

FREE

SUMMER 2022 | ISSUE 95



Children's
Cancer and
Leukaemia
Group

the EXPERTS
in CHILDHOOD
CANCER

contact

SUPPORTING FAMILIES THROUGH CHILDHOOD CANCER

MAGAZINE

Wellbeing

Caitlin Shorricks explains how her fear of cuddling her baby daughter while on cancer treatment led to her designing an innovative product



HOW COMPLEMENTARY THERAPIES CAN HELP WITH WELLBEING



SIXTY SECONDS WITH DR SUSIE WILLIS, CLINICAL PSYCHOLOGIST

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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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Your messages...



On Contact's last edition on 'New beginnings'

"Some really powerful and interesting stories from families affected by childhood cancers to read in the Spring issue of #ContactMagazine, especially around life after treatment. Thanks, @CCLG_UK."



Dr Catherine Pointer's determined and powerful story in Contact's last edition



"What an inspirational woman!"

Read the full article on our website ►



CCLG's Research Impact Report gives hope for the future



"This is super impressive and hope for those affected by childhood cancer!"

Download a copy of the report here ►



On CCLG's publications

"This was one of the single most useful booklets we received following my son's diagnosis. Pitched at just the right level, especially in those early days when things were so painfully raw."

Download our award-winning publications for free on our website

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



Hello!

Sun, sea and sand ... and holidays! It can be a challenge to go on holiday when a child has cancer, but it's a chance for families to leave the clinical routine behind and escape for a few days. Our helpful guide on pages 8-9 offers support and advice on planning a holiday. Sunny days can always help lift our mood and improve our emotional wellbeing even when life isn't going as planned. Elsewhere, psychologist Dr Amandeep Samrai gives expert tips on self-care and coping strategies and explains where to access support (pages 10-11). Enjoy our Summer edition!



Claire editor@cclg.org.uk

P.S. Don't forget September is Childhood Cancer Awareness Month - keep checking our social channels for updates!

REGISTER TO TAKE PART IN OUR 'PUP HERO' CHALLENGE THIS JULY 🐾

Walk 50, 75 or 100km with your dog during July and raise money for life-saving child cancer research.

Join our Facebook group to register and get your own fantastic free CCLG dog bandana.

PUP HERO CHALLENGE 🐾

www.facebook.com/groups/puphero



MEDICAL ADVISER

Dr Bob Phillips

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

It's a welcome change of this millennium that physical health is not the only thing we're now striving for, and that emotional wellbeing and good mental health are recognised as being just as important.

The wellbeing of children and young people affected by cancer is important to both maintain and improve. This needs input during treatment, as both the disease and the ways it is treated, take their toll. There are many skilled people with specialist knowledge to help with this in a number of different ways - play specialists, social workers, chaplains, psychologists, nurses, doctors and trained peer supporters from charities, who all have a formal place. Informal support through family, friends and community is also invaluable and crucially sits alongside what we professionals and charities have to offer. Some young people need very specific help with mental illness, too, which might be exacerbated or brought on through their cancer treatment. Here, the specialist services of highly-trained clinical psychologists and psychiatrists are needed.

All those very same people mentioned above can help other family members, too. Parents, carers, siblings and the wider family need their wellbeing protecting and promoting as well. This can be through very practical support – perhaps helping with looking after a toddler while you shower, lasagne for the freezer, or pick-ups from Brownies for your daughter. Or, it could be something entirely different and incredibly meaningful, like a ticket to the cinema or an hour with a counsellor.

I appreciate that having a professional, who is probably kind, but perhaps can't fully relate to what you're feeling, telling you what to do when your world appears to be cracking and you are holding it together with tape, can sometimes feel a bit much. But, please, if you need it, do make use of all the support available and lean on all those who can provide it.



NEWS IN BRIEF

New protocol to help improve diagnostic pathways

The protocol for the new Child Cancer Diagnosis Study has been published, which will help to close the gap between diagnosis and treatment of childhood cancer. It aims to better understand the current pathway of childhood cancer referrals and diagnoses and will look to determine exact reasons for delays and highlight areas of improvement. The collaborative project between the University of Nottingham and Children's Cancer and Leukaemia Group (CCLG), funded by CCLG and the National Institute of Health Research (NIHR), will use data from all UK childhood cancer treatment centres.

(Source: *BMJ*)

Increased risk of dental development anomalies for childhood cancer survivors

Childhood cancer survivors may be at increased risk of dental development issues, according to research. The study highlights the importance of dental care for patients who received cancer treatment at a young age (0–6 years), and will help doctors to establish international guidelines for follow-up and treatment.

(Source: *Nature.com*)

New patient information resources from CCLG

CCLG has published several new or updated information resources, available free to order from our website:

- Whole genome sequencing for children
- A parent's guide to kidney tumours
- Treatment options for relapsed Wilms tumour in children

Download here ►



PARENTS OF CHILDREN WITH CANCER NEEDED FOR RESEARCH

Liz Jestico, Senior Lecturer in Children's Nursing at Oxford Brookes University, is exploring parents' experiences of being supported by their network of family and friends when faced with making decisions about their child's cancer care. If you are a parent of a child aged 0-11 who has cancer or a non-cancerous brain tumour and living in the UK, and would like to speak to Liz about your experiences, please email 19001672@brookes.ac.uk or text/phone 07553 773728.

How sailing trips can help young people to recovery



The *Ellen MacArthur Cancer Trust* supports young people aged 8-24 in rebuilding their confidence after cancer through sailing and UK-wide adventure activities. **Scott Wilson**, Communications Officer at the Trust, explains the positive impact these trips have on wellbeing.

For many young people, simply picking up where they left off before their cancer diagnosis just isn't possible. So, when treatment ends, the Trust's work begins. The Trust inspires young people to believe in a brighter future living through and beyond cancer. Through free sailing and outdoor adventure activities, they meet others who have had similar experiences, rediscover independence away from home, and begin to realise what they're capable of again.

While they have lots of fun aboard the yachts - learning how to raise the sails, navigate, and be part of a crew at sea - sailing is just the vehicle. Everyone has stories to tell, mucks in, and does normal things, like cooking together. It's a new adventure, involving lots of things many young people haven't done since their diagnosis – or ever! The feelings of acceptance, independence and optimism young people gain through the Trust helps them re-establish their place in the world. A change in perspective on their illness and life helps many return to education or employment and reconnect with their friends and families.

Emily's story



Emily sailing with the Trust in 2021

For Emily, every trip she goes on is like getting closer to a lighthouse, having been in the dark, lost at sea, after her treatment for Langerhans cell histiocytosis. She explains: "When you see a ship coming to shore and it's the middle of the night, you think, 'Is it going to make it?'. Coming on a Trust trip every summer, it's the lighthouse that keeps me going. After each one, the light gets stronger."

Five years on from her first trip as a 15-year-old, and having most recently sailed with the Trust in 2021, she said each time she goes sailing it perks up her level of happiness. "It gives you a sense of hope, like the years are going to get better and better. So many young people struggle with the feeling of loneliness, especially after treatment and in remission. It's a reminder that you're not alone, that's the beauty of the trips. It would be an understatement to say they've only impacted my friendships or work, because they really do make a difference to every single aspect of your life."

Bhavan's story



Bhavan (front) with his crew mates

For Bhavan, a four-day sailing adventure was a new beginning and a chance to put the anxiety of cancer behind him. He hated talking about his experience of being ill with follicular lymphoma, while the thought of doing anything new would amplify his worries.

Before his first trip, aged 14, he "cried for a good two or three days before", but was soon glad he didn't back out. He said: "Going through that nervousness and apprehension is worth it. You feel better because you overcame it, and the trip opens your eyes to new things. They're like a life lesson. You do things you don't think you'd be able to do, and even if it's something minor like using the winch handle, you have done something new and feel like you can accomplish anything. You overcome your cancer and your treatment."

Any young person who's had cancer from across the UK can benefit from Trust support, if they were diagnosed before turning 25 and are eight by their first trip. There's no cut-off to when a young person can apply - even if they had cancer as a baby, they could still experience late effects.



To find out more or to sign up visit ellenmacarthurcancertrust.org or follow [@emctrust](https://twitter.com/emctrust)

How fear of cuddling my daughter led to an innovative invention

Caitlin Shorricks' daughter Theía was diagnosed with neuroblastoma in May 2020. She explains how a special vest she created to protect Theía is now helping other families caring for children with cancer

The most natural instinct for any mother with a sick child is to give them a hug and reassure them. However, when my tiny 14-week-old baby, Theía, was critically ill with cancer, I was absolutely terrified to cuddle her. The reason for that fear was the two central line tubes (also known as 'wigglys') dangling out of her chest. Medical staff at Great Ormond Street Hospital had warned me that if Theía or I accidentally pulled out or displaced the tubes, the consequences for her could be life-threatening.

It was agony. All I wanted to do was cuddle her but she was already so ill, I was terrified of hurting her. I had to call a nurse to help me every time I wanted to hold my own baby.



Caitlin and Theía in their room at hospital



Caitlin and her daughter Theía

The tubes used to administer the chemotherapy were also long enough to be tugged by little hands, get caught in her toes, and even reach her nappy, which could lead to sepsis.

I knew that Theía really needed to be cuddled and to feel loved to give her the best chance, so I was determined to find a safe way to be able to hold her.

My solution

I started working on ideas with my aunt, who is an experienced dressmaker, to create a garment with an internal pocket to keep the lines safely tucked away. We called it a 'Choob Toob' and it was a godsend. Not only did it keep the lines safe from little hands, it also meant that I could hold her with confidence.

Even after Theía completed her treatment, her central lines remained in place for months afterwards – and any problem with the line would have meant a rush back to the hospital. But as Theía wore a Choob Toob day and night, she was able to have tummy time, learn to roll and sit up without interfering with the tubes and, most importantly, me, my husband and Theía's grandparents were able to cuddle and play with her without the worry of accidentally pulling the line.

After treatment

After five months, Theía's central line was removed, and her consultant asked me how many infections and line pulls she'd had while I was caring for her at home. He

was surprised that she hadn't had a single one. When I showed him the Choob Toob we created to keep the lines safe, he was fascinated and suggested I should do something with it as there wasn't really anything like it available.

"All I wanted to do was cuddle her but she was already so ill, I was terrified of hurting her!"

I still feel traumatised today by the feeling of being too scared to cuddle my sick baby and I didn't want another parent to have to go through that anguish if I could help it. I can't imagine being back in that situation again, it still makes me cry even just thinking about it.

Starting production

My aunt and I set about making more Choob Toobs for other sick children, constantly refining the design with each garment being hand-crafted to order. It was important to me that they didn't look like medical garments and were not only comfortable and functional, but also fun and funky. This was especially important for older children. The Choob Toobs gave them back their sense of self and

improved their wellbeing. They were able to have fun and play with their friends, knowing that their central line was safely tucked away.

What other parents have said

The feedback I've had from parents and children has been amazing and invaluable for the continuing development of the garment – and it makes all the effort we've put into it worthwhile. As one parent wrote: "To look [at my child wearing a Choob Toob] you would never know he has a line. This has had a positive effect on him by eradicating the fears he had and allowing him to feel normal."

A five-year-old boy told his mother on receiving one, that it was the "best day ever because when I'm out, my line won't come out of my clothes and no one else will see it". Similarly, another mother said: "My daughter is very aware of her line and is terrified people will see it (most of all, her toddler brother who would most likely have given it a good tug!). Having it tucked away out of sight in the vest really has given her so much confidence."

Future plans

While I'm so happy that our creation is now helping so many poorly children, I have found it overwhelming at times to hear the heartbreaking stories of others, taking me back to a time any parent would want to forget. I think I'm still processing the trauma of Theía's cancer, her treatment in the middle of a pandemic when I was unable to have my husband with me at the hospital, and the guilt of being so afraid to hold her at first.

However, the knowledge that we've been able to help others has spurred me on. It's been the driving force behind wanting to be able to one day provide free Choob Toobs to every child who needs one, both here in the UK and abroad. We're still seeking ways to fund that dream, having recently taken steps to have our designs manufactured on a larger scale and creating a fundraising page on JustGiving to make this a reality.

Thankfully, Theía is now a clever, bubbly and beautiful two-year-old who amazes and inspires me every day.

Theía's central line



Theía wearing her Choob Toob



FOR MORE INFORMATION

Visit tinyteatrust.org for more information, the opportunity to donate, or to order your free Choob Toob using the unique code: 'CCLG2022'.

Planning a holiday when a child or young person has cancer



Cat Macleod

As part of **Cat Macleod's** role as a Young Lives vs Cancer social worker, she helps families plan and access trips and holidays while their child is on treatment. She explains the positive impact these breaks can have, and things to consider beforehand.

In my role with Young Lives vs Cancer, I have the privilege of working to support incredible children and young people, their parents, and carers. They amaze me by continuously finding the inner strength to live through the unrelenting challenges of life with cancer, and the seemingly endless appointments, procedures, treatments and scans. So, when I hear them say, "If only we could get a break from it!", my first thought is about how I can best support them to take a holiday.

Families often tell me they want to feel free, to "escape the clinical stuff" and "leave cancer in a box for a few days". Holidays are an opportunity for them to step away from their familiar, draining daily routine and focus on making new, happy memories together. I listen, tell them I hear them, and then in partnership, we get to work.

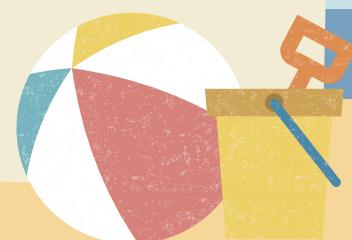
Here, I share some of my thoughts and ideas for planning and undertaking a holiday when your child is affected by cancer...



WHERE TO BEGIN?

Every holiday starts with an idea! A change of scenery, visiting that place you've always wanted to go to, or reuniting with friends and family you haven't seen in ages. But what if you can't find somewhere accessible that meets your needs, or that's affordable? When you've got cancer to think about, going on holiday can seem very complicated. However, experience tells me that with creative planning and motivation to make something happen, it's nearly always possible to create an opportunity for adventure.

- ▶ **Decide what you need from a holiday**
What are you looking for in a holiday? If it's a break from hospital life or a chance to have fun as a family, you might find you don't need to travel far. Remind yourself of your original intention when you're planning – if it all seems too stressful, perhaps there's a different way to achieve what you're looking for?
- ▶ **Don't worry about duration**
Quality experiences don't need to take a long time. Taking even a short break can help to distinguish one period of time from the next. For instance, between treatment cycles or following a scan
- ▶ **Accept help from others**
As anyone who's done it knows, caring for someone with cancer can take an enormous emotional toll. Don't be afraid to recognise this and accept support from others, whether it's a friend who wants to help or an organisation that could provide financial support or a place to stay. There are incredible holiday opportunities being offered to families affected by cancer – ask your clinical team or Young Lives vs Cancer social worker, or search online to find out your options



MANAGING RISK

Once you've worked out where you're going and when, it's time to take care of the medical stuff. Taking a clinically vulnerable child or young person on holiday may seem overwhelming, but it can be done, and it can have enormous benefits for everyone involved.

It's all about managing risk. How far are you happy to go, what is it that you want to achieve by being away from your safe and familiar space of home and, very importantly, what do those who care for the most health-challenged in your group think is wise? Have the conversations and seek others' opinions, but ultimately, make decisions you feel comfortable with.

- ▶ Allow time either side of your trip for the unexpected, i.e., changes to travel details
- ▶ If you have clinical support to take your holiday, still consider where your nearest medical facility would be and how you could access it if needed
- ▶ Ensure everyone going on holiday has enough of everything they may require, such as medications, mobility aids etc. Replacements may be hard to find. The item I find families often forget is a thermometer!
- ▶ If you're going abroad, research travel insurance and ensure you have the right documentation in place. Pre-existing medical conditions can make applying for insurance more complex, so make sure to start looking at this well in advance, include accurate clinical details in your application, and always read the small print! Your clinical team or Young Lives vs Cancer social worker may be able to help

WHEN IT ALL GOES TO PLAN

When you're planning a holiday with a child or young person with cancer, it's easy to imagine all the things that could go wrong. This can be true of any new experience, but with careful planning and risk management, remember that it could actually all go right! It's entirely possible that a holiday from whatever your current life situation is throwing at you could give you a newfound energy to keep going. Experiencing something new, and having exciting, shared moments to reflect upon with those you care for, live alongside and love, could be the best therapy ever!





Support and advice for emotional health and wellbeing

Dr Amandeep Samrai, Consultant Clinical Psychologist in Paediatric Oncology at Nottingham Children's Hospital, writes on the impact that a childhood cancer diagnosis can have on emotional health and wellbeing. She offers tips on self-care and coping strategies, and explains where to access support.

Receiving a cancer diagnosis and being treated for cancer as a child or young person can be scary and traumatic. Parents and caregivers can understandably feel overwhelmed and worried, and it's normal to feel shocked when first given the news. Treatment usually begins quickly, and there's little time for adjustment. Young people and their families can find themselves going from 'normal' everyday life to being given a treatment schedule and starting the treatment process almost immediately. It can feel daunting to be told about chemotherapy cycles, radiotherapy and surgery.

process. Sometimes, it can feel routine and mundane, but if there's a change in the schedule or some unexpected news, it's normal to feel a rollercoaster of emotions. There can be emotional peaks and troughs, which can be difficult when having been used to life being more settled.

Although most children, young people and families adjust to and manage the diagnosis and treatment of cancer, understandably some can experience longer-term emotional difficulties.

Living with uncertainty

A cancer diagnosis is life changing, and both during and after treatment there will remain some element of uncertainty. This can make it hard to think about what the future holds. We tend to feel more comfortable when we're able to plan and know what's coming next, which is why living with uncertainty can be so difficult. After treatment has ended, it is normal for feelings of uncertainty to remain. Although there are fewer hospital appointments to attend, many young people still require blood tests and scans. Sadly, relapse can also be a reality. Going for and waiting for the results of scans can be nerve-wracking and lead to 'scanxiety'.

As the time between follow-up appointments and scans becomes longer, you may find you adjust to living with uncertainty. However, the time it can take to adjust can vary hugely, so it's important not to put too much pressure on yourself and allow yourself the time you need.

Adjustment after treatment has finished

Young people and parents often focus on the end of treatment and going back to 'normal'. Although a cancer diagnosis and treatment is very difficult and challenging, the structure of treatment, hospital appointments and support from the team can provide reassurance.

Initially after treatment has finished, young people and parents may feel happy and relieved. However, ongoing hospital appointments, blood tests and scans are often required, and this can feel like treatment hasn't really finished at all. As a consequence, the end of treatment can feel like an anticlimax.

We tend to feel more comfortable when we're able to plan and know what's coming next, which is why living with uncertainty can be so difficult.

After a few months, life can settle into a rhythm of blood tests, scans, treatment, going to appointments and staying in hospital. This is sometimes referred to as the 'treadmill of treatment'. There's no 'right' way to feel during this



Overall, it can be a challenging transition, and it can be frustrating when it feels like things aren't 'back to normal'. Milestones such as having a line or nasogastric tube removed can help the adjustment process and make it feel more real. The emotional experience of the cancer diagnosis can also be something that young people and parents think about more after treatment. There is time to think and reflect on what you've been through and the impact it has had on the whole family.

As life changes, such as a child going back to school, or parents going back to work, new routines begin and it may become feasible to do activities that might not have been possible during treatment.

It's very common for it to take time to adjust to life after treatment, and this varies for each person and family. As life changes, such as a child going back to school, or parents going back to work, new routines begin and it may become feasible to do activities that might not have been possible during treatment. This process may help with the adjustment and some of the uncertainties of life after treatment. You may find that life doesn't go back to the way it was before the diagnosis, but a 'new' and different normal.

How to access support

Undergoing or completing cancer treatment is a difficult time that brings up complex emotions. There are several ways to access emotional and psychological support for children, young people and families during and after cancer treatment.

In some principal treatment centres, there are clinical psychologists who work in the paediatric oncology teams. You can usually be referred by your hospital consultant, clinical nurse specialist or another member of the team

for an assessment. In some hospitals, clinical psychologists work in paediatric psychology departments, and a referral can be made by your hospital consultant. Other members of the paediatric oncology team, such as Young Lives vs Cancer social workers, clinical nurse specialists and play therapists, can also offer support.

Alternatively, seek advice from your GP, and they can refer a child or young person to CAMHS (Child and Adolescent Mental Health Service) or a local adult talking therapies service. Your GP can also prescribe medication, such as anti-depressants for young adults and parents, if appropriate.

Coping strategies and self-care

There is no 'normal' way to cope with a cancer diagnosis or treatment, and it's important to allow yourself to feel sadness, worry and anger. There may be times when simply crying and voicing the unfairness of the diagnosis is what you need to do.

It can be challenging to prioritise emotional health and wellbeing during the physical and practical process of treatment. Self-care, which includes eating well, trying to exercise and getting rest, can be difficult when staying in hospital. When you have periods at home, it may help to focus on one of these things, but also to not be too hard on yourself if this isn't a priority. If it's possible to share overnight stays in hospital, take a break and allow yourself to spend the night at home and get some rest.

There are coping strategies that can help and it's important to find out what you find helpful, as this will vary from person to person. Some people find relaxation, drawing and colouring, mindfulness, and breathing exercises helpful. There are also a number of relaxation apps that might be useful to aid self-care.

Others might find reading, audio books and listening to podcasts beneficial. Writing down how you feel, keeping a journal, taking notes on your phone, or making voice notes about your experience are some alternative coping mechanisms.

It's important to spend time with people you care about, and this can include seeing family or friends. Having connections with other families and young people who you may have met in hospital may also help, in order to share the experiences and difficulties of treatment with people who understand.



USEFUL LINKS AND APPS

Hospichill (for children and young people)

Relaxation skills for hospital visits
www.hospichill.net

Insight Timer

Guided meditations for help with sleep, anxiety and stress
www.insighttimer.com/en-gb

Headspace

Science-backed meditation and mindfulness tools
www.headspace.com





How my cancer journey influenced me to start a skincare business



Lauren Murrell

Lauren Murrell was diagnosed with leukaemia aged 23. She tells us how her experiences inspired her into business with her sister to help others get back to themselves through wellness products.

Back in February 2012, a week of unexplained symptoms including fever, night sweats, lethargy and pains in my neck left me bedridden. After going to A&E, I was told it could be glandular fever or scarlet fever but the doctors weren't sure. However, my blood results the next day would give us the answer. The phone call came and I went back to the hospital - it was cancer, acute myeloid leukaemia (AML), and there was no time to delay. I was hospitalised immediately and treatment started the next day.

The shock was huge - I was an otherwise healthy 23-year-old and just a few weeks away from my final law school exams. My world was turned upside down and I was heartbroken that the career I'd worked so hard for looked like it was to be taken away from me in an instant. Over the months that followed, I had multiple rounds of chemotherapy, total body irradiation and a life-saving stem cell transplant from my sister, Sarah.

This period of my life was so, so tough, both physically and mentally. My body withered, my emotional wellbeing was tested to its limits and my positive mindset stretched well beyond my comfort zone. I spent weeks at a time in my hospital room, in protective isolation, battling for my life. In my darkest hours, I found the inner strength to keep going. I journalled to process my thoughts, stuck posters on my wall of New York and the Caribbean to remind myself of the world beyond the bare white walls, and reinforced positive affirmations. I'd stand in front of the mirror as my hair was falling out, saying out loud: "Stay strong, stay really strong."

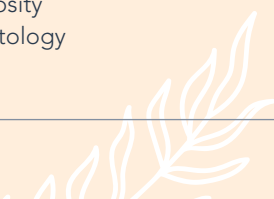
A positive and determined attitude

I quickly learned that everything is permanently temporary. The identity that I had for so long associated with what I did, where I went and how I looked, was lost. I came to see my mind as my best friend and developed a positive attitude at every opportunity. One way I did this was by focusing on fundraising from my hospital room and, with the incredible generosity of so many people, raised over £60,000 for the haematology unit at University College London Hospital (UCLH).



▲ Sarah (left) and Lauren (right)

"My emotional wellbeing was tested to its limits and my positive mindset stretched well beyond my comfort zone."





impact of sensitive, stressed skin and are empowering our community by helping people get back to themselves. It's a highlight of my day to read the many transformative stories we receive from our customers who have found hope and results with our skincare. I'm also really proud that we are a certified B Corp and meet the highest standards of social and environmental impact. As a purpose-led brand, we've committed to people and planet from the very beginning and I'm hugely excited by the difference we can continue to make.

"I never thought I'd become an entrepreneur, but this journey has presented me with so many amazing experiences."

Ten years on from diagnosis

On a personal level, this February marked 10 years since my leukaemia diagnosis and, in the same week, I became Vice Chair of The Little Princess Trust - the charity I first donated my hair to before it all fell out during my cancer treatment. It's such an honour to be part of this special charity, whose commitment to supporting children and young people who have lost their hair to cancer, as well as funding pioneering, life-saving research into childhood cancers, is deeply inspiring.

My cancer and what has followed has been a chapter of my life that I never saw coming and yet, my personal mantra continues to ring true: 'Live life as if everything is rigged in your favour.'



For more information, visit [bysarahlondon.com](https://www.bysarahlondon.com)

Two years later, I dusted off the books on my desk and returned to law school, before finally being able to begin my career as a lawyer in London. Determined to pick up where I'd left off, I balanced out-patient hospital appointments with my job. Spending so much time in protective isolation in hospital had made me even more determined to live the life I'd dreamed of. And a year or so later, I moved to the firm's New York office and fulfilled my dream of living in the most vibrant city on earth. It was a real career highlight.

Upon returning to London, my appetite for adventure was still strong. So, it wasn't long before I'd packed up my life into three suitcases and moved to the British Virgin Islands in the Caribbean, the most beautiful place I'd ever seen - with the same aquamarine water and lush green palm trees from the poster I had on my hospital wall. Sadly, life as a lawyer in paradise ended abruptly for me in September 2017 by the onslaught of Hurricane Irma, a terrifying category-5 hurricane that tore through the house I was sheltering in and left me stranded for days without any contact to the outside world. After eventually being rescued and evacuated, it was the perfect storm which brought me back to the UK.

A new direction

It was then that my sister and I took a leap of faith, leaving our corporate jobs behind to launch 'By Sarah London', the digital-first skincare brand for stressed, sensitive skin. Sarah had developed skincare initially for me when I was in hospital as my skin became so fragile and sensitive, shedding like a snake and reacting to many 'natural' product ranges. Free from common irritants like essential oils and fragrance, our collection is specially formulated for even the most sensitive skin.

It's these formulations which have since become our multi award-winning collection, featured on This Morning and in Vogue, The Times and The Telegraph, with celebrity fans including Trinny Woodall and Deliciously Ella. If I had to choose a personal favourite product, it would be the Hero Facial Oil. This was the first formulation that Sarah developed for my skin and I've loved it since the very beginning! I never thought I'd become an entrepreneur, but this journey has presented me with so many amazing experiences that I otherwise wouldn't have had. As a business, we understand the physical and emotional





“I always find it helps me to talk about my experiences with cancer”

Matteus Irsø-Coombes, Community Fundraising Coordinator at CCLG, was diagnosed with leukaemia aged 24. He tells us how his outlook on life has been altered by his cancer journey and how talking about his experiences has helped him mentally.

I'd always thought that your mid-20s were when you started to plan your life out, building the foundations for the years to come, whether this be in your work or home life. But for me, this all changed in October 2019, when I was diagnosed with acute lymphoblastic leukaemia (ALL), a month before my 25th birthday.

Before I was diagnosed, I was living like most people my age: going out and enjoying myself with nothing much to worry about. But things started to change when I began to feel lethargic and tired, to the point where I'd even fall asleep at work. I'd naively put this down to pushing myself at the gym and not eating properly. I perhaps should have clicked that something was wrong when I started to suffer from night sweats and waking up in the middle of the night in a soaking bed. Again, I told myself there was a simple explanation for this, like the humidity of summer.

Then I began having serious pains in my knee, but despite a lot of discomfort and after numerous doctor's appointments, no problems were found. My doctor asked me if there were any other problems I was having and I mentioned the sweating. At that moment, my doctor knew something wasn't right and I was told I needed to have some blood tests. A few days later, I was told I had leukaemia and was immediately put on steroids to slow the spread of the cancer. For several months, I had daily chemotherapy, which was followed by a stem cell transplant. During this time, I spent several months in hospital due to a multitude of complications, but I tried my best to remain positive and think of where I would be in a year's time.

different walks of life. That said, there's been moments where it's been difficult to not think about the time I've lost, and things that I feel I've missed out on doing as a result of my illness, such as progressing my career, or even starting one. However, this only strengthened my resolve to find something I really wanted to do. Knowing I wanted to use my own experiences to benefit others, this led to me joining the fundraising team here at CCLG, where I help to support our amazing Special Named Funds.

"Knowing I wanted to use my own experiences to benefit others, this led to me joining the fundraising team here at CCLG, where I help to support our amazing Special Named Funds."

Now, just over two years since my transplant, my perspective on life has changed significantly. I've become much more aware of my own mortality, and feel I need to do as much as I can with my life and not waste a single moment. I look forward to being able to travel again and see what I can of the world, exploring different cultures, eating new foods and meeting people from



It means a lot to me to be able to help other people, and for World Cancer Day, I took part in a Q&A to share my journey and offer advice to other young people going through a similar journey. I always find it helps me to talk about my experiences with cancer, whether that's to consultants, colleagues, friends or family. I find it cathartic, and it helps to alleviate some of the pressure I feel from time to time. It clears my mind, and it's important to talk, so that people know how I am feeling and to get help and support when I need it myself.



Matteus in hospital during treatment

A parent's view...

Learning to look after your own wellbeing during treatment

When **Beth Kellie's** son Kai was diagnosed with leukaemia, she struggled to maintain her mental and physical health while adjusting to life during his treatment. She writes on how she learnt to look after her own wellbeing and the importance of doing so.

When my six-year-old Kai was diagnosed with acute lymphoblastic leukaemia (ALL) in 2021, I went into a state of shock. In those early weeks in hospital, while his treatment was established, I slept badly, ate comfort food from M&S (microwave lasagnes were a favourite) and chocolate. I did what I could do to get through from one day to the next. The cliché of 'putting on your own oxygen mask first' doesn't work when your child is seriously ill.



Kai's diagnosis sent my anxiety through the roof. I couldn't watch TV or read and, while I'm usually an avid knitter, I just carried it around with me. The hospital psychiatrist reassured me it was a normal response to the situation and suggested asking friends to help distract me, so that not every message or phone call was about cancer. I was lucky to have friends overseas who sent me pictures of beautiful beaches and sunsets and a small group knitting chat who, with my blessing, just carried on as normal.

Getting home helped. It was easier having two adults to manage the new routine of meds and round the clock care and we could eat much better, but I went to bed early most nights as sleeping was better than thinking and worrying. The psychologist sessions continued and we

talked about living in the 'fight or flight' state and the toll this takes on the body and mind. I tried (and mostly failed) to remember to stop and take slow, deep breaths to calm the nervous system for a few minutes when doing the washing up.

I started going for a walk and listening to audio books every day, while we also bought family gratitude journals and sat down with them after dinner each night.

As Kai started to improve physically, I wanted to feel better as I knew I needed to be in the best health possible to take care of Kai and our daughter, Grace. I didn't want to feel so vulnerable anymore. I had put on almost a stone in weight. My husband Toby and I signed up for the 'Hope Programme' for parents of children

with cancer and it encouraged regular, gentle exercise and goal-setting. I started going for a walk and listening to audio books every day, while we also bought family gratitude journals and sat down with them after dinner each night. It was great listening to the children and seeing their pictures and ideas, and it often descended into a competition of who had the funniest picture or story, with a lot of laughter. I read books that would help ('Dare' by Barry McDonagh was a good one) and got myself a counsellor.

Nearly all of it went out of the window when Kai headed into another round of intense treatment, but the foundations were there, and I knew what would help even if I wasn't actually doing it. This time, I took salads from M&S into hospital. I was also ready to ask friends and family for help, which made the burden easier. One friend would suggest walks so I could offload, another lent toys so Grace had something different to play with as we semi-isolated again. This has no doubt been the hardest year of our lives, but physically and mentally, we are in a better place now and I'm grateful for the coping techniques we've found.



Beth and her son Kai



▼ Kai, Beth, Grace and Toby



How complementary therapies can help emotional wellbeing

Kate Beddow uses types of complementary therapies such as Reiki and journaling to help the wellbeing of families affected by childhood cancer. Here, she tells us more.

What is Reiki?

Energy healing has grown in popularity over the last 20 years and is now offered in some cancer centres or by cancer charities. Perhaps the most common form of energy healing is Reiki, which originated in Japan in the 1920s. It's a gentle therapy which involves the Reiki practitioner either hovering their hands over the body, or gently placing their hands in key positions. Reiki practitioners believe this increases the flow of energy around the body, to allow it to heal itself more efficiently.

WHY I USE REIKI:

- It's gentle
- You don't need any equipment (as long as you have your hand, you can help someone)
- Anyone can learn Reiki
- Where medicines aim to heal the physical body, Reiki aims to work in a holistic way supporting emotional issues and wellbeing

All of these benefits are particularly relevant when you support a child through cancer treatment. An example of a way Reiki may help is if they are anxious and can't sleep, Reiki could help calm them down.

Journaling

I have worked with the Childhood Cancer Parents Alliance (CCPA) for many years, providing everything from talks at conferences and Reiki sessions at pamper days, to online mindfulness and support for parents with their wellbeing. Most recently, I've been running online journaling sessions for CCPA. Journaling is a wonderful way to process the events we're experiencing, and when we write something down, we are able to release it from our minds.



As well as a way of improving emotional health through processing our experiences, some research studies suggest that when people write about upsetting experiences, for as little as five minutes a day, it may boost their immune system and may even heal wounds more quickly. The advantage of writing therapy is that, again, there is no specialist equipment needed. You can

sit in bed with a notebook and scribble away and the effects can be profound.

There are so many ways that we can support our physical and mental health, and energy healing and journaling are two of them. As someone who is passionate about them both, I cannot recommend them to you enough and hope that they can help you.

FOR MORE INFORMATION



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Does virtual 'acceptance and commitment therapy' work for young people with brain tumours?



- ▶ **PROJECT TITLE:** What helps and what hinders in remotely delivered 'acceptance and commitment therapy' for survivors of childhood brain tumours: A diary and interview study
- ▶ **PROJECT TEAM MEMBER:** Katie Powers, assistant psychologist (pictured left)
- ▶ **INSTITUTION:** Nottingham University Hospitals NHS Trust
- ▶ **AMOUNT AWARDED:** Approx. £14,065 (funded by CCLG Late Effects Project Grant)

Young people who have been treated for a brain tumour are found to have the worst quality of life of all cancer survivors. And, despite their psychological and social needs being so important, they're often overlooked in research. In an effort to improve the physical and mental health of young people diagnosed with or treated for a brain tumour, the ACT Now study (funded by The Brain Tumour Charity), is investigating whether a psychological therapy called 'acceptance and commitment therapy' (ACT) is both useful and possible. ACT uses techniques to help people accept the things they cannot change, whilst committing to doing things that really matter to them personally. In our study, ACT is delivered by clinical psychologists once a week for 12 weeks. To start with, sessions were going to be mostly face-to-face but, because of the pandemic, we actually delivered all sessions virtually.

We're delighted that CCLG has funded a further study, which will help us understand what young people think about ACT as video-therapy, including what helped and hindered their engagement with the therapy. To start with, we're conducting interviews with some of the young people who have finished their therapy within the ACT Now study. We are asking what it was

like to work with a clinical psychologist and receive ACT virtually, and the overall impact that the therapy has had on them.

So far, we've interviewed 12 young people and are starting to see some recurring themes in the interviews. For many of these young people, this was their first time having psychological therapy, which made it difficult for them to know what to expect. However, many of them hoped to learn some techniques to navigate their feelings and cope with the everchanging pressures of adolescent and young adult life.

When asked about what it was like to receive therapy virtually, almost everyone said that it was easier for them to access therapy this way, despite occasional technological difficulties. The clinical psychologists were able to be flexible around the interviewees' busy schedules, which would have normally made accessing therapy more difficult. ACT gave the young people an opportunity to learn about themselves and how they can live life in a more personally fulfilling way. They told us that they found being involved in the study a positive experience, and that ACT helped them psychologically, physically and socially.

Making sure that young people feel this video-therapy works for them is a key priority. Hearing the experiences of all the interviewees so far has helped us think of how we can make sure we deliver

the best possible video-therapy for young people diagnosed with or treated for brain tumours. We can also use these findings to help develop video-therapy techniques for young people who have other cancers in the future.

We're so grateful to CCLG for supporting this project and for the young people in the ACT Now study who have volunteered to take part in the interviews so far. We hope to capture even more experiences in the coming months.



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

60 SECONDS WITH

Dr Susie Willis



Clinical Psychologist at Royal Belfast Hospital

for Sick Children (RBHSC) talks to us about her work.

Q: Tell us about your career so far?

A: I qualified as a clinical psychologist from the University of Surrey in 2010. Upon qualification, I initially worked in London, but moved to Northern Ireland at the end of 2011 to begin working at RBHSC.

Q: Tell us about your role in supporting children and their families affected by childhood cancer?

A: My role is incredibly varied, which is one of the reasons why I love my job. Day to day, my time is split between supporting inpatients and their families on the ward, and seeing patients in my outpatient clinic. Clinical psychologists use their knowledge of behaviour and feelings to try and understand any problems that children and their families may be having. We listen to concerns and then, along with the medical team, try to find a helpful way forward together.

During treatment for cancer, this work might include adjusting to a diagnosis, supporting procedures and/or difficult aspects of treatment, developing coping strategies to manage pain/symptoms of treatment, supporting uncertainty and difficult decisions that need to be made, juggling cancer and everyday life, carrying out neuropsychological assessments, and helping support families whose child is at the end of life.

In addition to the therapeutic work, I'm also involved in training and teaching other professional groups, offering staff support and being involved in service development initiatives, research and audits. There are so many rewarding prospects in paediatric and adolescent cancer care for clinical psychologists.

Q: Did you always want to be involved in childhood cancer care?

A: I knew during my doctorate training that I wanted to end up working in paediatrics, but it wasn't until my first post at University College London Hospitals (UCLH), where I was working in the Teenage Cancer Trust Unit, that my passion for this patient group began. I realised then that this was an area of work that I loved.

Q: What's the most rewarding thing about your job?

A: Too many things! Having the privilege to get to know and work alongside families during one of the most challenging times of their lives, has to be one of the most rewarding parts of my job. It never ceases to amaze me how children, young people and their families cope and manage with cancer treatment, and to be invited to support them

during this journey is an honour. Working alongside amazing colleagues, who are equally as committed and passionate, is also incredibly rewarding. There's no price you can put on feeling valued in work.

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

A: I can think of many moments where I've felt proud of the work I've done, and proud of the teams I belong to. But creating systemic change, whereby families directly benefit from something I have supported and/or stood up for, gives me the most pride and job satisfaction.

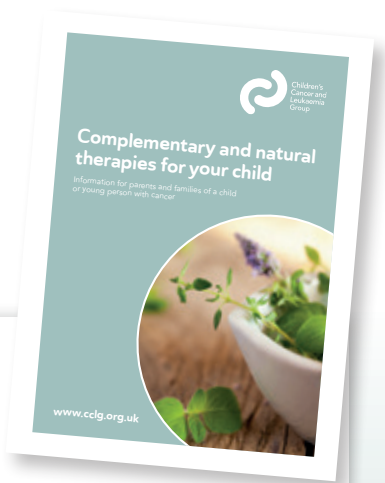
Q: Do you have any advice for families affected by childhood cancer to help with their wellbeing?

A: Try and be kind to yourselves and remember how amazing you are. You can only do so much. Whenever you can, breathe in fresh air and nourish your bodies with some gentle movement and rest. Learn how to find joy in the simple things in life that matter to you, whether this is the smell of coffee, the beauty of cherry blossom, or the sound of the sea (even if it's only on an app!).



▲ Susie and team

ASK THE Expert



What are complementary and natural therapies?

Complementary therapies can play a part in supporting children and teenagers through treatment by offering relaxation and calmness. They are typically used alongside a patient's standard medical treatment and though they do not treat or cure cancer, they can offer relief from symptoms and help promote feelings or emotional or physical wellbeing.

What can they be used for?

- Helping children cope with the side effects of treatments, such as feeling sick, pain and tiredness
- Helping children to comfort themselves and ease their fear and stress
- Helping children sleep better
- Triggering the release of feel-good hormones to feel better and more peaceful

Where can I find a complementary therapist?

Complementary therapy for children isn't as readily available as it is for adults so finding an experienced practitioner may take a little time. A free complementary therapy service may be available within your child's main treatment centre or local shared care centre. Your child's nurse specialist or keyworker will be able to tell you more about what is available.

Your hospital's information centre may have local information on what might be available. You can also ask your GP, local support services and local voluntary organisations who may offer free complementary therapies.

You can also search locally for private therapists but a cost will be involved. It's a good idea to check the credentials of the therapist to ensure they have received the correct training and have experience of working with cancer patients.

What examples of complementary and natural therapies are there, and what do they do?

- Acupuncture – inserts needles into the skin at various points of the body, which stimulates the nerves to release feel-good hormones. This may help with sickness, pain and breathlessness
- Aromatherapy – uses essential oils to help cope better with stress and emotional wellbeing, promoting healing and relaxation of the body, mind and emotions
- Art therapy – helps children to express confusing and distressing thoughts and feelings through fun artistic activities
- Music therapy – uses music and sound to help improve emotional wellbeing and relieve stress. It's also fun and engaging for children

- Massage – helps to soothe tension and stiffness by improving the flow of lymph fluid and blood around the body to promote a feeling of overall wellbeing. It's useful in calming children and helping them to sleep better

How can relaxation techniques help and what are they?

Relaxation techniques offer simple and easy ways to help your child to relax and reduce stress and you can try these at home. These include:

- Deep breathing exercises – there are many apps and online resources to help with this
- Using imagination - to create a peaceful environment such as playing on a beach or hearing the sound of the sea
- Mindfulness – focusing on the present moment so you become more aware of the sights, smells, sounds and tastes that are around you at any one time, which can help to reduce stress and anxiety, and help children to release bottled up emotions

Adapted from the CCLG publication 'Complementary and natural therapies for your child'.



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

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



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