

FREE

WINTER 2023 | ISSUE 101



Children's
Cancer and
Leukaemia
Group

the EXPERTS
in CHILDHOOD
CANCER

contact

SUPPORTING FAMILIES THROUGH CHILDHOOD CANCER

MAGAZINE

Food and nutrition

What types of nutrition support are there in children's cancer care?
What research is happening to improve nutrition for patients?



BREASTFEEDING
DURING TREATMENT



INNOVATIONS IN
HOSPITAL FOOD



Family Story

Hannah Longstaff, mum to Matilda who was diagnosed with leukaemia last year, tells us how her daughter's appetite increased after being put on steroids, and about the support she has received **Page 6**

BACK TO BASICS:

**Eating and nutrition
while on treatment**

Louise Henry, Advanced Dietetic Practitioner, provides an overview on nutrition during childhood cancer care and offers some tips to families **Page 8**



TAKING BACK CONTROL

Emily Piszton, diagnosed with craniopharyngioma when aged 11, explains how her tumour and its treatment caused her to gain weight, and what she did in response to this

Page 14

INSIDE THIS ISSUE... ON FOOD AND NUTRITION

Winter
2023

- 05 Rudi Keyser, whose daughter was treated for cancer in 2011, tells us how a decade later he developed an innovative food-ordering app to help young patients eat while on treatment
- 06 Hannah Longstaff, mum to Matilda, tells us how her daughter's appetite increased after receiving steroids while on leukaemia treatment and about the support they received
- 07 Sarah Cripps, whose son Teddy was diagnosed with acute myeloid leukaemia as a toddler, explains the crucial role diet and nutrition played throughout his treatment

EVERY ISSUE



- 04 **Medical adviser**
Dr Ren Manias introduces the theme of 'Food and nutrition'
- 04 **News in brief**
A round-up of the latest updates in childhood cancer
- 08 **Back to basics**
Louise Henry, an advanced dietetic practitioner, provides an overview on nutrition during childhood cancer care and offers some tips to families
- 15 **A parent's view**
Claire Crowley describes the challenges of feeding her son James while he was on treatment for leukaemia and the nutrition support he received
- 17 **Research focus**
'Starving' brain tumours: A research project funded by The Little Princess Trust in partnership with CCLG
- 18 **60 seconds with...**
Laura Sealy, a specialist paediatric dietitian, talks to us about her work and research
- 19 **Ask the expert**
Professor Bob Phillips explains why your child might feel sick during treatment and the effect this could have on appetite

ON THE COVER



- 10 Dr Mark Brougham and Dr Raquel Revuelta-Iniesta tell us about the importance of nutrition and what research is happening to improve this area of care for patients
- 12 Karen Jepson, an advance paediatric dietitian, explains the positive impact breastfeeding during treatment can have for young children with cancer
- 14 **Patient story**
Emily Pitsztan, diagnosed with craniopharyngioma when aged 11, explains how her tumour and treatment caused her to gain weight, and what she did in response to this
- 16 Breeana Gardiner, a specialist paediatric dietitian, explains the different types of nutrition support for childhood cancer patients

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...

From Contact's last edition:



"Really interesting. Thank you!"



Insightful webinar on late effects welcomed by families



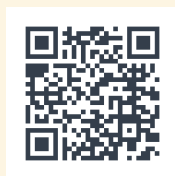
"What a fantastic webinar tonight presented by @CCLG_UK with Nicky Webb. All about children's cancer survivors late/long-term effects... So refreshing to see acknowledgement that it doesn't end with the bell."



"Nicky was clearly very passionate about the topics she covered and was very knowledgeable. Was very insightful and answered my questions without having to ask any."



"What a truly fantastic webinar yesterday. As an 'end of treatment family', we often feel isolated and ignored. Whilst you don't wish health complications following treatment on anyone, it was refreshing to hear we aren't on our own."



Watch our webinars here ▲

CCLG's award-winning information supports families across the world



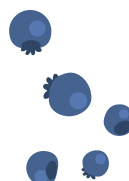
"Folk from all around the world rely on and value these factsheets. Thank you, CCLG."



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!



Children are known for being fussy eaters anyway, so coping with eating and drinking during cancer treatment can be even

harder. Food can taste strange, it can be difficult to swallow or digest, and often children just don't feel hungry. Or, the opposite is true, where children on steroids are constantly hungry and crave food all the time.

Both issues can cause huge pressure at home where families are trying to deal with tense mealtimes at the end of a long day. Babies and young infants are also affected and continuing to breastfeed can help them to feel comfort and calm. In this issue, we learn more about how children are supported with their food and nutrient intake to make sure they stay as healthy as possible throughout their cancer experience and beyond.

Claire



There's still time to send digital Christmas cards...

Stay in touch with loved ones with our animated paperless Christmas cards.

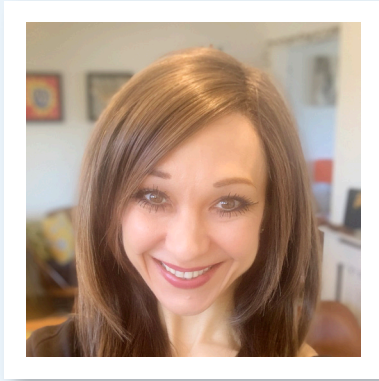
All proceeds will support CCLG's work supporting families and funding life-saving research.



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MEDICAL ADVISER

Dr Ren Manias

Consultant Paediatric Oncologist at Southampton General Hospital and CCLG member

Encouraging children to eat well can be challenging at the best of times, but feeding children undergoing cancer treatment is an entirely different ball game. Children can swing from demanding food at all hours to refusing to eat at all because of nausea and appetite loss. Taste preferences change and children may 'go off' foods they previously enjoyed. For some, eating is one of the only things they can control, whereas others are afraid of feeling or being sick or experiencing pain.

Eating well in hospital can be difficult, too. Food has a reputation for not being particularly nice, and cooking your own healthy meals while on an oncology ward isn't easy. Weight loss/gain leads to very visible changes in the appearance of children undergoing treatment, and parents can feel huge pressure to prevent both. The stress and lack of control can have a hugely negative impact, compounding an already anxious and distressing time.

There's also the issue of deciding what type of foods to provide. Oncology wards have dietitians who can help advise, monitor weight and prescribe enteral and parenteral feeding regimens. This can be helpful, but by no means solves all underlying problems.

Some parents worry children will develop bad eating habits during treatment. Requirements for tube, PEG or IV feeding can cause concerns that children will forget how to eat, and others worry that giving in to steroid-fuelled demands for crisps and chocolates will negatively impact them later in life. While most feeding and weight issues resolve when treatment stops, some conditions do lead to long-term problems with appetite and weight. Tumours in certain parts of the brain can cause an insatiable appetite and rapid weight gain, which can be very difficult to manage for both parents and children. This has a huge psychological impact, which is important to acknowledge and develop coping strategies.

As professionals, we could all benefit from thinking more carefully about how we approach feeding and nutrition. I hope we can learn from what is shared here by parents, children and professionals to help improve this important aspect of care.

NEWS IN BRIEF

New tool can help analyse quality of life after childhood cancer

A new measurement tool will help assess the quality of life of childhood cancer survivors. Doctors in the Netherlands have worked with patients and survivors to develop a set of outcome indicators that measure health issues. By making the balance between survival and quality of life measurable, the outcome indicators will help improve care for children with cancer.

(Source: *News Medical Life Sciences*)

Breakthrough in screening genes for the right treatment

Australian researchers have found they can improve the chances of finding the right drug to kill a high-risk child's individual cancer through a new system of rapid drug screening. 'High-throughput' drug screening involves growing cancer cells from a patient's primary tumour sample in the laboratory, then screening these cells against potential drug treatments to see how the cancer responds. Once drugs that have the potential to kill an individual child's cancer are isolated, these are tested in patient-derived tumour models of the cancer to further validate their potential effectiveness.

(Source: *MedicalXpress*)

Predicting risk of second cancers in childhood cancer survivors

A polygenic risk score can predict the risk of second cancers in childhood cancer survivors who were treated with chemotherapy, according to researchers in the US. They believe a polygenic risk screening approach may be a valuable complement to an early screening strategy on the basis of treatments and rare cancer susceptibility mutations.

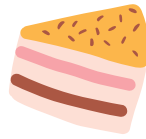
(Source: *Journal of Clinical Oncology*)

Healthy diet lowers risk of cardiovascular disease in childhood cancer survivors

Research from the USA supports recommendations that a diet rich in fruits, vegetables and whole grains and with a moderate intake of animal-based foods, sugar, and salt may lower the risk of cardiovascular disease (CVD) in long-term adult survivors of childhood cancer, as it does in the general population. Given the high burden of CVD in childhood cancer survivors, nutrition education and dietary interventions early in survivorship care need to be a part of CVD prevention and management.

(Source: *BMC Medicine*)

How a food-ordering app in hospital is helping young cancer patients



Rudi Keyser's daughter was treated for cancer at Great Ormond Street Hospital (GOSH). He tells us how a decade later, as its Interim Head of Catering, he implemented an innovative app to help young patients to eat.

In 2011, my then 18-month-old daughter always seemed to be poorly. Despite numerous GP visits, we were told it was simply seasonal colds/flu. However, eyebrows were raised during a visit to her paediatrician, and a few days later, she was diagnosed with acute myeloid leukaemia. This began a six-month stay at GOSH, where 10 years later, in November 2021, I became Interim Head of Catering. It was, and still is, an organisation I hold very close to heart.

"I decided to build a new system which would allow patients to order food when hungry, with the aim of delivering freshly cooked food within 30 minutes from order - within their own 'appetite window'!"

I spent my first few weeks observing how the catering service worked. The kitchen and catering staff were brilliant in so many ways, though the feedback around food was often negative. I also observed that the food provision hadn't changed since my daughter had been discharged. During her stay, I'd bought into the idea that young patients on chemo don't eat because of flavour

profiles changing, but during my chats with patients, parents, dietitians and ward staff, it dawned on me that the issue wasn't only about this or poor food choice, but also about mealtimes.

Hospital catering has been burdened with getting lots of food out at specific times throughout the day, causing service bottlenecks. This resulted in hot meals being served cold, or delivered hot to a patient who wasn't hungry at that time, so the meal was left at the end of the bed. By the time the patient lifted the lid, the meal wasn't very appetising.

I decided to build a new system which would allow patients to order food when hungry, with the aim of delivering freshly cooked food within 30 minutes from order - within their own 'appetite window'. Over nine months, I implemented a basic food-ordering system. I had an ever-changing list of patients, generally referred by dietitians, identified as struggling with food choices or flagged for not taking in enough calories.

Each day, I'd do my 'rounds', asking patients what they'd like to eat and, more specifically, when. The answers were simple. Teenagers and young adults don't want dinner served at 5pm. They want dinner around 7pm and love a 'takeaway'. So, that's what we did. My fantastic team made deliciously dirty burgers and cheesy, saucy loaded fries, sweet and sour chicken noodles, fragrant curries and more! These were all delivered by hand, in a brown paper bag in a takeaway experience.

I remember the first patient, a teenage boy, on his third round of chemo. He was losing weight and refusing to eat. After his first personalised 'dirty

burger', his mum said he'd have "eaten the wrapper", had he been able. A teenage girl, really struggling with treatment, set us challenges every day. It was a highlight for her and for me, seeing her eyes light up every time we took her order or delivered her food.

By the time we got signed off to run a 'proof of concept' for my food app, my team was well-drilled in tweaking orders and running food directly from kitchen to bedside. The app was so simple in its complexity. Think Deliveroo, but for hospital! Each bedside was given a QR code, linked to the patient's dietary requirements which could change daily. The patient, parent or team member could scan the QR code, and a menu, dynamic to the patient, would be populated. We rolled this out across six wards, for six weeks, offering tailor-made meals to patients and even parents, too!

The findings were overwhelmingly positive and the GOSH innovation team concluded the app should be rolled out permanently. The concept was also submitted to Public Sector Catering Awards for Best Innovation - and won!



Dealing with food cravings while on steroids

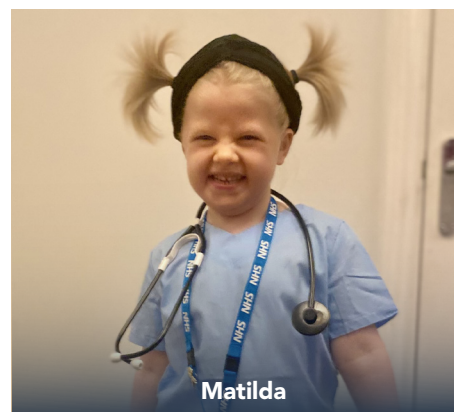


Hannah Longstaff's daughter, **Matilda**, was diagnosed with acute lymphoblastic leukaemia (ALL) in February 2022, aged three. She tells us how Matilda's appetite increased after being put on steroids and about the support she has received.

I think for all oncology parents, hearing the word 'steroids' makes the hairs on the back of your neck stand up. This is the case in my house, anyway. Children with cancer already face so many rigorous side effects of chemotherapy, but on top of that, they also have to deal with a whole host of other side effects from other medications they may be on, such as steroids.

We have a very complex relationship with steroids in our house. As part of her treatment, Matilda has a five-day course of dexamethasone twice daily, every four weeks. On one hand, we're grateful that they get our daughter Matilda eating and thankful they're helping to fight the cancer. However, the challenges of the accompanying side effects have really hit us hard. These haven't just been perhaps the more commonly known side effects like 'roid rage' and tiredness, but Matilda has also experienced a massive increase in appetite. The sheer amount of food that's consumed during those five-day courses is enough to feed a bodybuilder for a week!

The cravings from the steroids can arrive at any time, and I often find myself cooking pasta and pesto at two in the morning for a very 'hangry' little five-year-old. Matilda's 'go-to' food while on steroids is eggs. This could be in any form, from boiled to scrambled, fried to poached, and we're often finding ourselves getting through 30-40 eggs in a five-day period. The increase in appetite was a shock to the system, especially in the induction phase of treatment because she went from losing weight from not eating, to having an insatiable appetite and we just couldn't fill her.



Matilda

sometimes this could be difficult because when Matilda wasn't eating we just wanted to give her calories, no matter the form or nutritional content.

Matilda is now five years old. She's 19 months into treatment with six months left and doing well. She's recently started school full time and is coping really well with this new change. Her school has been amazing with helping to accommodate her food cravings while on steroids. They've allowed Matilda to bring in her 'super snack pack' and keep it safely refrigerated in the kitchens to make sure any food that's taken in is stored safely due to her immunocompromised state. They've also set up a little area called 'The Hive for Matilda', where she can go if she's feeling stressed and overwhelmed while on steroids. Matilda also has support from teaching assistants, so if at any time she needs a rest or a snack in the hive, she can do so straight away. The support from the school has been incredible and Matilda has really started to thrive in this environment.

If I could offer some advice to other oncology parents navigating their way through treatment, it would be to take everything one step at a time. It's going to be difficult, but there's support out there if you need it.

If I could offer some advice to other oncology parents navigating their way through treatment, it would be to take everything one step at a time.

We received support from the hospital dietitians on how to try and maintain a healthy balanced diet, which was really helpful. The dietitian suggested eating three healthy meals each day along with snacks that were more filling. Having regular meals rather than having lots of smaller snacks throughout the day would help Matilda get the nutrients she needed. It was suggested that quick and easy healthy snacks to have on hand when needed, such as cucumber, carrots and celery sticks with a dip, boiled eggs and nuts, was a fun way to provide a filling, healthy snack. Trying to limit processed foods such as fast foods, cakes and sweets was recommended, too, though



Matilda (right), Hannah, dad Oliver and little sister, Clara

Why I'm determined to advocate for better nutrition during childhood cancer treatment

Sarah Cripps' son, Teddy, was diagnosed with acute myeloid leukaemia (AML) when 18 months old in April 2022. She explains the crucial role diet and nutrition played during Teddy's treatment.

I vividly remember watching Dr William Li's TED Talk, 'Can we eat to starve cancer?', on YouTube. It filled me with hope and relief. Dr Li, a Harvard-educated doctor, offered a new perspective on how to help my 18-month-old son, Teddy, who was diagnosed with only 3% AML in his blood after a short period of night sweats and swollen lymph nodes. Our doctor initially sent us away for six weeks, but my gut told me to seek a second opinion.

Less than 48 hours later, a 7am phone call from another doctor who'd taken Teddy's blood told us to rush to A&E. "We need to rule out leukaemia," he said. It was a whirlwind of emotions. Teddy would need chemotherapy and a bone marrow transplant due to the leukaemia's unfavourable genetic profile, which gave him only a 13% chance of event-free survival.

After the initial shock, and lots of wine, I gathered my strength and set my sights on giving Teddy the best possible chance at beating this terrible disease. My background in nutrition studies provided me with valuable insights into the role of gut health and the immune system. I knew that 80% of the immune system resides in the gut, and the gut microbiome was gaining importance in medical research.

Do I believe that food cures cancer? No, I don't. But I firmly believe that nutrition played a crucial role in my son's survival. It's fuelled my determination to advocate for better nutrition in oncology treatment and recognition of its importance. While Teddy's journey through treatment was exceptional, every child deserves the same chance.

Teddy flew through his treatment. He didn't experience mucositis, didn't require milk feeds or total parenteral nutrition, and he didn't lose his hair until after the transplant. Studies are now emerging that demonstrate how a good diet can reduce side effects and improve outcomes for cancer patients. Nutrition works cooperatively with medical treatments, rather than against them.

"Smoothies, homemade juices and broths played a crucial role in Teddy's diet."

My approach was to 'eat the rainbow' and hide nutrients wherever I could. I wasn't willing to settle for hospital food, so I worked closely with the hospital kitchen to cook to my recipes. Teddy ate cooked meals because they were gentler on his body, which was already facing cancer. I took inspiration from the American Gut Project and made delicious, nutrient-rich meals and used herbs and spices for flavour. I learned that when taste buds change during treatment, gradually increasing the flavours helps combat the blander taste. Herbs and spices became my best friends in creating meals that Teddy enjoyed.

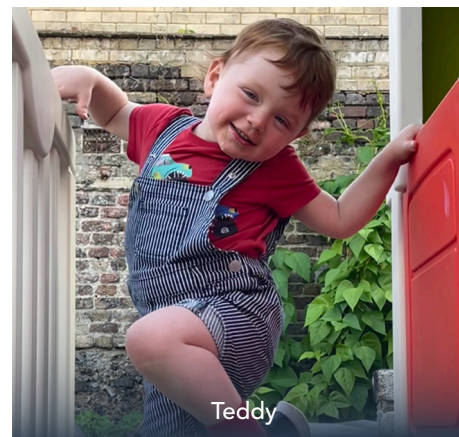
Smoothies, homemade juices and broths also played a crucial role in Teddy's diet, particularly before treatment cycles. These options ensured he received the essential nutrients while undergoing intense treatments.



Teddy (right), Sarah, dad Kurt and Teddy's twin brother George

While improving nutrition may take a lot of effort and dedication, it can only benefit the child. Teddy is now a vibrant three-year-old, living life to the fullest, attending nursery and playing in the park with his twin, George. He's 15 months post-transplant and has a 97% probability of a cure. His journey has inspired many others, some of whom have seen remarkable results by focusing on nutrition.

I'm sending my best wishes and hope that your outcome is as positive as ours. Taking care of your mental health, even through something as simple as maintaining a healthy diet, is essential. There are no words I can offer to make your journey easier, but please know that my inbox is always open on social media, and you don't have to face this battle alone.



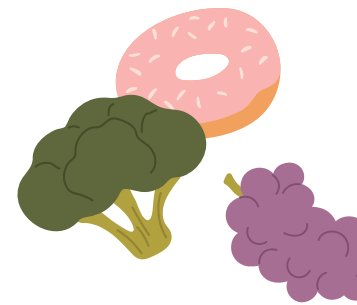
Teddy

 @teddys_tonic

 chuckingthekitchensinkatcancer



Eating and nutrition while on treatment



Louise Henry, *Advanced Dietetic Practitioner (Paediatrics and TYA) at The Royal Marsden Hospital, gives an overview on nutrition while a child is receiving cancer treatment, including its challenges and tips to support families.*

Nutrition is an important part of supportive care for all children receiving cancer treatment. Research tells us that patients who are well nourished, which means not too thin or too overweight, tolerate treatment better and may even spend less time in hospital. Having good nutrition, which includes all the energy, protein, vitamins and minerals they need, supports the child throughout treatment and beyond.



How is diet and nutrition affected by cancer and its treatment?

Every child's different when it comes to the impact of their cancer and its treatment on their appetite and diet. For some, the challenges may resolve themselves quickly, while for others they may come and go depending on their treatment cycle, and for a few, they may exist throughout treatment. Usually, children will return to their pre-diagnosis

eating and drinking patterns at the end of treatment.

Many factors affect how children feel about eating and drinking when on treatment and it can be very stressful for patients and their families. Younger children are often diagnosed at a stage in their development when they're exploring foods and developing their own food habits, likes and dislikes.

Having treatment that affects appetite, taste and bowel function means the normal development of food behaviours can be affected, leaving some children with very selective eating habits. For older children, they may already be selective eaters, or they may use what they're willing to eat or not eat as a way of trying to make a statement or control one aspect of their care. At any age, the key is to work together with your healthcare team to support your child and use different strategies to encourage a balanced diet. Unfortunately, there isn't a quick fix, but it can be helped by being consistent and trying some of the tips on the opposite page.

Who is most likely to have problems eating and drinking?

Every child is different, and it's difficult to say who will have the hardest time eating and drinking. Younger children, children undergoing transplant or high-dose chemotherapy, children having radiotherapy affecting the mouth or throat, and those with larger tumours are at higher risk of struggling to eat and drink enough. Children who have steroids throughout treatment or have problems with mobility have a higher chance of gaining too much weight.

What can I do if my child is losing weight or won't eat?

Nutrition isn't only about keeping a healthy weight. We also need to make sure that children have enough protein, vitamins and minerals in their diets, too. If you're worried about your child's diet, ask to speak to the dietitian who'll be able to make a full assessment and provide advice on how to improve the balance of their diet, how to enrich or fortify foods, and if you need to give your child extra vitamins or minerals. If eating and drinking is difficult, they may recommend a form of 'nutrition support' (see page 16). Its aim, no matter what type is used, is to return to eating and drinking as soon as possible, although many factors affect how quickly this may happen.

What if my child's gaining too much weight?

This can be a problem for some children, especially if they're taking steroids. Research has shown that some children find it difficult to have a balanced diet or lose any excess weight at the end of treatment, so it's a good idea to look at their diets early on in treatment and to try to avoid excessive high fat, salty snacks if they have a good appetite. Try to keep a balanced diet with plenty of fruit and vegetables and wholegrain carbohydrates to keep your child feeling fuller, for longer. Aim to stick to three meals per day with two or three 'healthy' snacks in-between and encourage your child to keep active, where possible. The NHS website has lots of useful tips and ideas for promoting healthy eating for children and you can speak to your dietitian for more individual advice.

Should any foods be avoided?

Children having treatment for cancer can become very unwell if they develop food poisoning. The NHS recommends avoiding foods known to have a higher risk of causing food poisoning.

Foods to avoid	Safe alternatives
Raw or lightly cooked eggs	Well-cooked eggs with a solid yolk, well-cooked scrambled eggs, omelette
Pâté	Cold meats or fish
Pasteurised or unpasteurised mould ripened soft cheeses with a white coating (brie, camembert) or soft blue cheese such as gorgonzola or roquefort (unless cooked until piping hot)	<ul style="list-style-type: none"> • Hard cheeses made with pasteurised milk such as cheddar, stringed cheese, gruyere, edam, stilton • Soft cheeses made with pasteurised milk such as a cream cheese, cheese triangles, feta, halloumi or paneer
Unpasteurised milk, cream or yoghurt	Pasteurised milk or cream, yoghurt (some centres ask you to avoid probiotic products and yoghurts)
Raw meat, raw shellfish or food made from raw shellfish	Well-cooked meat or shellfish are safe to eat
Uncooked smoked fish such as smoked salmon or raw sushi	Smoked fish can be eaten if thoroughly cooked

Good food hygiene is essential for all patients and the NHS website and Food Standards Agency have some great advice on the safe preparation, cooking and storing of foods. The food hygiene rating scheme in England and Wales (the free 'Scores on the Doors' app) is very useful if you chose to eat out.

Other useful resources



Download or order our 'Helping your child to eat well during cancer treatment' publication by scanning the QR code



Or visit:

- www.scoresonthedoors.org.uk/
- www.nhsinform.scot/healthy-living/food-and-nutrition#food-safety-and-hygiene
- www.food.gov.uk/safety-hygiene/home-food-fact-checker
- www.infantandtoddlerforum.org
- www.bda.uk.com/food-health/food-facts/all-food-fact-sheets.html



HELPING WITH SELECTIVE EATING

- **Make sure your child's symptoms are well controlled:** speak to your team about medication to control nausea or vomiting, mouth ulcers and infections, constipation and diarrhoea
- **Try to keep normal food routines:** encourage regular meals and, if possible, try eating together (even in hospital, parents, brothers and sisters are great role models for encouraging eating and making mealtimes fun)
- **Never force-feed children** or follow them around with food as this can add to stress and anxiety around food and doesn't usually help them eat more
- **Mealtimes should last no longer than 20-30 minutes.** Remove any leftover food without comment or fuss
- **Taste changes are very common:** experiment with lots of flavours and textures, especially if your child reports that food doesn't taste nice or as it should
- **Involve your child in preparing and cooking food.** This is a great family activity and often inspires children to try new foods
- **It can be helpful to limit food choices at mealtimes** – children often don't know what they want to eat, so having a couple of easy-to-make choices can help them decide
- **Clear the table, have a break and offer some food later** if a mealtime is getting too stressful



How we are making sure all young patients receive the best nutrition care and support



Dr Mark Brougham and **Dr Raquel Revuelta-Iniesta** co-chair the Cancer and Nutrition working group for Children and Young People, part of the National Institute for Health and Care Research (NIHR). They tell us more about the group, the importance of nutrition and what research is happening to improve nutrition for patients.

Who are we?

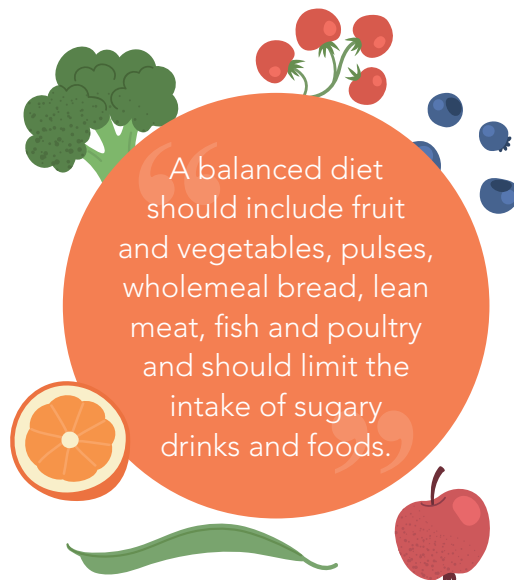
We are multidisciplinary, and include oncologists, nurses and dietitians with both clinical and research experience. Our aim is to improve nutrition for children and young people with cancer, at diagnosis, during treatment and throughout long-term follow-up.

Why is nutrition important for children and young people with cancer?

We all need good nutrition for normal growth, development and general wellbeing. Being malnourished means that the amount of energy, protein and other nutrients aren't at ideal levels in our bodies, which leads to health problems. Usually, we think about under-nutrition where people are too underweight. However, there are some cancers which lead to weight gain, usually due to treatment.

Although patients may gain weight, this can mean less muscle mass, made worse by being less physically active. Both under- and over-nutrition can lead to a lack of important nutrients. Studies show that many young people with cancer have problems with nutrition when they're first diagnosed. Unless this is managed carefully, these may get

worse during and after treatment. This is a particular concern in cancers that require more intensive treatments.



These issues are important because nutrition can affect various aspects of cancer treatment. It's well documented that children and young people with cancer who are well nourished react better to treatment and have improved outcomes. The way the body handles drugs, including chemotherapy, varies according to each individual body. Chemotherapy dosing is usually based on body weight, so if there's weight loss, doses may be reduced, resulting

in less effective treatment. Impaired nutrition can also negatively impact the immune system, which is already weakened by cancer treatment.

Many children and young people with cancer need surgery and poor nutrition can weaken the body's ability to heal wounds. Those with poor nutrition also report low energy levels and a reduced sense of wellbeing, affecting both psychological and physical health. Follow-up studies show that young cancer patients can also have long-term consequences of impaired nutrition, and these are often under-recognised and difficult to manage, as discussed below.

How do we measure nutrition status?

Nutritional screening is an important part of patient care, which includes measuring weight and height, to identify those at risk of becoming under-nourished and begin thorough nutritional assessments by a dietitian. Nutrition assessment in childhood cancer is an evolving process, looking into a child's growth (body mass index (BMI) and body composition), blood markers, including micronutrients (vitamins and minerals), clinical history, treatment and likely side effects that might affect food intake.

Also, what children eat and other factors that might affect nutritional status should be assessed. Monitoring is essential in highlighting when and if further nutritional support is required.

Traditional measures of weight, height and BMI are used in practice to assess whether a child is growing how they should be, particularly during treatment. However, BMI has limitations and may not accurately reflect nutritional status. This is because loss of muscle mass often develops during treatment but can be accompanied by an increase in fat mass and fluid, which results in the patient's weight appearing satisfactory. 'Arm anthropometry' is used to measure the circumference of the mid-upper arm to estimate muscle mass, the 'triceps skinfold thickness' to estimate fat mass, and 'bioelectrical impedance' to estimate body composition (muscle and fat mass).

These assessment methods are quick and non-invasive, and aren't affected by fluid or tumour mass, giving a more accurate assessment. However, they take time and are performed less often.

For children over two years old, diet quality and intake are assessed by performing a diet history, using a food diary or food record chart over several days, at home or on the ward. These can provide further information to help with nutrition support.

What can we do to support a patient with their nutrition?

How we improve nutrition depends on the patient's nutritional status: under-nutrition or overweight, and the reasons for this. With under-nutrition, support aims to promote weight gain and growth. This may involve one or more of the following:

- adding extra nutrients or calories to food
- giving oral supplements
- giving nutrition direct to the stomach or intestines through a tube
- giving nutrition directly into the veins, bypassing the gastrointestinal tract, called parenteral nutrition. This is given to those who have issues with their gut function such as severe mucositis and enteritis

We make decisions after a thorough nutritional assessment and discussions with the patient, families and the multidisciplinary team.

Healthy eating guidelines are important to minimise weight gain associated with steroids, which may be used in treatment, most commonly for those with acute lymphoblastic leukaemia (ALL). A balanced diet should include fruit and vegetables, pulses, wholemeal bread, lean meat, fish and poultry and should limit the intake of sugary drinks and foods. These recommendations can be very difficult to follow, particularly when patients experience taste changes and nausea due to chemotherapy and prefer high-energy, sweet or very salty foods. Expert advice is therefore essential.

Are there any issues after treatment?

Many studies show that children and young people who have finished treatment may have long-term issues related to nutrition. Patients are particularly at risk of being overweight and can develop 'metabolic syndrome'. This describes a combination of excess weight, high blood sugar levels, high blood pressure and high cholesterol, which can lead to heart disease, stroke and type 2 diabetes. Those treated for cancer may also have less dense bones. These are all monitored during long-term follow-up of patients.

What research is happening to improve this area of care?

As cancer treatment advances and survival rates improve, more research now takes place in supportive care, such as nutrition, to help reduce side effects and improve quality of life. Research has mainly investigated how cancer and different types of treatment affect nutritional status, to understand more about when nutritional support is needed and what support is most effective. Some studies have compared the effectiveness of NG and PEG nutrition in young people having chemotherapy, but more studies are needed to provide evidence on what the best approach is in different circumstances.

Apart from vitamin D, micronutrient status isn't routinely measured, due to limited research and difficulties in interpreting results. Emerging research suggests micronutrient deficiencies and toxicities are common during cancer treatment, and these may be associated with more side effects. However, more research is needed to find out

what the ideal micronutrient levels are and how much supplementation should be recommended.

In the meantime, advice is based on national guidelines, such as a diet high in fruit and vegetables, which have been shown to decrease infection rates and mucositis in ALL patients. This is encouraging and highlights the need for more children- and family-centred dietary support.

Being overweight can affect how some drugs work, and therefore some patients may need extra support to lose weight. This approach differs to historical weight-focused, high-energy, high-protein diets for all young people with cancer, which doesn't differentiate between nutritional needs of those with different diagnoses.

These newer, targeted approaches give insights into the impacts of diet and lifestyle changes early in treatment and show that support related to nutrition and activity can be provided early to help patients.



Breastfeeding during your child's cancer treatment

Breastfeeding during treatment can have lots of benefits for infants with cancer. **Karen Jepson**, Advanced Paediatric Dietitian at Cambridge University Hospitals NHS Foundation Trust, explains more about the positive impact it can have.



Karen Jepson

Each mother's breast milk is tailored to the child and is the perfect food for young children, including those having treatment for cancer. Easily digested and containing antibodies which change according to the child's needs and mother's environment, it's particularly useful and protective for those with lowered immunity, and can help them recover more quickly after periods of illness or mucositis.

The unique bonding experience it gives enhances overall health and development, promoting feelings of warmth, closeness and normality at a time of stress. Even during periods of not being able to feed, nurturing skin-to-skin contact has proved to be beneficial and, as well as having a calming effect, it helps weight gain and to sustain milk supply.

Can there be challenges?

It can be hard and exhausting. Mothers isolated from their usual support networks need to constantly adapt to their child's changing needs in unfamiliar surroundings. A child may need to be fasted for procedures or refuse feeds when unwell. Sometimes, they can be too tired or unwell to effectively breastfeed, develop mouth sores – making latching on difficult – or they may suffer from side effects from treatment such as nausea, vomiting or diarrhoea. If breastfeeding less than usual, or your child needs to rest their tummy, mothers can express their milk to maintain supply. If a child can't feed from the breast, they may be offered expressed breast milk as mouth care and/or via a nasogastric tube.

Some have additional requirements and need a specialised formula to supplement breast milk. A dietitian will ensure mothers are able to make an informed choice on how best to support their child while continuing breastfeeding.

If you are breastfeeding be kind and look after yourself

It's normal for parents to experience a mixture of feelings and emotions after giving birth, which is escalated by the uncertainty of having a child with cancer. It's important you are kind to yourself and reach out for help. A good place to start,

which will make a world of difference to your confidence, is to check the hospital room to make sure:

- you have a comfy chair that offers good support
- you have a breast pump at the bedside and know where and how to store your milk

How to look after yourself:

- Sleep and rest when you can
- Block off time to be left undisturbed and let people know you need some quiet time
- Eat and drink well with regular meals and snacks
- Take a breastfeeding multivitamin and mineral supplement
- If your child is more demanding and clingier, remember to move position regularly and take a break, even if just for a shower or a short walk
- If your child is fasting, ask family or staff members to help and distract

Though breastfeeding your child while dealing with the rigours of treatment may have its challenges, with patience, practise and support, you can navigate through them and enjoy a fulfilling breastfeeding journey. Remember, prioritise your own wellbeing, seek assistance and cherish the precious moments spent nourishing your little one.

Don't be afraid to ask questions

Share your worries and reach out for help and support. Your child's dietitian, lactation consultant or health visitor can support you, while the charities below offer free advice:

- La Leche League GB (www.laleche.org.uk)
Helpline 0345 120 2918
- National Childbirth Trust (www.nct.org.uk)
Helpline 0300 330 0700
- The National Breastfeeding Helpline: 0300 100 0212
- Association of Breastfeeding Mothers: 0300 330 5453
- First Steps Nutrition (Independent Health Nutrition Charity) www.firststepsnutrition.org/eating-well-infants-new-mums



Lauren Mercer's four-year-old son **Murray** was diagnosed with Ewing sarcoma, at 11 months old. She tells us about her experiences of breastfeeding Murray during his treatment.

Lauren's story

Murray was a natural when it came to breastfeeding and, as my second, I was also better, so our breastfeeding journey started off brilliantly and I was very lucky for it to continue without a hitch. But never did I expect Murray's consultant to politely ask me to continue breastfeeding during his treatment. As a parent, you never want to have this conversation about your child, and it wasn't easy having a lot of pressure put on me, as his mum, to be the main caregiver during his treatment. Unfortunately, for us, this was also during the pandemic, so 'main' caregiver turned into 'sole' caregiver.

I can't write this and say it was an easy path to follow, but if you were to ask me if I would go back and make the same choice, the answer is easy. Yes. I can confidently say that breastfeeding gave Murray a level of comfort he sorely needed and the added immune support it provided was something I'm glad I could offer. Plus, being a breastfeeding mum meant the hospital fed me, so I was very grateful to the staff for bringing me endless dinners, cups of coffee and chocolatey snacks! The downside to breastfeeding during treatment was that I had to leave my other son at home, and my husband Carl couldn't help in the way he wanted to. I know he wished he could have done more, but we still believe it was the right choice to make.

The hardest part of our journey was during our stem cell transplant where Murray developed VOD (veno occlusive disorder) and I was told he couldn't be fed. This was hard on two levels. Firstly, I wasn't able to provide the comfort he needed and the drink he very desperately wanted. It made for one very grumpy Murray! Secondly, hand pumping in a tiny hospital bath isn't one of my most dignified moments in life! But, we got through it.

When Murray finished treatment, I was still able to feed him and we kept going until he was two-and-a-half years old and was ready to stop. He then moved on to eating properly and devouring anything sugar-coated like any normal toddler would, and I also enjoyed a glass of wine.

It was a longer breastfeeding journey than I had expected, but as I said, I would go back and do it all again in a heartbeat. I'd advise any mothers out there who have been asked to keep up breastfeeding during treatment to do it. It will be hard but worth it, and it's truly something that I believe made our journey that little bit easier. A word of warning though: make sure your team allows someone else along for any appointment that requires fasting - that isn't easy for anyone involved!



Prof Sam Behjati, Murray's consultant

When I first met Murray and his parents, there were many complex and difficult things to discuss. At some point, there was an opportunity for me to raise the question of breastfeeding, which Lauren responded to with cautious enthusiasm.

From my perspective, in addition to nutritional and emotional benefits, breastfeeding is a powerful way of providing comfort to young children as they undergo intense treatment. Moreover, it serves as a very useful indicator of how well a child is. Breastfeeding is hard work for children – it requires energy, focus and coordination. Therefore, when Murray went through treatment, especially the more intense stretches, monitoring his ability to breastfeed helped us greatly in our clinical assessment of him.

A downside of breastfeeding is that it can be somewhat impractical. And when it doesn't work, it can be an additional source of stress in already most difficult times. I'd therefore like to emphasise that breastfeeding should be considered a useful extra in the treatment journey of a young child. If it works, great, and if it doesn't, or isn't for you, don't worry.



Murray receiving treatment



Murray now



Taking back control

Emily Pizton was diagnosed with a type of brain tumour called craniopharyngioma in 2022, aged 11. Now 12, Emily explains how her tumour and its treatment caused her to gain weight, and what she did in response to this.

Before my diagnosis, I was really active. I enjoyed horse riding, roller skating and swimming, and I loved school. But life changed for me when I began getting headaches at the end of 2021, and these became increasingly intense as time went on. I initially thought they might have been due to COVID-19 or bumping my head while horse riding, but my mum became worried when they didn't get any better. I also put on quite a lot of weight, which was put down to stopping playing sport during the COVID-19 pandemic.

After going to the GP several times, my parents took me to Slovakia to stay with my grandmother and undergo further investigations for my headache. While there, I had an MRI scan which showed I had a brain tumour, and an operation was performed to remove it. Since then, I've also had treatment with proton beam radiotherapy in London.



Emily paddleboarding at the beach

I've experienced a lot of physical and emotional challenges from my tumour and its treatment. Craniopharyngiomas lead to an increase in appetite and make it very hard to resist food. They can also cause problems with hormones and reduce metabolism, making it easier to put on weight. This happened to me, and I put on quite a lot of weight in a short amount of time.

My metabolism wasn't working properly, and I was also always hungry and couldn't really control that hunger. That led to extra little snacks, and me eating at night and hiding food, too. Emotionally, this was a really tough time for me. I was very self-critical and really didn't like what I did or how I did it. I felt guilty, but I just couldn't control it.

Then, one night, my mum found me eating in the pantry. We had a tough yet honest conversation about everything and then we started to learn how to control the food and what to eat. We made a plan to help me not eat as much, or make healthier versions of things I was eating, like really cool desserts.

Mum really helped me and made these nice, healthy breakfasts and lunches. I ate loads of salads, vegetables and fresh fruits, cut out sugar and had no takeaways or fast food. Everything was fresh and homemade, with little seasoning and no oil. We swapped biscuits for sugar-free versions, and because I love to bake, I then started baking my own with banana and oats. Mum swapped potatoes for butternut squash, and tried to replace high-calorie foods with foods low in calories and that helped a lot.

I also had problems with digestion and at one point I was constipated for a long time and had to go to hospital. I then stopped eating meat and haven't

done since spring this year and have felt much better since. I'm still sometimes eating fish to get some protein and eating lots of walnuts to help my memory and brain function, and Brazil nuts to help my thyroid.

Mum's been great and gives me so much comfort and support. She searches all the time to find new ways of helping me. I know for some children, it's hard to talk to their parents, but I'd say try to if you can. Don't hide a problem, as it will only get bigger. I also want to tell them to keep going. Be resilient, never give up, but be kind to yourselves, too.



Emily and her friend, Buster

Dr Ren Manias, Emily's consultant

Emily has managed to take control of the situation in a truly inspirational way. It's a remarkable achievement for her to lose weight despite her diagnosis. She has an amazingly positive attitude and has shown incredible strength and determination.

A parent's view...

Embracing support

Claire Crowley's son, **James**, was diagnosed with leukaemia in November 2014. She describes the challenges of feeding James while on treatment and the nutrition support he received.

Feeding your children is a primary responsibility of parenting. It's one of the basic human needs that our little ones need us to provide for them. So, when it's challenged - because of a cancer diagnosis - we can sometimes feel like we're failing, but this simply isn't true.

James has Down's syndrome and has always had difficulties with food. In fact, he needed an NG tube for the first 11 days of his life as he struggled to feed. By the age of seven, he was typically eating Weetabix, baby food pouches, smooth yoghurts, Heinz fruit puree pots and cheese Wotsits. As well as having a small mouth cavity, children with Down's syndrome often have low muscle tone, making the tongue appear too large, which can affect eating development. James also has sensory processing difficulties and is genuinely frightened of new foods (and oral medicines).



James during treatment

So, when he was diagnosed with acute lymphoblastic leukaemia (ALL), I immediately requested an NG tube, surprising everyone. Don't get me wrong, I don't love them, but they are a pretty clever way of putting foul

tasting medicines into the stomachs of children who feel sick because they're on chemotherapy! Bypassing the tastebuds in the mouth is most sensible.

Anyone who has managed an NG tube knows the battle when re-passing a tube (they come out too easily when chemo causes vomiting), the tape hurting the face and, of course, the tube not aspirating when you need to do a pH test (resulting in a trip to have an X-ray and possible repositioning or replacement). But what they do give you, is the ability to feed your child at a time when they need good nutrition to cope with treatment.

"If you are watching your child suffer with weight loss, vomiting and a lack of appetite, don't think in any way you're failing, because you're not!"

Other than tiredness and some visible signs of low platelets, James didn't seem too poorly when he was first diagnosed - that was, until he started his chemo! Within a week, he was being sick regularly, struggling to eat and needed Peptamen feeds via his NG tube to supplement his calories and fluids. Just over a fortnight into treatment, his cold sores and mucositis were so severe he needed lots of pain relief as well as complete gut rest and was put on total parenteral nutrition (TPN). His mouth was so sore he even stopped talking.

Watching him lose so much weight in that first few weeks was petrifying. His muscles wasted away, and he turned a pale shade of grey. But, with the help

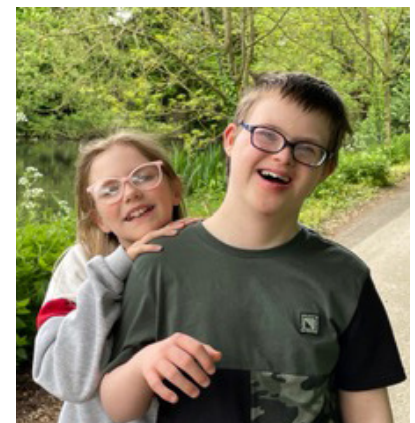


Claire Crowley and her son, James

of his NG tube, James continued on treatment and gradually gained weight.

After about eight months, we had a traumatic weekend where we simply couldn't re-pass a new NG and he ended up going into surgery for a gastrostomy. He had his inserted via keyhole surgery, so I've never referred to it as a PEG (percutaneous endoscopic gastrostomy). Once it had settled, it was replaced with a low-profile gastrostomy button (he now has a tummy button close to his original belly button). We had some problems with over-granulation initially, but a surgeon cauterised it (burned it off) and it has been pretty much trouble-free ever since. He can bathe and swim with it and at night I attach an extension and plug him into an overnight feed. I buy fabric button pads which absorb any moisture from the stomach (which is acidic).

It's so important to remember that if you are watching your child suffer with weight loss, vomiting and a lack of appetite, don't think in any way you're failing, because you're not. But do embrace the medical options - these devices are designed to help us care for our kids while they go through treatment.



James with his sister, Anabelle

Nutrition support options in childhood cancer

Sometimes, due to the effects of their cancer and its treatment, children may require extra support to get the nutrition they need. **Breeana Gardiner**, a specialist paediatric dietitian in haematology/oncology at Great Ormond Street Hospital, explains more.



Children with cancer may need additional nutrition support with advice from a dietitian in order to get enough nutrition and help maintain normal growth and development. The dietitian will conduct an assessment which considers weight pattern, cancer type and treatment, symptoms, medications, diet and food/cultural preferences. From this assessment, your dietitian may recommend certain strategies to ensure your child gets enough calories and protein, along with the necessary vitamins and minerals.

Food-based approaches

These are recommended during treatment if your child is having difficulties with their usual eating. They include 'fortifying' foods with high energy/ fat and protein components such as nut butter and cream. Your dietitian can also advise you on modifying your child's diet if they're experiencing taste changes, nausea or constipation, for example.

Oral nutritional supplements

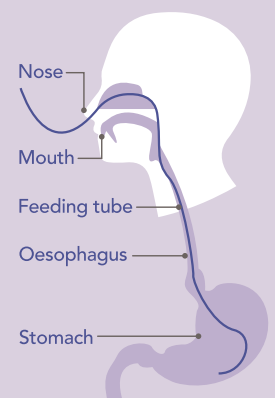
Usually milk or juice-based drinks, these might be recommended in addition to food-based approaches if your child needs additional nutrition. The type of supplements recommended will depend on your child's taste preferences and age. These can be taken between or after meals.

Tube feeding

Tube feeding may be advised if your child continues to struggle with eating, is losing weight, or can't take supplement drinks. It may be recommended early in treatment, where side effects could lead to weight and muscle loss. Parents may feel upset about this, but tube feeding is very common and for some treatments or types of cancer, nearly all children will need it at some point. It can relieve the pressure around mealtimes and can allow meals to remain a positive experience, while additional nutrition can be provided through the tube.

The most common type of tube feeding is a nasogastric tube (NG), a flexible, thin, plastic tube that goes down the nose to the stomach. It can be put in by the nurse or if your child is having a general anaesthetic for a procedure and can take a few days to get used to. A gastrostomy tube (PEG) is a feeding tube surgically placed directly into the stomach. The dietitian will discuss the best type of tube for your child, while play specialists can help prepare them for having the tube.

Your child can be given their usual formula milk, expressed breast milk or a different liquid feed in addition to oral intake through the tube. The feeds are all nutritionally complete with the right calories, protein, vitamin and mineral intake and can be adjusted to your child. Tubes can also be used to give extra water and medication. Families can be taught how to use the tube and feed through it at home safely.



▲ NG tube

Intravenous nutrition or parenteral nutrition (TPN or PN)

A specialist form of nutrition given via your child's central line directly into the blood. It might be recommended if it's not possible to give extra nutrition through a feeding tube or if your child's gut isn't working properly and needs rest, usually because of sickness, diarrhoea or mucositis. It's usually only available in your child's main treatment hospital and not usually for home feeding. It provides energy, protein, fat, vitamins and minerals and must be given for at least five to seven days. Blood levels need to be closely monitored when a child is receiving PN.

Remember...

Your dietitian and treatment team are there to help and will discuss and guide you through all the decisions regarding nutrition support.

'Starving' brain tumours



Dr Madhumita Dandapani

- ▶ **PROJECT TITLE:** Exploring alterations in amino acid metabolism as novel therapeutic targets in paediatric glial tumours using advanced metabolomics methods
- ▶ **LEAD INVESTIGATOR:** Dr Madhumita Dandapani
- ▶ **INSTITUTION:** Children's Brain Tumour Research Centre, University of Nottingham
- ▶ **AWARD APPROX:** Approx £99,000 (Funded by The Little Princess Trust in partnership with CCLG)

The idea for this project came from earlier research work I'd done on ways in which cancers manipulate normal cellular processes to their advantage. Basically, we know that cancer cells grow rapidly when compared to other cells, and therefore need more nutrients overall. Sometimes, a particular cancer will require specific nutrients (not dissimilar to certain types of plants needing special fertilisers) to grow or survive.

Identifying and disrupting these specific processes could lead to selective death of cancer cells. Normal cells would usually tolerate nutrient deprivation, and this offers the prospect of kinder, more effective therapies. I'm particularly interested in amino acids, which are the building blocks of proteins, and how cancer cells respond to modulating the different amino acid levels in the laboratory.

The project was carried out in three stages:

- 1) We looked at existing datasets with information on genetic data from the different types of brain tumours. We looked at whether different types of brain tumours had differing levels of genes involved in using or making specific amino acids
- 2) We checked if we identified the right amino acids in each

tumour type by staining tumour tissues for key proteins

- 3) We looked to see if we could detect these amino acids in the cerebrospinal fluid (CSF – the fluid that surrounds the brain) of children with a type of brain tumour called ependymoma and whether their levels differed from children who didn't have a brain tumour

What have we found?

We've identified specific amino acids that are altered in ependymoma and high-grade glioma which are both hard-to-treat cancers. We've published our results which show that both tumour types are addicted to an amino acid called arginine. High-grade gliomas also use lots of another amino acid called tryptophan. We're now focusing on understanding the role of arginine in promoting tumour growth as well as trying to block this pathway to see if this kills the tumour cells.

We've also identified certain chemicals (metabolites) in the CSF of children with ependymoma that are different to non-tumour CSF. We're carrying out further work to characterise these metabolites and understand their role in the disease process. We're now working on large scale CSF analysis to study changes in samples taken from children with brain

tumours. This method may help us identify patients at high risk of relapse at the end of conventional treatment. We're also validating the amino acid pathways identified by this project, with a view to developing new therapies for these difficult-to-treat cancer types.

At the moment, the research is still in its early stages and not at the point where it can alter treatments. However, we have several exciting leads which we are verifying, and I'm also trying to develop new drugs or repurpose existing drugs from drug libraries, with colleagues in the cancer field. If this work is successful, we may have prototype drugs to carry out further research before they can be tested in early phase clinical trials in a few years' time.

A final message

I'd like to thank CCLG and The Little Princess Trust for funding this work and our subsequent work. We'd also like to thank patients and families – your altruism in consenting to tumour banking for research enables researchers like me to make new discoveries with a view to finding better, kinder treatments for children and young people with cancer.



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

60 SECONDS WITH

Laura Sealy

Specialist Paediatric Dietitian at
Bristol Children's Hospital



Q: Tell us about your career so far?

A: I studied archaeology and anthropology at university and only discovered dietetics a few years later when I realised I could combine my love of food and interest in healthcare into a job! I qualified as a dietitian working with adults 20 years ago, then specialised in paediatrics 15 years ago, and have been working with children and teenagers undergoing cancer treatment at Bristol Children's Hospital for the past seven years.

Over that time, I've discovered that while the energy and passion of many paediatric oncology dietitians to support patients and families is there in abundance (both in the UK and internationally), there's a need for high-quality research to guide us in many aspects of nutritional care. I wanted to contribute to this research, so applied to the National Institute for Health and Care Research (NIHR) internship programme for the opportunity to improve my research knowledge and explore how we support nutrition for those undergoing treatment.



Laura with her patient, Ida

Q: Tell us about your role in supporting young people and their families?

A: As the lead oncology dietitian at Bristol, I help manage nutritional supportive care of young people having treatment under the haematology, oncology and bone marrow transplant teams. This involves getting to know many young people (and their caregivers) and their unique dietary preferences, requirements and experiences, and responding to the different nutritional challenges the cancer and treatment might pose.

A day's work may include discussing food hygiene and safety practices with a new patient or how to optimise the nutrient quality and dietary patterns of a toddler who's recently started steroids, working out a nasogastric tube feeding plan to support someone experiencing mucositis, or advising on the best initial foods to try for gut graft versus host disease. We might also be contributing to a parenteral nutrition prescription for someone whose gut is temporarily unable to digest food or discussing ways to wean a young child back onto an oral diet after they've been completely dependent on tube feeds over treatment.

One important thing I've learned in my time on the job is that nutrition needs never stay the same over treatment and it's essential to plan with the young person and their family to anticipate how they may change and how we can respond to this in a way that's effective and acceptable for them.

Q: What does your job mean to you?

A: I'm proud of feeling a useful part of a team of expert colleagues. Being able to contribute positively to care is really important to me.

Q: Tell us about your NIHR research?

A: I'd like to find out how to best support young people's nutrition while having treatment for osteosarcoma. Due to intensive chemotherapy that affects taste, appetite and the ability to digest nutrients, many children lose weight and strength. We know this can be linked to their risk of catching infections and impairs their quality of life and the ability to tolerate the chemotherapy itself.

Nutrition can be supported differently for this condition across the UK, and I'd like to explore what effect different approaches might have on patients' psychological and physical health, and their experience of treatment. I firstly need to review what evidence is out there already and then I hope to survey both healthcare professionals and those with direct experience of osteosarcoma, on their thoughts around what we currently do and how it might be done better.

Eventually, I'd like to be able to support the development of guidelines on nutritional care for this diagnosis.

Q: How can patients support your research?

A: If you've gone through or are going through osteosarcoma treatment and are interested in telling me about your experiences around nutrition and what you think of my project plan, please do get in touch by emailing laura.sealy@uhbw.nhs.uk.



ASK THE **Expert**



Professor Bob Phillips, Consultant Paediatric Oncologist and Contact's medical adviser

Why might my child feel sick on treatment?

The biggest factors are the effects of treatment directly, and the anticipation of feeling sick from previous experience. The drugs, and to some extent radiotherapy, can affect the lining cells in the gut, leading to feeling sick. Some of the chemo can directly affect cells in the 'vomiting centre' of the brain too, as can anaesthetics and some other medicines. If the gut gets slowed down, with drugs or the effects of tumours, surgery or infection, it can lead to the stomach being fuller, and vomiting from this, too.

How can feeling sick or the anti-sickness drugs affect appetite?

Sometimes, chemo can just stop children and young people wanting to eat, while the anti-sickness drugs can also sometimes reduce appetite - some through slowing the movement in the guts, some through making the child or teen feel sleepy. Conversely, some, like steroids and nabilone, can have the opposite effect and increase appetite.

What can help my child feel less sick?

Anti-sickness drugs given as prescribed can be helpful. Each type of drug acts on the signalling systems which tell the body to vomit in different ways. If they don't seem to be working, please let your medical team know as they may be able to alter the medications to use a different way to reduce the nausea signals. Overall, the drugs don't really work any better if given intravenously, orally or by patch, though we know that some children develop a strong vomiting response to some tastes or tablets. When chemo is finished, it's rarely of value to keep on giving anti-sickness regularly, but occasional doses may be needed, while for some drugs, a longer course is required.

Another, less talked about aspect of care is how managing constipation can reduce vomiting. Trying to help keep nice, soft poo coming out daily will make it less likely that there'll be big problems with sickness. This is one of the reasons why carrying on giving anti-sickness drugs, like ondansetron, can be counterproductive, as one of its side effects is increased chances of constipation.

When a child is receiving chemotherapy, it can also be helpful to not ask about feeling sick too frequently. This can raise an expectation that it's going to happen

and can start the feeling of nausea. Providing plenty of things to distract from the chemo going on can be helpful. Some respond to scents of home or a calm and relaxing place - though for others, this could be unhelpful as it then makes home remind them of times spent in hospital. Occasionally, the 'travel bands' acupressure devices can help, and some find foods with ginger useful.

My child feels sick the evening before chemo, would it help to give them more anti-sickness drugs in the days before?

For nearly all anti-sickness drugs, the answer to this is 'no'. The nausea which develops before chemotherapy isn't caused by the drug in the system, but instead by anticipation and the brain and body getting worried about the nausea which might be coming. In fact, we know that children who do get given extra are more likely to feel sick. This type of nausea is a 'conditioned response'. We know good control of nausea and vomiting can help, as can some relaxation/distraction/hypnosis approaches. Your hospital play specialists and/or psychologists are happy to advise on these type of approaches to help.


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.




Give the Gift of CHANGE

Virtual gifts from CCLG are expressions of love, support and hope. Each gift is a donation that directly contributes to our mission of changing the future for children with cancer.

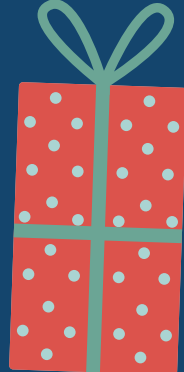


GIVE THE GIFT OF SUPPORT
for £10 to help us provide expert, reliable information and advice to families facing a childhood cancer diagnosis



GIVE THE GIFT OF HOPE
for £20 to support an hour of vital childhood cancer research

GIVE THE GIFT OF TIME
for £50 and help support our early diagnosis work



HOW IT WORKS

- 1 SELECT YOUR GIFT**
Choose from our exclusive collection of virtual gifts, each designed to make a meaningful impact
- 2 PERSONALISE YOUR MESSAGE**
Receive a premium A5 greeting card and a personalised gift certificate
- 3 SHARE THE GIFT**
Send the beautifully packaged virtual gift to your chosen recipient, spreading joy and making a difference

GIVE A VIRTUAL GIFT TODAY BY VISITING
shop.cclg.org.uk/virtual-gifts



Children's
Cancer and
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