Sometimes decision making is hard, especially for children and particularly when they are stressed or upset. However, they may become increasingly involved as time goes on, and it's important to think about how to offer them choice. You could provide two clear options, and offer the chance to ask questions to increase understanding. Remember, it's ok if they can't make a choice or you don't know what they want. If it's too hard, why not ask your child if it's ok to make a decision for them? This in itself is providing them with some form of choice.

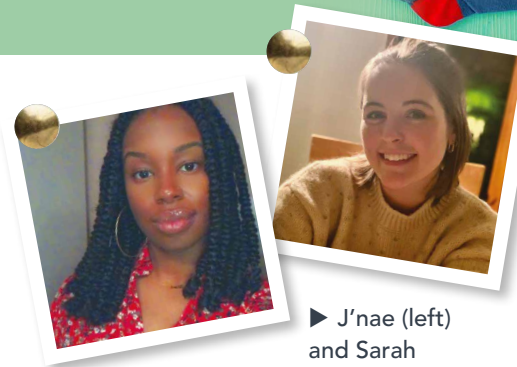
It's also important to remember that decision making can be a process, it doesn't have to be a definite or

immediate choice. It can be something that is continually reviewed.



All children are different, and this makes them special. You know your child best. Consider their understanding, and what choices they can reasonably make. Big choices might be overwhelming but perhaps they could choose:

- ▶ What they bring into hospital
- ▶ Who is with them at key points
- ▶ Elements of treatment and procedures e.g. time of day
- ▶ If or when they shave their head
- ▶ 'How' they want to take medication, rather than 'if'
- ▶ What helps when they're feeling sad or scared
- ▶ How transition to adult services is managed



▶ J'nae (left) and Sarah

## Offering choices on challenging days

For difficult procedures, you could create a 'recipe for success'. This is where parents or clinicians work with a child to create a plan for the day, offering them choices where possible. It's then written down and shared with their medical team.

## Communication is key

We always remember the way something made us feel. Communication ensures children understand their care and can make informed decisions. Some children might prefer to hear clear facts, but for others this may feel scary, and they'd prefer to be told a story. Choices about communication could include:

- ▶ How staff introduce themselves
- ▶ What your child would like to be called
- ▶ How doctors deliver news
- ▶ How information is provided: verbally, written down, or visually

## Final thought:

When a lot of things are out of their control, consider what your child can choose, even if it's just the colour of their socks. Something like this is incredibly simple, but it can have a hugely positive effect on them.

# ‘Standing back’ became an irrelevance



*Alexander Clarke was diagnosed with a soft tissue sarcoma aged 19, meaning he was old enough to make his own treatment choices. His mum Denise describes how he helped lessen their worries by involving them throughout, even when there were no further treatment options left for him.*

When Alexander was diagnosed, he'd been full of hope for the future and enjoying life at Birmingham University. He'd made some wonderful friends and was experiencing his first taste of freedom away from home. It was a time to discover more about himself and learn to make his own decisions, big and small. He loved his new independence.

So, it was a devastating blow to have to return home and give up so much of this new-found freedom and once again be subject to mum and dad 'fussing around'. As parents, we wanted and needed to be strong for him as he began his treatment, but this posed certain questions about how we could support him without appearing to interfere.

As a 19-year-old, Alexander would be an adult patient, even though he had a paediatric-type tumour and would be treated mainly by paediatricians. How would this work and how would Alexander and the doctors feel about parental involvement? Should we keep in the background or could we have some input when asked?

It was a major concern but resolved itself well, thanks to Alexander's skill in knowing when to invite us to consultations and when to make tough decisions about the next stage of treatment. It must have been difficult for him to balance being 'grown up' enough to cope but at the same time wanting mum and dad there to prop him up when he needed it most.

**“ When no more treatment options were left, Alexander chose to live his remaining weeks to the full, visiting Egypt, swimming with dolphins and working with St John Ambulance ”**

He took control and helped us to confront the reality of the situation. He made the most uncertain and difficult time of our lives so much easier to

bear. Alexander had chosen to include us throughout and it could all have been so very different had he not insisted that it was his wish to have us 'on board'. The doctors respected his decision too.

We are forever grateful and the fear of having to 'stand back', watch and wait, became an irrelevance. Alexander was our guide and to a certain extent, to the doctors as well. At a time when his self-esteem might have crumbled, he remained confident and focused, giving us added courage and strength. He also

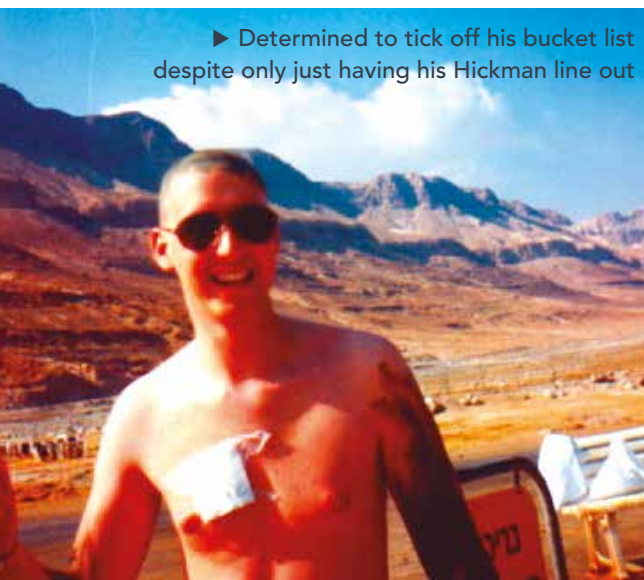


Alexander ready in his wetsuit to swim with dolphins

told us, in no uncertain terms, when to make ourselves scarce during certain hospital visits (on an adult ward, thankfully) so he could have time alone with his girlfriend or brother, or even for chill out time at home! It was so important for us to listen to him and to offer advice when he asked us, which was often. When no more treatment options were left, Alexander chose to live his remaining weeks to the full, visiting Egypt and swimming with dolphins, working with St John Ambulance, catching up with friends, spending precious family time at home and even sorting things for his own church service.

He so enriched and blessed us with the love and courage he showed and shared. His choice to involve us and stay upbeat and positive at such a difficult time has brought huge pride and comfort ever since. Alexander was one amazing, brave, thoughtful and loving son and a wonderful young man who taught us so much.

► Determined to tick off his bucket list despite only just having his Hickman line out





# A digital adventure exploring one child's cancer journey

Theatremaker **Toby Peach** tells us about his new project in collaboration with **Carmen**, who was diagnosed with a brain tumour aged 7.

Three years ago, a nine-year-old girl walked up to me in a drama session and said: "Toby, Toby, you've had cancer!" That little girl was Carmen. She told me she'd had a brain tumour and had read about my story in this very magazine while in hospital.

Telling stories about cancer is incredibly important for those who go through it, but also for those around them - and the power of a story can help find a language, find a way to talk to others and share what might be happening. I now run Beyond Arts, which amplifies the voices of young people who have experienced cancer through arts and storytelling projects.

Children's stories of cancer often get retold by adults - by healthcare professionals or parents/guardians - so we've been working together to find the best way to share Carmen's own story, in her own words, with her own toys. Carmen inspired me when we met through the way she told her story, her insight into the unthinkable and the wise lessons she learnt (and now shares). We've slowly explored her experience, taking care

to look after everyone involved and I'm so honoured that she chose to share her story with me, and we've now found the perfect way to share it with you.

After three years of play, Carmen and I have just released the imaginative and joyful interactive digital story, 'The Origin Of Carmen Power'. Originally due to be a live theatre show, COVID restrictions meant we had to pivot the show into a digital space. However, now completed, we can see this was the perfect way to reach young patients and their families who might be going through similar experiences.

It's a digital adventure filled with monsters, magic powers and unicorns, made especially for 7-13-year-olds and explores Carmen's experience of discovering a brain tumour, aged 7, and the superhero who came out of it. On the website, you'll meet Carmen Power who shares her real-life experience and uses play and imagination to express the challenges she's faced and overcome. All with the help of her trusty sidekick, Tremendous Toby.

'The Origin Of Carmen Power' enables children to explore at their own pace, for as long as they wish. As this story contains emotive subject matter, you may wish to explore this story together with your child.

While this is about one child's story, it also has a universal message about finding our inner strength and resilience, and asks what we can learn from life's most unexpected moments.

► [www.originofcarmenpower.co.uk](http://www.originofcarmenpower.co.uk)



# A parent's view...

**Shielding...a term unknown until March 2020! Tash Larcombe**, whose nine-year-old son, **Finley**, has leukaemia, writes on what shielding has been like for her and her family.

Although it wasn't uncommon for many oncology families to have to 'shield' from the rest of the world before the pandemic, this was on a different scale. As coronavirus gripped, and with Finley undergoing treatment for acute lymphoblastic lymphoma (ALL), we decided to shield two weeks before the government advised to do so.

Despite knowing this was best, the decision wasn't taken lightly. Secretly, I was so relieved when shielding was announced and any parental guilt I felt for removing our children from school was taken out of my hands. When the official letter came through, I cried. Seeing in black and white how vulnerable your child is, brought everything back home and the reality they're living with cancer. We decided to stop all hospital visits for a few months after chatting to Finley's consultant and only had weekly bloods via the community nurse.

**“The pandemic is not too different from having a cancer diagnosis, from the hand hygiene and temperature checking to the income loss and being off work.”**

We were very lucky with my husband's work, they've been so understanding, and he was put on furlough. Homeschooling Finley, his brother Olly, 5, and 13-year-old sister Ebony during the first lockdown was non-existent, as we didn't put too much pressure on ourselves. Keeping everyone well and safe was our top priority, but the latest one, we've achieved a bit more. We kept entertained by spending time in the garden, gaming and cinema nights. When we got the permission to go out, we actually did a lot of things we hadn't done in a long time. We would discover new walks and

local places to go and had some lovely days out as a family doing the simplest of things!

The pandemic is not too different from having a cancer diagnosis, from the hand hygiene and temperature checking to the income loss and being off work. We applied these experiences and took each day as it came. Our CLIC Sargent social worker kept in touch and we also still received virtual support from the Rainbow Trust, while CCLG kept updating their COVID advice when needed.

I knew I was suffering from various mental health issues due to Finley's diagnosis but never had the time to seek help. And, with the pandemic on top, I was so focused on keeping Finley safe that I forgot about myself. A lot of underlying issues came to light and I sought help from our trust's psychology team. I've had ongoing sessions since September and am now on the mend. If anyone out there needs it, seek help if you're ready - don't struggle alone, be kind to, and look after, yourself. Whatever self-care means for you, do it. You're not selfish, and you deserve that 'Me' time! Personally, I run a bath and stick 'Friends' on while I am in there...it needn't be anything extravagant, something simple that you like doing can really recharge those batteries, ready to face whatever obstacle is next.



**Tash Larcombe,**  
Finley's mother

“Keeping everyone well and safe was our top priority. We kept entertained by spending time in the garden, gaming and cinema nights.”



► **Finley (left)**  
and siblings

▼ Carly Doswell,  
Special Named Funds  
Programme Manager

A SPOTLIGHT ON:

# CCLG Special Named Funds

*CCLG's trailblazing and innovative Special Named Funds (SNFs) programme provides a positive platform for families, friends and communities to raise funds in the name of a child affected by cancer. Carly tells us more.*



What are now referred to as CCLG Special Named Funds can be traced back many years to families or donors, many of whom still generously support us today, who wished for their donations to be put towards a specific cause. This could be

for research into a specific tumour type or a certain area of our work

such as publications, and we always ensured their wishes were respected. Over

the years, we also noticed groups of people would participate in events in

support of a particular child they knew with cancer, and the

community support was incredible. We started

to get to know some of the families involved and their supporters and realised that we could offer something different to them, which was to give them their chance to have a say in where the money they were raising would be spent.

Our 60th fund opened in 2020. To date, our funds have collectively raised over an incredible **£2 MILLION!**

In 2014, our SNF programme was created offering families an alternative to starting and running a new charity by themselves, allowing them to focus specifically on their fundraising, without administrative burdens and costs. They can give their fund a special name and choose where the funds should be targeted (whether this is research into a specific type of cancer, patient information or our general work helping all children diagnosed with cancer). We support them with all their fundraising needs and then make sure the money they raise is spent on an area of our work which means most to them.

As members of the AMRC (Association of Medical Research Charities), CCLG has demonstrated that we follow the body's rigorous standards in peer review, enabling us to ensure the research we fund is of the highest quality, so families can be assured that their funds are being channelled into life-changing studies.

Today, we continue to ensure families are supported to the best of our ability through help with events, promotion, in-house design support

and printed merchandise and materials, so they can go about their fantastic fundraising in the easiest way possible.

Our funds are a really positive way for families, friends and their local communities to come together and make a difference. Over the years, I've been lucky enough to attend many charity events organised by our families. These events really give me an insight into what it means to parents and supporters, to build a sense of positivity during ongoing treatment, celebrate milestones or in some cases keep the memory of their child alive, helping to prevent other families having to go through what they have by funding research to help find new treatments.

When the first funds were set up, we had no idea how the programme would grow. It has just been amazing to see and we are so proud of our many amazing families and their supporters who are so committed to changing the future for children with cancer.



[specialnamedfunds.cclg.org.uk](https://specialnamedfunds.cclg.org.uk)



[fundraising@cclg.org.uk](mailto:fundraising@cclg.org.uk)



Danny's Dandelion Appeal



Super Ruby's Rhabdo Raiser



Kayla's Rainbow Appeal



Team Jake



# Decision making in rhabdomyosarcoma

Our supporters help us to continue our important research through fundraising and donations, with many of our research projects supported by our Special Named Funds.

“We continue to carry Ben in our hearts and are so grateful for the incredible support for Ben’s fund, Pass The Smile. We are humbled by the chance to contribute to research that might eventually deliver cancer-free futures for rhabdomyosarcoma patients.”

Scott Crowther, dad to Ben who sadly passed away in June 2019

## Understanding treatment decision-making processes in families where a child or young person has relapsed/refractory rhabdomyosarcoma

Lead researcher: Dr Bob Phillips  
Institution: University of York  
Amount awarded: £96,200

This project was funded in December 2020 by CCLG, thanks to CCLG Special Named Funds **Angus’ Door, Jacob’s Join, Pass The Smile for Ben Crowther, Ollie’s Star, Super Ruby’s Rhabdo Raiser, Team Jake** and a donation from **Elliott’s Trust**.

In children whose rhabdomyosarcoma hasn’t responded to treatment (refractory), or has come back after treatment (relapsed), there are difficult decisions to be made about what treatment to give next. Only around one in five children with relapsed or refractory rhabdomyosarcoma can be cured, and therefore there are choices to be made about how to prioritise their care.

The options might include:

- ▶ aggressive treatment aiming to cure
- ▶ treatment to reduce the amount of disease, and therefore help symptoms
- ▶ experimental trials of new treatments (also called early phase studies)
- ▶ symptom control

Choices made at these times may be extensively re-examined and become a cause of distress months, and years,

after the decision. Within this project, two studies will be undertaken that are linked into understanding how decisions are made about treatments.

**1 SYSTEMATIC REVIEW** - looking at all previous early-phase studies in relapsed or refractory rhabdomyosarcoma and seeing how effective the different treatments are for different children. This will help to give families and professionals more accurate information about what to expect from the options available.

**2 INTERVIEW STUDY** - speaking to patients and families about how they have made, or are making, decisions about treatment in relapsed or refractory rhabdomyosarcoma. This will help researchers understand the decision-making process and how best to support families making these choices.

The results will be shared with families and professionals and combined into a best practice statement which will provide advice and support to clinicians and families about important things to consider when discussing treatment options. Importantly, the project will include patients and parents in designing and performing the research to get the best results for families in the future.

Research lead Dr Bob Phillips, University of York, said: “At a time where research funds are being squeezed, we’re overjoyed to have been awarded this funding to undertake a complex piece of research on decision making in relapsed/refractory rhabdomyosarcoma.

“The project should help us understand what can reasonably be expected from experimental treatments, and also how different families and clinicians approach making the choices around treating patients in this tricky situation.

“Fundamental to all clinical studies, we argue repeatedly, is including families and young people in helping create, steer and share the research. This project is being undertaken with this desire to include families affected along the way, to make sure the studies are sensible and meaningful.”

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

60 SECONDS WITH

# Dan Saunders

Consultant Clinical Oncologist and CCLG Trustee

talks to us about his career and interests



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

**A:** I'm a clinical oncologist (doctor who gives radiotherapy and chemotherapy). I did my general medical training in the Midlands and then my formal specialist oncology training was mainly in Leeds. Then I became a consultant back in the East Midlands before moving to Manchester (at The Christie) just over three years ago to join the proton therapy service.

**Q: Had you always wanted to work in paediatric oncology?**

**A:** I became interested in paediatric oncology during my training years having been lucky to work for four colleagues who inspired me and helped fuel my interest. They all know who they are and I am forever grateful to them for sparking my interest and guiding my development.

**Q: What is your proudest career achievement?**

**A:** Seeing my first patient successfully treated with proton therapy in Manchester rather than having to send them abroad. We review all of our patients at least once a year and it is a genuine pleasure to see so many of them doing so well after treatment.

**Q: What does your job mean to you?**

**A:** It's a genuine privilege to care for children and their families at a challenging time for them. I enjoy working with a wide variety of patients, all of whom have different challenges but are all genuinely inspiring in their own way. I'm also delighted to work with a team of great colleagues whom we all learn from and where we are able to support each other.

**Q: What does the future look like for radiotherapy?**

**A:** Radiotherapy remains an essential part of treatment for many childhood cancers. The treatment is becoming more sophisticated which we hope will mean better outcomes both in terms of improved cure rates but also reduced long-term side effects. There's more that we have to learn and increasingly this will need national and international collaboration so that we all learn together.

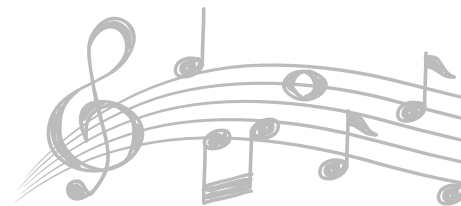
“Treatment is becoming more sophisticated which we hope will mean better outcomes.”

**Q: What future developments are you excited about?**

**A:** In the next few years, we will start to evaluate outcome data from our own proton therapy programme. We're also just starting to open clinical trials in the UK which include important radiotherapy questions which will help improve our evidence base. There will then be an important period of learning and reflection so that we can improve our approaches to treatment of childhood cancer in the UK.

**Q: What are your interests?**

**A:** I also treat adult sarcomas and I'm Associate Medical Director at The Christie. I've been a Trustee of CCLG for nearly six years now. In my spare time I am a reasonable amateur oboist and play for several orchestras in the North West and I also try to find time to get out on my bike beyond the usual commute in the rain every day.



**Q: What message do you have for children and their families affected by childhood cancer?**

**A:** Every child is unique and treated as an individual. Although this will undoubtedly be a daunting and challenging time, the collaboration between and across different paediatric oncology teams is designed to help and support you all to offer the best outcome from treatment as possible.

“It's a genuine privilege to care for children and their families at a challenging time for them. All have different challenges but are all genuinely inspiring in their own way.”

# ASK THE Expert



**Louise Henry**, Paediatrics  
Senior Specialist Dietitian  
at Royal Marsden

## How can I help my child to eat well during treatment?

Eating well during treatment is really important as a well-nourished child is able to cope better with their treatment and fight infection. It will also help their body repair healthy body tissues that have been damaged by chemotherapy or radiotherapy.

### How do I choose the right foods for my child to eat?

All children should be encouraged to eat a variety of foods. This will ensure that they get all of the energy (calories), protein, vitamins and minerals they need for a balanced diet.

- ▶ **PROTEIN** (meat, fish, dairy, nuts, pulses) helps the body to grow and repair and maintains the immune system
- ▶ **CARBOHYDRATES** (bread, potatoes, rice, pasta) are the main source of energy for physical activity and good organ function
- ▶ **FATS** (butter, margarine, vegetable oil, olive oil, nut oils, ghee, cream) are good sources of energy and contain fat-soluble vitamins
- ▶ **FRUIT AND VEGETABLES** are a good source of vitamins, minerals and fibre
- ▶ **WATER** is essential to health and all body cells to function

### Can my child be involved in choosing what to eat?

You can encourage your child to be involved in choosing and preparing their food but limit their choice to a few different foods or snacks as having too much choice can be overwhelming.



### MEALTIME TIPS:

- Don't put too much food on the plate as it can be off-putting, and don't force your child to eat, as sometimes they just won't feel hungry. Instead, wait a while and try a snack or nutritional supplement drink later
- Try to also include the family at mealtimes and aim to eat at the same time as your child. This can help take the focus off eating and make mealtimes a social occasion

For more  
information visit  
[cclg.org.uk/3puDr7j](https://www.cclg.org.uk/3puDr7j)



*Do you 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 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.

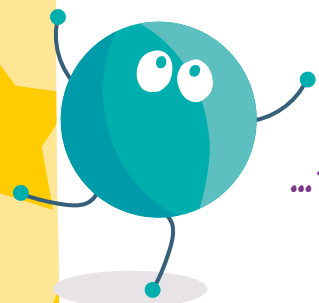




## Get involved today!

Organise a virtual Big Play Date® in support of CCLG... join in the fun this May half term!

We're really looking forward to this year's #BigPlayDate. Why not hold an online games competition, inviting your friends to compete for a prize? Here's some ideas:



- ...longest time hula-hooping
- ...colouring competition
- ...the most balloon keepie-uppies
- ...a family-friendly quiz

Make it a challenge, why not invite people to take part in a mini treasure hunt around your local area? Adults can have a #BigPlayDate too! Go retro, play your favourite childhood games or have an online karaoke evening.



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)



Children's  
Cancer and  
Leukaemia  
Group

the EXPERTS  
in CHILDHOOD  
CANCER

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