Be aware of the

Early Warning

signs of childhood cancers

2nd Edition

EVERYONE KNOWS WHAT THE PINK RIBBON STANDS FOR, BUT DID YOU KNOW WHAT THE GOLD RIBBON STANDS FOR?

CHILDHOOD CANCER AWARENESS

"You may choose to look the other way but you can never again say you didn't know."

They ride tricycles in the hallway, not in the park. They know the names of their chemo instead of their classmates. Nurses and doctors are there new family. Their laughter will make a heart melt. Their strength will make a grown person cry. If you've ever seen a kid fight cancer, it will change your life forevever!

Be aware of the Early Warning signs of childhood cancers

2nd Edition

The Chartwell Cancer Trust
is a local registered charity that supports
The Chartwell Cancer and Leukaemia Unit in
The Princess Royal University Hospital,
Farnborough, Kent,
the children's Tiger Ward at
Queen Elizabeth Hospital,
Woolwich, London
and
services and initiatives in
King's College Hospital,
St Thomas' Hospital,
Guy's Hospital and
Croydon University Hospital.

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"Although September
was designated
**CHILDHOOD CANCER
AWARENESS MONTH**,
for some families it's:
January
February
March
April
May
June
July
August
September
October
November
December."

What's Inside

FACT: **What is Cancer?**

The body is made up of millions of cells. There are about 200 different types, which will all do different jobs.

During a child's life, cells divide and make copies of themselves. The new cells help them grow and replace older cells.

If something goes wrong when the cells are dividing, an abnormal cell may be produced. Sometimes abnormal cells continue to divide and duplicate. **Cancer** is the name given to an abnormal growth of malignant cells.

About Us

The Chartwell Cancer Trust Charities have been supporting cancer and leukaemia services in the Princess Royal University Hospital in Farnborough, Kent since 2005. We have been supporting Children's Cancer and Leukaemia Services in the Paediatric Oncology Shared Care Units in the Queen Elizabeth Hospital in Woolwich since 2014 and Croydon University Hospital since 2016. We also support projects and research initiatives that are shared with King's College Hospital, Guy's Hospital and St Thomas' Hospitals in London.

We hold monthly Meet Ups for Oncology Families in Bromley, Brixton, Croydon and Woolwich. We are very much a local Charity providing support for patients and families with children undergoing treatment. Our website has full details of the support we provide to NHS Services and the patients they care for.

This book is free of charge to you and your guests when you host an *Early Warning* Coffee Morning or Prosecco Evening. Hosts receive our Fun Pack which includes coffee or prosecco and full guidance to ensure a successful event. Please call our office or visit our website for details.

FACT: **Common Cancers**

In the UK, around 3,600 children and young people under the age of 25 are diagnosed with Cancer every year.

The most common type of Cancer in children under 15 is Leukaemia.

In young men aged 15-24, the most common Cancer is Testicular Cancer, and in young women in the same age group, the most common Cancers are Melanoma, Hodgkin's Lymphoma and Ovarian.

"Your life as you know it stops the second you hear the words 'Your child has Cancer'..

The same when it's your grandchild."

Foreword

I hope that you find the time to read this book. If you do, it may help you to recognise the signs and symptoms that could lead to an early diagnosis of Cancer or Leukaemia, possibly reducing your treatment level and maybe saving your life. It's written from a layman's perspective for busy people with normal levels of medical knowledge.

We start with stories written by parents of very young children who have been diagnosed with Cancer or Leukaemia and I warn you that some of the stories may bring you to tears. I urge you to read all of the stories because there is a message that runs through them. The symptoms are, in many cases, just the same as the symptoms of many other less sinister illnesses. However, after reading the stories you will know that lumps in unusual places, night sweats, easy bruising, unusual or excessive fatigue or unusual bleeds need to be investigated immediately.

The adult section starts with a short paragraph on most of the common and uncommon Cancers and types of Leukaemia. If you wish to expand on the short version there are more details further into the book.

Special thanks to the parents and families for sharing their stories, stories that would have been very hard to write, and giving us permission to share them with you. This edition has been compiled and edited from the design stage through to the final print by Barbara Field-Holmes of Bigg-In Words and I am most grateful to Barbara for her advice and guidance throughout the project. Special thanks to Natalie Reilly and Melody Berthoud for their continuing support and to Jan Bridge for proofreading for me.

I hope this book will encourage you to act promptly if you have any doubts about your health or the health of your children.

Michael

Michael Douglas
Trustee
The Chartwell Cancer Trust

"For me, one of the scariest parts about childhood Cancer and the lack of awareness that surrounds it, is the 'it could happen to anyone' aspect. It really doesn't care who you are or what you do. It's indiscriminate."

Annamaria's Story...

As told by her Mum, Lucia

Annamaria was diagnosed with Alveolar Rhabdomyosarcoma, a particularly nasty type of soft tissue Cancer which does not show up on X-rays, in June 2015. She died 18 months later, on the 26th December 2016.

The first warning signs appeared in early May 2015, a few months before Annamaria's 12th birthday. It all started with a stitch-like pain on her right side: she woke up on a Tuesday and told me she had been having this pain since the weekend. As was very typical of her, she had just soldiered on for two full days before mentioning anything to us. There had not been any trauma, sport accident, nor a fall in the previous days, and the pain was bad enough to take Annamaria to the GP practice. They thought there could be a possible issue with Annamaria's appendix and sent us straight to Lewisham A&E. Many hours later, after a cursory check, we were sent home with the usual recommendation to take paracetamol, wait and see. There were no other symptoms, no loss of appetite, no swelling, nothing unusual. Except that Annamaria was in pain all the time and she could not lie down in bed or stand straight because the pain became worse if she did.

Two or three days later we went back to the GP because there was no improvement; we were sent to A&E again to have her liver and gall bladder checked. Unfortunately, she was not considered to be ill enough and all possible explanations were given for her pain, such as "Her period might be starting soon", "She is stressed out

Annamaria enjoying time in her favourite dog-walking park with her beloved Nica.

because of her upcoming school exams", "It's all psychological". Five hours later we were still in A&E when Annamaria started having difficulty breathing because of the pain. She was sent immediately for a chest X-ray but, of course, nothing was detected because her type of Tumour is transparent to X-rays. In the meantime, she had to be excused from PE and other physical activities in school because she was in pain all the time, and also had to endure the scepticism of her teachers and the taunting of her classmates who accused her of faking it.

A few more days and we had to go back to the GP practice again. The Doctor this time was very dismissive and almost offensive, suggesting we were wasting valuable NHS time for something that was clearly the result of

Annamaria trying out one of the new gaming chairs that The CCT funded for the new teenager's room in the Tiger Ward.

a sport injury in school. He just would not hear that Annamaria had sustained no injury at all!

So Annamaria continued to endure her worsening pain, kept calm and carried on. Two weeks later, on a Saturday afternoon, we were watching TV when we both heard a crack, similar to what you would hear if someone did some extreme finger joint cracking: she looked at me and said: "That was from inside me!" We thought that was very weird, but as it did not happen again we dismissed it, until 11pm that night when Annamaria came down to say she had found a lump the size of an egg on her lower ribcage. I started getting very worried, but did not want to put her through a full night waiting in A&E, not on a Saturday night full of drunks, and because her pain had actually subsided over the previous few hours we decided to wait until the morning and call Seldoc instead. On Sunday morning we were told to go and see the Seldoc doctor next to the Lewisham Hospital's A&E. He said the lump was nothing at all, that it must be the result of an inflammation issue and had nothing to do with the pain Annamaria had been having over the previous month. He then asked us to go to the GP on Monday morning, get a blood test to look for inflammation markers and take it from there. We asked if we could do the blood test there and then, since we were already at the hospital and she had been unwell for so long. We were refused.

The GP we saw on the Monday morning understood immediately that the issue was serious, although she said this was the first time in her career that she had seen anything like this. She took pictures of the lump, sent us for blood tests and we resigned ourselves to wait for the results. I knew there was no time to waste, going again to A&E was not an option as Annamaria risked being dismissed and ignored again. I was then advised by a friend, who is an Ultrasound Specialist, to get from the GP an immediate and urgent referral for an Ultrasound scan at a different hospital. I did so, pulled Annamaria out of her school exams and took her to Chelsea and Westminster Hospital. The scan was performed in front of a Paediatric Specialist and this time they were taking us very seriously: even I could see a large mass under Annamaria's ribcage on the computer screen.

The rest is history: additional scans, tests, biopsies, the official diagnosis, the start of Chemotherapy (one of the most harsh and aggressive Chemotherapy treatments existing on the planet), the Radiotherapy, the attempt to carry on as much as possible as per normal. By the time the Tumour had finally been spotted it was 10cm in diameter and Annamaria was stage four as the Cancer had spread to neighbouring Lymph Nodes.

The strange thing is that Annamaria's pain had not been in the area where the Tumour had developed (inside her

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ribcage), but lower, where the tumour was pressing on the liver and other organs nearby – this is the reason why everyone was looking for problems with her appendix, liver or gall bladder. The cracking noise we heard hours before the first lump appeared was due to the Tumour finally bursting through the ribcage, and lessening the pressure and therefore the pain on the other organs.

Unless it develops in an area such as the head, neck or the groin, where it can be easily seen, Rhabdomyosarcoma is difficult to spot: X-rays do not detect it because it is a soft tissue Cancer, it is 'transparent'. And it is tricky to get an MRI or a CT scan if there is no other symptom or obvious reason to be suspicious.

Annamaria was in a lot of pain, but this did not count for those who assessed her. She was dismissed as a pre-teen having growing pains. We, as parents, knew something was very wrong and our instincts were spot on. But the NHS is bursting at the seams and there was no capacity to give Annamaria the attention she deserved and needed. Alveolar Rhabdomyosarcoma is a killer Cancer, which develops at an incredible speed: we were told that it is likely the Tumour had started developing only two months before diagnosis, a couple of weeks before Annamaria started feeling any pain. Even with an early diagnosis, nothing would have changed in the long run, she would have died anyway. But she would have had a few more months, maybe years, to do things she liked, fulfil more special wishes, go and mush with huskies in Alaska, which was her top desire. And we would have had more time with her.

Left and above, Annamaria's bench was installed in her favourite dog-walking park, and in use the same day.

CHILDHOOD CANCER AWARENESS

"If your child has any of the symptoms below, or you are worried, please see your GP to get them reviewed."

FACT: Symptoms

Weight loss • Sickness or nausea • Your child looks pale • Has a swollen tummy • Persistent pain (anywhere) • A swelling or lump • A new limp • Being constantly tired or irritable • Bruises easily or has excessive bruising • Nose bleeds or blood in urine • Night sweats or frequent high temperature • A new squint or problems with vision • Headaches or unusual white appearance of pupils (in eyes) in photos.

Most of the time, the cause of these symptoms will not be anything serious. However, if it is **Cancer, an early diagnosis can save lives.**

FACT: Diagnosis

When a child has symptoms that could be linked to Cancer, they are usually referred to a specialist hospital for further tests.
Tests include some of the following:
Blood tests • MRI scan • Biopsy • X-ray • CT scan • Lumbar Puncture • Bone Marrow tests • Bone scan • Ultrasound scan

DID YOU KNOW?

"Chemotherapy drugs are so toxic that the nurses need to wear protective clothing, specialist gloves and headwear.
Some chemo drugs are photosensitive and cannot be exposed to light."

"As a parent you are consenting to your child being pumped with poison because there is no proven alternative.
We need kinder treatments..."

Andrew's Story...

As told by his Mum, Melody

Andrew (three years old) and I were at our local singing group on Monday morning, 1st October 2012. In the afternoon he developed a temperature and was quite sleepy.

The following morning he had a fluid-filled spot on his tummy and I thought, "Aha! Chicken Pox". He'd had it before, I'd had it twice as a child, but I thought it was best to get him checked out anyway. I rang the GP and got an appointment for one hour later.

I arrived and went in to the consulting room where the GP instantly said: "Gosh, he is pale isn't he?" I agreed and answered: "Yes, actually my friends have commented on that." She asked me what else was wrong.

I listed a few issues other than the paleness. He had been sick on Saturday night, was really sweaty at night, and had had a few small nose bleeds on his pillow cover. He was very lethargic, walking him to pre-school was hard work. He didn't want to leave me and all he really wanted to do was flop about watching TV. We had been to Coolings Nature Trail at the weekend and he didn't want to walk, so my brother had ended up carrying him around.

As I was saying the list of symptoms I thought to myself, "I know what this means – Leukaemia". We were sent for a blood test at Queen Mary's Hospital in Sidcup. There, the doctors were obsessed over two bruises on his legs, which to me seemed like normal 3-year

old boy bruises. They took bloods (eventually) and then we waited all day for the blood results but then were sent home as the results had not come back.

That night, Joseph (Andrew's father) and I searched the Internet for the symptoms of Leukaemia and we talked ourselves out of it as it talked about 'excessive weight loss' and 'multiple infections', which we had not experienced.

I went to work the next day in Chafford Hundred. Joseph rang me in the morning to say that he had been told to pack a bag and go into the Tiger Ward at the Queen Elizabeth Hospital in Woolwich. Once there they told him that Blast Cells had been found in the blood. Joseph rang me again and told me to come straight away, which I did.

In hindsight and from looking back at the photos, we could see his tummy was big (enlarged spleen) and that he was looking pale and tired in photos from around August 2012. However, we were lucky that main symptoms to diagnosis was only three days.

"My heart goes out to everyone who is dealing with this illness."

"The pharmaceutical companies need to find something, yesterday!"

"Shame there doesn't appear to be a choice."

FACT: **Did you know?**

Chemotherapy was developed from the chemical weapon Mustard Gas. The first drug used for Cancer Chemotherapy was not originally intended for that purpose. Mustard gas was used as a chemical warfare agent during World War I and was studied further during World War II.

"Yes, what do we do? It's not as if we have a choice. We want our child to get better!"

"I had it for my Hodgkins' disease back in the 80s."

LITTLE KNOWN HAZARD OF CHILDHOOD CANCER:

Many children with Cancer are still in nappies. Parents are required to wear gloves and gowns to change their child's nappies while the child is in active treatment. They have to protect themselves from the toxicity of their own child.

Beau's Story...

As told by her Mum, Larissa

In May 2014, just two weeks into my new job, Beau, who was then just 2-years old, started to become unusually tired and slightly irritable. We put it down to my new work schedule but a week later, after a weekend away, her excessive tiredness started to ring alarm bells.

That weekend we took her to A&E at the Princess Royal University Hospital, who sent her home saying it was a virus of some sort. By this time Beau was incredibly pale with a large distended tummy. A couple of days later we took her back to the GP who could find nothing wrong with her. However, later that day the GP called me to say while she wasn't sure, it was probably a good idea to use my private health insurance and take her to a Paediatrician.

Months later I asked the GP if she had suspicions at the time, which she admitted she didn't so I'm grateful for her instinct. Just a few days later on a Saturday morning, barely two weeks into Beau's symptoms, we prepared to go swimming later that day after an appointment at the Sloane Hospital, Beckenham, to see the Paediatrician. I remember how excited the girls were for a swim – little did I know those swimming bags would remain untouched in the boot of our car for several weeks.

The Paediatrician didn't even examine Beau, he simply asked if she was normally so pale and about a few bruises, and then requested us to take her to the Queen Elizabeth Hospital at Woolwich. On hearing this my whole

Beau during her treatment...

body shook and I just knew. I remember asking him what was special about that hospital, being so far away, and looked him in the eye and asked if he thought it was Leukaemia? He confirmed that was his suspicion.

After dropping our elder daughter Eden off to her Grandma's, we had no idea Eden would end up living there for the next two weeks. Matt drove to the hospital forever the optimist that it could never be Leukaemia, but in my heart I just knew...

We didn't wait long in reception. They quickly sent us to a private room, where

the on-call Paediatrician again, didn't even examine her, but this time made it clear that he expected a Leukaemia diagnosis – only now, looking back at her appearance, can I understand his certainty. Then the nightmare began of the several attempts of cannulas, listening to your child in agony asking why we were hurting her. Just one hour later two doctors and a nurse walked in the room and of course we knew, it wouldn't take so many to tell you good news.

At that point our worlds imploded in a single second. My initial reaction was practical, what would we do about work, who would take care of Eden? They indicated we might need to be in hospital for a couple of weeks with treatment for a couple of years! There and then they told us it was ALL (Acute Lymphocytic Leukaemia) the 'good' Leukaemia, but it would need to be confirmed. I quickly learned to despise that term of 'good', having known several children to lose their lives to this 'good' disease!

After a day of hell at the Queen Elizabeth Hospital, Woolwich, of tests, pokes, cannulas, and the despair of telling loved ones, we arrived at The Royal Marsden Hospital and the reality hit me like a steam truck, while of course I knew Leukaemia was a Cancer, the sheer enormity only really hit me on arriving at the McElwain Ward – an impossible weight we are forced to carry, which only an Oncology Family can truly understand. Like many others our journey since that time has had ups and downs, I am always grateful for how well Beau has coped but the enormity and heavy weight of the uncertain path we tread is often unbearable.

We could not be prouder of how both our girls have coped, their tenacity and strength is inspirational. Clearly it has been harrowing to believe this is actually happening to our beautiful little girl. It is painful to watch her endure treatments which are so brutal for anyone, let alone a child, when all you want to do is protect her and take her place. Without any clues or warning, we were thrown into a world no parent or child should be part of. Quite honestly, it is a world we wish we knew nothing about, but it is a world filled with some of the most inspiring children you might wish to meet, children who show such incredible courage, who cope with traumatic treatments every day and they do so positively and with a smile. We are so proud to see how Beau has become one of these heroes.

We thank The Chartwell Cancer Trust for supporting us in so many ways; they have helped us as a family through the toughest of challenges any parent could ever face. The CCT have enabled Bromley Oncology Families to connect and support one another, which is an invaluable way of helping families through this journey.

Thank you for reading our story.

Beau 2015, after treatment, a brave 'hero' who showed enormous courage and bravery.

David's Story...

As told by his Mum, Toni

On 4th July 2013 we were given the most devastating news of our lives; "David has Cancer" My attempt at articulating the feeling that the impact of this had, would be to say that the world immediately exploded and crumbled around me. I know that for as long as I live I will never, ever recover from the shock of those three words.

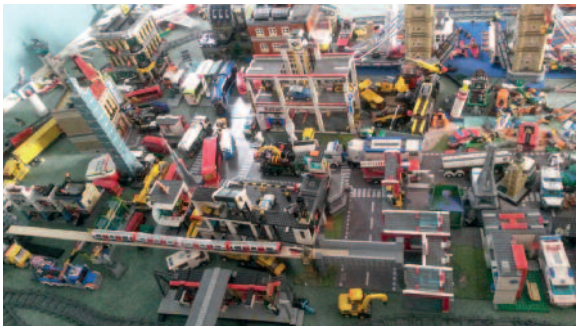
David instantly brought sunshine into our lives on 25th September 2003, and six weeks later I had the unforgettable experience of seeing his first ever magnificent and infectious smile. This smile gave us a glimpse of the huge character that was beginning to develop and become David's most striking and memorable feature.

By the age of four, David's passion for all transport, particularly trains, was well established as were his skills in design and construction, and by the age of six his now famous Lego City creation had begun. This became David's lifelong project and he would add to or update his city on a regular basis. Everyone that knew David agreed that he had the potential to become a great engineer or architect.

David was the happiest person I knew and always had such a lust for life. It was an absolute pleasure to be in his company and we always had plans together. Our 2013 summer plans included at least five dates (as we fondly called our days out) and a trip to Morocco we were preparing for. However, during July of 2013 we would instead experience the most traumatic and disturbing events imaginable.

A specific diagnosis for the Tumour found at the back of David's right nasal cavity was never established. Undifferentiated Nasopharangeal Carcinoma, Sarcoma and even benign were discussed. Initial treatment plans were postponed as we waited for a date for the removal and biopsy of this to be performed. Horrifically, the extremely aggressive nature of the disease emerged as the Tumour suddenly grew at an alarming rate, filling David's right nostril until a huge mass sat above his lip. Yet during this traumatic ordeal my son continued to laugh and smile, joking that he looked like an elephant.

Following David's emergency, life-saving surgery in the middle of the night on 2nd August and subsequent admission to Peadiatric Intensive Care Unit (PICU), his surgeon delivered the devastating biopsy results stating that the remaining mass would never respond to treatment and he possibly only had months to live. David's case was one of only 40 worldwide. However, once transferred to The Royal Marsden Hospital our Oncology Consultant remained extremely positive and hopeful that complete remission was possible.



Above, part of David's Lego City, and right, David's Tower Bridge and Architecture Display, on show at James Wolfe School.

Throughout the next four months David handled every gruelling round of treatment and scans with so much courage and dignity, way beyond his years and despite the awful side effects he suffered, he never complained. He continued to laugh and smile throughout, perfecting his impersonations of many of the medical staff members he met during his care, and he danced at every opportunity. The lovely aspect of his long, regular hospital stays was that David was still able to indulge in one of his passions – Lego building. David almost always returned home with a new addition coupled with a new design idea for his Lego City.

At the beginning of April 2014 we received the incredible news that the impossible had been achieved and David was now in remission. For the next two months we had the time of our lives, enjoying every moment of David's health and freedom. I will forever treasure the memories we created.

Heartbreakingly, this was short-lived. On 4th July 2014, a year to the day from his original diagnosis, it was confirmed that the disease had metastasised. The prognosis was awful but David was far too loved for us to ever give up hope.

It felt beyond cruel telling my sweet, brave boy that our summer dates and holidays were again being cancelled because "the naughty lumps" had returned. After a very brief period of anger, David's response after asking what his new treatment entailed was astounding. "I can handle that," he said.

Within six weeks a detected Pneumothorax marked the beginning of David's deterioration as the disease stopped responding to treatment. Further bouts of this recurrent episode of Pneumonia and other horrific symptoms emerged.

David's strength and positivity remained extraordinary. His primary concern throughout his whole ordeal remained Mum not being too sad or worried. David's Oncology Consultant agreed that the images in the scans depicting the extreme progression of his disease did not match his physical appearance. He remarked that the way David continued to handle his illness and treatment was "astonishing" and coupled with me begging, he agreed to the approval of the administration of two further treatment plans.

In David's case Chemotherapy was definitely the lesser of the two evils. I will always be beyond grateful that

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David's doctor authorised this further treatment. As well as allowing him to live a much more confortable life as his symptoms became less aggressive, it even enabled David to live out his dream.

On 21st November 2014 my son drove three trains on his favourite line of the London Underground system, the Jubilee Line. He was in his element and I had never seen him as content as he was on that special day.

David passed away in my arms at home in the early afternoon of Sunday 25th January 2015. I clung to his body for hours afterwards, never wanting to let my baby go. As I looked up, out of his bedroom window, I remember realizing that there was no colour in the sky at all. This observation was so symbolic of how my life had become from the moment of my beautiful son's passing – colourless.

The night before he died David told me that he wished he was famous. He had also told me the year before that once he "retired from Lego building" he would like for his city to be turned into a museum piece. These conversations gave me a focus – to share David's story and Lego city at every opportunity. The opportunities that have arisen include participation in a Paediatric Doctors' Seminar in the Autumn of 2015 and the subsequent contribution of part of David's story in the book *Learning from Paediatric Patient Journeys* published in July of 2016. We have also been extremely fortunate to now have five different sections of David's Lego city displayed. Three of these at The Royal Marsden Hospital in Sutton, his architecture designs reside in the reception area of David's Primary School (James Wolfe in Greenwich) and

David in hospital – always with a bright smile.

Living his dream on the Jubilee Line.

his Grand Emporium/Cinema section sit behind the desk of Tiger Ward, in the Queen Elizabeth Hospital. David also has a website which I try to update regularly and which has been viewed in at least four different countries. This website is a special space for loved ones to contribute their photographs, memories and thoughts of David.

On reflection I am so glad I told David how much I loved him and how proud I was of him every single day of his life. Three years on though my regret is that I didn't tell him how easy he made it for me to care for him, during the good times and the tough times. If I could go back I would tell him this and I would try to make him understand that he was the colour in my world.

FACT: Side effects

It doesn't take much imagination to realise the awful side effects Chemotherapy has on the bladder and bowels considering you have to protect yourself with gloves when changing a nappy or handling anything soiled because it's so toxic. Side effects include: Constipation – sometimes lasting way over a week • Acute diarrhoea • Sores • The worse nappy rashes you've ever seen • Repeated urine infections • Incredible pain

"This is why we need new treatments. What saves lives also causes other problems. I had to sign a form to consent to start chemotherapy and that I understand this could impact on my son's future fertility...
Hair loss is the main thing that people see, but it's so much worse than that. The treatments are barbaric, and the side effects so bad that my son was begging me to make it stop, but it's the only option we have... the Chemotherapy saved his life!"

FACT: More side effects

All treatments have side effects because of the way the Cancer cells are targeted:
Mouth ulcers • Weight loss • Hair loss • Skin changes • Sickness • Taste changes • Infections • Blood changes • Dental problems • Loss of hearing • Mood swings • Mobility issues • Mental health issues and depression due to the Chemotherapy affecting the chemical balance in the brain • Emotional and psychological issues • Secondary Cancer • PTSD and cognitive delays • Weight gain • Fertility problms

Fraser's Story...

As told by his Mum, Fiona

We drove to Scotland just after Christmas and everything was normal but when we arrived 10 hours later, Fraser (aged four years), had huge glands on both sides of his neck. We took him to the local GP who said that it was just a virus and sent us on our way.

We enjoyed the rest of our break and headed back home. The glands were getting bigger so we took him to our GP, who got a second GP to take a look. They sent us to our local Urgent Care Centre to be checked. The Consultant at the UCC had a quick look and told us that it was infected glands and sent us home with antibiotics, and his Registrar told us to come back in a few days if they weren't going down.

Two days later we took him back as they were getting even bigger and spreading under his chin. This time we saw a different Consultant who straight away sent Fraser for a chest X-ray and Ultrasound. After a couple of hours we were told that they were sending us by ambulance to Queen Elizabeth Hospital, where we were taken to the Tiger Ward and kept in.

After a terrible night with Fraser having to be nebulised twice, due to Sleep Apnoea, he was taken for a CT Scan. After a while of not knowing what was going on, Dr Schuller came into the room and told me the terrible news that I just wasn't expecting. Fraser had Cancer. My world fell to pieces and on top of that I had to make the call that no one wants to make to tell my husband.

Pictured top, Fraser during his treatment, and above, before his diagnosis.

Worse was to come. We were being sent to St George's Hospital PICU

(Paediatric Intensive Care Unit) because of the Sleep Apnoea episodes. We were transferred by ambulance with sirens and lights because Fraser was getting floppy and being sick and the ambulance crew were not trained to deal with it!

We arrived at St George's and Fraser was admitted. The first night I stayed with him sleeping on a chair, but after that we weren't allowed to stay and that upset Fraser, so most of the next night I sat in the parents' room waiting to be called every time he woke crying. He even wet himself because he didn't know how to tell anyone, he was so young and it was horrible having to leave him.

The next day he was taken to theatre to have a biopsy to determine what type of Cancer he had. We were told worst case, he would be in hospital for six months and best case, he would only be in for a week or so and then back and forward. The wait was horrendous, the results finally came back four days later and I was taken to a room and told that it was the best case scenario. He had T-Cell non-Hodgkin Lymphoma and would need treatment for over three years.

FACT: Steroids & their side effects

Some children have to take steroids alongside Chemotherapy and other treatments, depending on the type of Cancer they have. There are different types of steroids and all have different side effects including:

• Increased appetite • Disturbed sleep • Weight gain • Water retention causing swollen ankles, feet and hands • High risk of infection • Changes in blood sugar • Changes in mood and behaviour

"I dreaded it when my beautiful little girl went on steroids – the mood swings were out of this world, they changed the shape of her face and I can still see it now..."

"I hate steroids. They are so hard on the children and the the parents who have to care for them..."

Grace's Story...

As told by her Mum, Denise

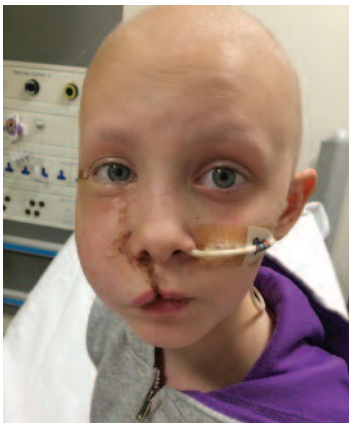
In November 2015 we were living a happy, normal life. We had just moved house and got a dog. One Saturday Grace went to gymnastics, when she came out I noticed a very slight swelling on her face. I took her to the Walk-in Centre and they thought it was dental, so for that week we gave her an anti-biotic as it was believed to be an infection.

At the end of the week and after two dentist appointments, with no result, the swelling was getting slightly bigger. We took her back to the doctor on the Friday and after a visit to the PRUH (Princess Royal University Hospital, Orpington), we ended up at King's College Hospital. They looked and said "just wait and see", but as we were about to go another doctor came in and said: "I think we need to do a biopsy." I followed her outside and asked why? She said: "I can't rule out something nasty." I remember thinking, what does she mean, although I did know.

On the Monday, I took Grace for a biopsy. We were told that the results would take a week, but they wanted to do more tests, which they did and may do an MRI. All that week I kept saying to myself, if they don't ring for an MRI, it will all be fine. On the Thursday we had a call telling us Grace needed an MRI. Then another call to say we needed to see a Consultant the next week. Every night of that week, I woke up crying, so scared of what was to come. The following week we went for the appointment, the date 9th December 2015, forever engraved in my memory. We knew before we went in it was not great news. The doctor said Grace's lump was Cancer, an Embryonal Rhabdomyosarcoma; she was nine years old.

Grace, before the lump was removed...

Leigh and I looked at each other with tears in our eyes. Leigh said: "She's going to die." I said: "No, they didn't say that." They told us we had an appointment the next week at The Royal Marsden Hospital (RMH), Sutton, but first that afternoon we had the MRI. When we left that room, we walked into the one next door where Grace was. That was one of the hardest things I have ever done. I had to paint on a smile and pretend my heart wasn't broken and my whole world shattered into a million pieces. We took her for her MRI and while she watched a film, I held her hand and sobbed. The following week we went to The Royal Marsden Hospital and met an Oncologist. She explained to us, as we hadn't told Grace, the treatment plan outcomes. Grace had her Hickman line implanted the following week. By then the lump had grown exponentially and the decision was taken to start Chemotherapy.



...and afterwards.

Above: Grace in Oklahoma, USA, for Proton therapy.

We then had the hardest job in the world. We had to tell her. Afterwards she simply said, "I had already guessed, Mum" and at that point my heart broke some more. She just said that she didn't want her hair to fall out, but I couldn't promise that. Grace's first Chemotherapy was the 23rd December for 48 hours. We woke up on Christmas Day in The RMH. Surreal doesn't even describe what was happening. We were suddenly in a world we knew nothing about with a language we didn't understand. It was akin to having a new baby and learning how to look after them.

Grace started the first Chemotherapy Protocol and had numerous lengthy stays, with temperatures and neutropenia, which is life threatening. After cycle four of six, we noticed the lump was getting bigger. The Tumour had stopped responding to the Chemotherapy. A new protocol was started and we were told Grace was eligible for Proton Beam Therapy in the US, in Oklahoma. The NHS funded the treatment, our accommodation, car hire and flights for three of us. We needed to pay for our living expenses and our youngest daughter's flights. We set up a Crowdfunding Page and people held events to raise money for us. Our little family found ourselves in the middle of such generosity from people we didn't know. But so much more than that, we felt so loved and supported, which meant so much. Lovely people wanted to help our beautiful girl get better, such kindness, we are forever grateful for.

Grace underwent very invasive facial surgery. An operation that took four hours and 45 minutes: the longest hours of our lives. They removed the Tumour and with it, Grace's right cheek and all her upper teeth on that side. We then went to the US. Grace had a new Chemotherapy and the highest amount of Proton she could. She was so poorly when we were there and there were days when we thought we would lose her. But we hadn't reckoned with the courage, strength and tenacity of our beautiful girl. On the days we could barely put one foot in front of another, Grace led from the front. She pulled on her big girls pants, put on her fight face and fought for her life. She led and we followed, totally in awe of her. When we got home she finished this very brutal Chemotherapy regime and started maintenance Chemotherapy for six months. Her post-Proton Beam Scans showed the Tumour had reduced.

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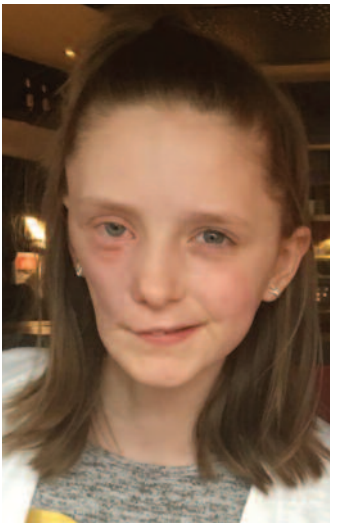
Grace rang the end of treatment bell in June 2017.

In May 2017 Grace finished her Chemotherapy and on June 8th 2017, she had her Hickman line out. In June 2017, Grace rang the end of treatment bell, the sound of that bell is so emotional. It signifies the start of a new beginning. Grace still has scans every three months but continues to amaze, astound and astonish us every day. She is at school full time and about to do her SAT's and will go to high school in September. I cannot begin to tell you how proud of Grace we are. It is an honour and a privilege to be Grace's parents. I have never in my life met anyone as brave, fearless and tenacious as Grace and I never will, I'm sure.



Grace today.

FACT: **How is IV Chemotherapy given?**

An intravenous injection of Chemotherapy can be given in two ways:

- Through a PICC line (peripherally inserted central catheter) which is inserted in a vein in the child's arm and fed through to a bigger vein above the heart
- A central line, which is a tube placed in the child's chest and fed through to a vein near the heart. This is done under general anaesthetic

The 3 main lines are **Hickman**, **Broviac** and **Portacath**. Young children often refer to them as 'wigglies'.

"My Mum made special wiggly bags for my son – they were Bob the Builder – he loved them."

Nathan's Story...

As told by his Mum, Alison

Nathan, our second child was a lovely healthy child, very clever and a star at nursery. He was born at home (planned); a simple birth, nothing out of the ordinary. My husband had had a quadruple heart bypass aged 44, 18 months before Nathan's birth and was on medication for this. I was 40 shortly before his birth. So life was good and our eldest child started infant school in September.

Nathan got an ear infection in the same month. He had a slight history of ear infections and had a course of antibiotics which seemed to help, but he was not his usual bouncy self. However, he'd changed from nursery to a childminder so I didn't worry too much.

In October his ear was still sore and he didn't like loud noises. He started to get quieter, but at two years old we just thought he was reacting to all the changes – we were more worried about his elder brother starting school.

November came and we got more antibiotics for the ear (always the right one). A week after this course I went back to the doctor as Nathan did not seem right and we had found a small rash on his feet. We had checked the internet to see if it was Meningitis but it looked different. The doctor thought it was a trauma bruise!? He advised us to give him Nurofen over the weekend, to make sure he drank plenty of water and to come back if he didn't improve.

Over the weekend he wouldn't eat and drank little – with hindsight, I should have taken him to A&E. On Monday,

after dropping our elder son at school, I got an appointment with the senior GP. I knew Nathan was pale but he's blonde and I'm pale, but friends told me he looked 'grey'. I didn't see it, too close I guess.

The GP looked him over and called Princess Royal University Hospital and sent us with a letter straight to A&E. Nathan was given treatment for Meningitis and bloods were taken. A bed was made available and he was taken to intensive care in the children's ward. His heart had enlarged to twice its normal size to try to get oxygen to his vital organs and he was in renal failure, and his haemoglobin was 3.2. We almost lost him.

He was given two bags of red blood and one of platelets. After this he started to look much better, but was still a very poorly boy. Once he was stable enough (the next day) we were transferred to The Royal Marsden Hospital in Sutton. Whilst there he had many blood tests

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each day, first cannulas in his podgy little hands, then his feet – the screams and trying to hold him still were heart breaking. He had a portacath fitted and bone marrow aspiration, and started treatment for Acute Lymphoblastic Leukaemia (ALL) regime A. It turns out the trauma bruises are not that at all, but a clear indicator that there is a big blood problem and a lack of platelets.

Nathan is doing very well and although we have had a number of set backs, including needing a replacement Portacath, Pneumonia, Shingles, Rotavirus, Slapped Cheek and assorted blood transfusions and high temperatures, he will be due to finish his treatment at the end of January 2016. We have been blessed to meet some amazing people along the way and we hope to spend long happy futures in their company.

Harry's Story...

As told by his Mum, Danielle

Leading up to Harry's diagnosis in October 2016 Harry had a few nose bleeds during the night, which seemed heavier than normal. He played a lot of football and the day before he was diagnosed, he woke up unable to put any weight on his left foot. We took him to urgent care thinking he had broken a bone as he had played in a match the day before. The scans came back all clear and at this stage there were no other symptoms.

The next day Harry was still unable to put weight on his left foot and also had a fever. He seemed very lethargic and pale, so I took him to see the doctor who checked him over and came to the conclusion that it was viral. The doctor was concerned about him being so lethargic and asked me to bring him back on Monday if he was still unwell. As I was about to leave, the doctor suggested taking him for some blood tests just to rule anything out. After arriving at Darent Valley Hospital, Dartford, they immediately took his blood and attached him to a drip. It was at this point we were concerned that the doctors thought it was more than a virus. Within the hour we were told

Harry played a lot of football so having bruises was quite normal for him.

Harry had Acute Lymphoblastic Leukaemia (ALL) and immediately began antibiotics for an infection.

Harry also had a few bruises on his legs but this was very normal for him with all the football he played. His symptoms came on very quickly and were diagnosed within 48 hours of feeling unwell.

FACT: What does Remission mean?

It means that after treatment there is no sign of Cancer in blood tests, scans and X-rays – NED = No Evidence of Disease

Partial Remission means that there is still some evidence of Cancer detected, but the treatment has had some effect and the Cancer doesn't appear to be growing – Stable Disease = the Cancer has stayed the same after treatment.

"Complete Remission doesn'tmean it's the end. There are late side effects from the Radiotherapy and Chemotherapy that blind you 20 to 25 years later."

"Not all children get distressed but, there's not one parent who hasn't heard a screaming child on a ward getting their Portacath accessed and seen their Mum or Dad with silent tears rolling down their face as they tell them 'it's going to be ok'."

FACT:

THERE HAS ONLY BEEN FOUR DRUGS EVER SPECIFICALLY DEVELOPED TO TREAT CHILDREN'S CANCER. MOST TREATMENT PROTOCOLS HAVE NOT CHANGED IN OVER 30 YEARS!

"With very little or no research going into many childhood Cancers our children are being treated with protocols that are at least 30 years old and designed for adults."

"The harsh nature and severity of the treatment can cause life-threatening and chronic problems for many in later years."

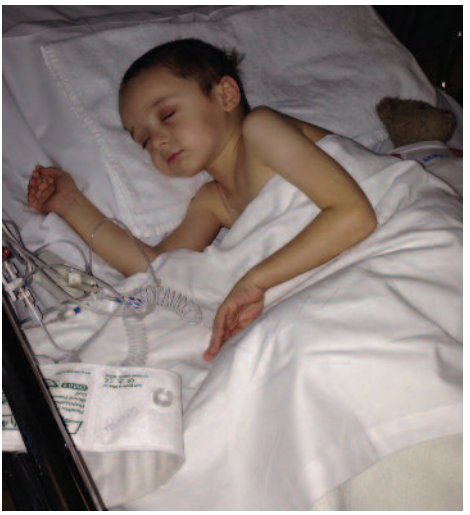
FACT:

Many children absolutely hate having their Portacath accessed on Cancer treatment because of the big needle. They often get very distressed and need to be restrained and held down by a parent and nurses in order for the procedure to be carried out. This is incredibly upsetting and soul destroying for any parent.

George's Story...

As told by his Mum, Ruth

Our son George was four years old when he was diagnosed with Acute Myeloid Leukaemia (AML) in late January 2015. For a few weeks prior to the diagnosis, he had been sweating in bed and complaining that his legs were tired and he didn't want to walk to school. He was also pale, had a slight cold and above one eye was swollen. One day we dropped him at school in the morning and they said they were happy to accept him as his eye was not itchy or red, but by the afternoon they called to say that both eyes now looked swollen. We visited the GP and she felt George was coming down with something and that we should leave it until it had come out in him.



George was transferred to the Royal Marsden and admitted to the Oak Centre.

By the weekend George's eyes looked very puffy, his skin was paler and he had fallen asleep at a family meal out, which was not like him. On the Sunday my daughter and I took him to A&E at the Princess Royal University Hospital in Orpington. I asked the doctor we saw for a blood test. He agreed that a blood test seemed the best way forward and he sent us through to Paediatrics. The nurses looked quite intensely at George and we realised that he now looked worse.

When the bloods were taken the Consultant asked me to get my husband to take my daughter home, and then to return to the hospital. I knew then it was bad. We sat together in a small bay where the Consultant told us that George had Leukaemia or a very severe infection. His blood definitely showed abnormalities but the person looking at it under the microscope couldn't say for definite what it was. We would know in the morning when his superior would confirm, but for now George would stay in hospital overnight. My husband went home to look after our other children Emma and Henry. George had blood transfusions and platelets immediately during the night. He was looking very unwell indeed; he was neutropenic and at high risk of infection so we were kept separate from the rest of the ward.

On the Tuesday we travelled by ambulance to The Royal Marsden Hospital where George was admitted to the Oak Centre. We met with the Consultant who confirmed that George had AML and we were told of his treatment plan. The next day George had a lumbar puncture with the first treatment of Chemotherapy and he had a Hickman line fitted. One of us would stay with him while he was an inpatient. The treatment for AML is a high dose of several different Chemotherapy drugs administered in four sessions over a six

month period. The treatment for AML in children is exactly the same as that given to adults and has been the same treatment for over 30 years. We were told AML had a success rate of around 70%. The intention was to take George's blood cells back to zero and hope the Chemotherapy would bring remission.

George was very poorly from the Chemotherapy. He was pumped with huge amounts of fluids, steroids and so many blood transfusions and platelets that we lost count. He hated swallowing the medicines and it was so hard to administer them to him that he agreed to have a Nasogastric tube fitted for his medicines and water. When he had severe Mucositis, food was also given through it. The first night with the tube George screamed all night for the nurses to remove it, keeping the whole bay awake. However, by the next day he realised the benefit of having it and became protective of it, and we learned quickly how to tape it firmly in place for him and to administer his medicines through it. The Mucositis caused him awful pain and temperatures and he struggled to swallow. He lost a lot of weight and he was put on Morphine until he began to hallucinate. At one stage he was taking steroids, five different antibiotics and his Chemotherapy drugs. The Chemotherapy made him vomit and he suffered such severe diarrhoea. We shaved his head in bed when his hair started to fall out.

George spent 43 nights as an inpatient on this occasion before being well enough to go home for a few days, which actually turned out to be only one night before he had a temperature, and was admitted into our local hospital, on to the Tiger Ward at the Queen Elizabeth Hospital, Woolwich.

George spent his 5th birthday in the hospital. He had regular blood testing, ECHO, MRI and CT scans. Having spent so long in bed and having some very strong medication, George found walking very difficult and we had to use a commode at home to save us from carrying him up and down stairs. We were loaned a pram to use when we went out. At home we would set alarms to give him his medicines at night.

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Below, George soon realised the benefit of having the Nasogastric tube fitted and became very protective of it.

George enjoying time at home with big sister Emma and brother Henry.

George is an incredibly brave little boy.

George celebrated his 5th birthday in the Tiger Ward.

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During the six months of treatment we very nearly lost George twice, but he was most poorly during the first two treatments.

The entire time was difficult too for his sister and brother who found their lives turned upside down. They heard scary things from school mates and missed their brother and their normal lives. It took a really long time to get some normality back at home. We met and lost some lovely friends – children who touched our hearts and were taken too young. It was gruelling.

George was recently granted a Wish by Starlight and in October we had an amazing trip to San Francisco where he was allowed a most memorable tour of Pixar Studios. We then travelled to Los Angeles, a very special experience and a spectacular treat for the whole family. This holiday made us all feel a little lighter.

We are so very lucky. George is now nearly three years post treatment and as yet, has not needed a bone marrow transplant. He is now having six-monthly appointments with his Consultants and has forgotten a lot of what he went through. Sometimes we don't think about it but when George gets a cold or complains of a pain, it brings it all rushing back.

FACT: **What causes Cancer in children?**

The cause of Cancer in children and young people is still not known, despite years of research.

• It is not contagious, you can't catch it or pass it on. • Some babies are born with Cancer or are diagnosed soon after birth. It is thought something may go wrong when the cells divide rapidly. • It is also thought that rapid growth in young people/teenagers can trigger cells to divide too quickly and something goes wrong. • Some genetic conditions can increase the risk of a child getting Cancer. • Some Cancer treatments can cause secondary Cancers.

FACT: **Platelets**

Platelets are tiny cells that are made in the bone marrow and are released into the blood. They are responsible for helping the blood to clot. • Sometimes the platelet count is lower than normal, which can be due to Chemotherapy, Radiotherapy or if the bone marrow isn't working properly. • The risk of bleeding increases when the platelets get too low and often the child suffers from nose bleeds, bleeding gums and easy bruising. • Platelet transfusions are given by a drip in the same way as a blood transfusion and usually takes about 30 minutes.

"There is nothing more gutwrenching than listening to a child with terminal Cancer talking about what they are going to do when they grow up, knowing they never will..."

96% of us rely on just 4% of us TO GIVE BLOOD. Please don't leave it to someone else.

"Not many people realise this, but kids with Cancer often need multiple blood transfusions throughout their treatment, and sometimes beyond. It's not uncommon for them to need at least one transfusion per Chemotherapy cycle and often, by the time treatment finishes, they can have had 20 or more transfusions. PLEASE DONATE BLOOD IF YOU CAN, IT IS LITERALLY LIFESAVING."

Jake's Story...

As told by his Dad, Spencer

Our son Jake was diagnosed with Acute Lymphoblastic Leukaemia on 30th April 2016; he had just turned three. A few weeks before his diagnosis we noticed that he had a raised gland in the side of his neck and a few bruises on his legs. He had also started to take longer naps in the day. We didn't like the look of the gland and made an appointment to see our GP. The GP thought he may have a virus, but decided to send him for blood tests just to make sure. Two days later we took him for the blood tests. About six or seven hours later the same day, we had a call from the surgery explaining that they had received the blood results. They were concerned by some of the results and asked us to take Jake straight to the hospital. We were extremely anxious, but fairly resolved to the idea that this was an overly cautious measure to clarify a virus.

Once at the hospital, more blood was taken for tests and Jake was examined. At this stage, no Leukaemic Blast Cells were showing in Jake's bloods, although this was something they suspected and were checking for. Alarm bells started to ring but we were assured this was just one of the many things being checked for. It is easy to convince yourself that everything will be okay. Another appointment was made for a week later. During this time Jake was still very tired and napping in the day, but still wanted to attend pre-school.

When we returned to the hospital more tests confirmed that his bloods had dropped again. On this visit we were told by a Doctor that they were looking for something in Jake's bloods; it could either be a virus or it could be very serious. We were advised to go home whilst they did further tests and spoke to other Consultants.

A few hours later we had a call to say they were referring Jake to St George's Hospital in Tooting for a bone marrow aspiration, but he would need a blood transfusion before going. This was the moment we realised something dreadful was happening. From that moment on, everything changed. We found ourselves in a different world. Our son was hooked up to a blood transfusion and we were being briefed about a bone marrow aspiration; where they would go into his spine to take a "core" of marrow to be examined. This was another universe; we had been plucked from normality and suddenly fearing for our son's life in a very unfamiliar environment.

Jake had the transfusion and was transferred via ambulance to St George's the following day. He had his bone marrow aspiration on the Friday. On the Saturday a Consultant who was unfamilier to us entered the room, with an Oncology Nurse Practitioner who we had come to know as being senior. The fact they had come in with someone who was clearly another grade above themselves, was enough to signal what had grown from a fear that wasn't worth considering because it could never happen to us, to confirming the words that no parent should ever hear. The Consultant suggested that we step out of the room, which was another clear signal of the news we were about to receive. Jake's mother, Sarah, was still clinging to the idea that some other reasonable explanation was the issue.

Jake during his treatment, with sister Freya.

She hadn't accepted anything and had protected her feelings the entire time by not accepting what was increasingly looking the most likely outcome. We decided against stepping out of the room and I made the decision on the spot to hear whatever the news was together.

The Consultant explained that Jake had Leukaemia. The words coming from his mouth left a ringing in our ears that left my wife with a vacuum inside her chest. A hollow void rapidly engulfed her entire body. I myself needed to hear the next words: "What did it mean? Was it terminal? If so, how long did my son have left to live? How much of that life would be quality and how much further pain would he need to endure?"

The Consultant clearly didn't want to provide too much at once. The words that your son has Leukaemia are overwhelming. However, I needed more and had to hear as much as I could get. He explained that Jake had ALL, a form of Leukaemia that has a good prognosis for survival. It has a 90% survival rate and can increase depending on further tests. However, the treatment was three years (it's actually three years and three months for boys, but slightly longer in Jake's case due to a further complication).

This is what I needed. Some hope. It was devastating news, but we had something to grab on to. A long treatment time, but with our support and resolute commitment to his health and well-being, we could get him through this and he wouldn't die.

Jake was in St George's for just over two weeks to start treatment then we were allowed home to continue treatment via The Royal Marsden Hospital and Queen Elizabeth Hospital. We were loaded with information and medicines and were eager to get him home where he belonged. However, we were home just under 48 hours and Jake spiked a temperature so we had to go straight to Tiger Ward at Queen Elizabeth Hospital. Jake had become very subdued, not eating, not talking, just lying on his bed. Due to him starting treatment, having so many medications and being on steroids we thought these were side effects; we just weren't used to the treatment and believed it was likely part of that. His hair also started to fall out so we shaved his hair and I did mine too, so that we looked the same.

Dr Schullar checked Jake over and was concerned that Jake was displaying some signs of having a Stroke, so again we were transferred by ambulance back to St. George's to Intensive Care, where they carried out an MRI scan and noticed some changes on Jake's brain. At the time the Doctors were not sure if it was caused by one of the injections or if he had developed a fungal infection. It is our firm belief that Dr Schullar saved Jake's life that day. If she hadn't noticed the symptoms of bleeding on the brain, he surely would have passed away. She saw through his ALL treatment, and recognised something different. For this, we will forever be in her debt.

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During this time and his first month of intensive Chemotherapy they had to make changes to Jake's treatment whilst finding out what was happening. During this time he had various MRI and CT scans and Heart Ultrasounds. They found that Jake has developed a fungal infection that had spread over his chest, liver, spleen and brain. This was the most frightening time we could ever imagine as our world just came crashing down around us and there was nothing we could do but rely on the doctors and nurses to get Jake through this. Just a month previous we received what we thought would be the worst news ever, but we were wrong. This was worse.

We had been back in St George's for several weeks and Jake was having a constant temperature of 40+. More tests and an MRI scan showed that the infection was spreading rapidly across his brain and they needed to add more medication quickly to prevent Strokes, Fits and Seizures. We were told to prepare ourselves for the worst if they could not get this under control. This was the worst day of all our lives. Our son was dying. He was losing weight, losing control of his own body and becoming increasingly despondent. He was getting worse and the medicine wasn't working. He was going to have a massive Stroke that would kill him, or leave him severely brain damaged for life.

This was the darkest time of my life. What would I rather have for our son? For him to lose his life or be so severely brain damaged that he was a shell, trapped in his own body. Perhaps being strong for my son in this case would mean easing his pain and being there for him while he died.

We were told that we would be in St George's for quite some time and they managed to get us a room in the Ronald McDonald House. My parents moved into our home so they could look after our older daughter Freya, who was attending school and we really only saw her at weekends.

After two weeks with increased and intensive IV medicines (which came with other side effects due to the dose being so high), Jake's body finally started to take control of the fungal infection. His temperatures had started becoming fewer, less intense and less frequent. Eventually his temperature dropped to safe and normal readings and he had taken back control.

During this time we lost count of the number of different specialists we saw, transfusions Jake had and IV antibiotics he was given. He was hooked up to IV antibiotics for approximately 20/22 hours each day. The infection had not gone without a fight though as Jake lost the use of his legs and his upper body strength was incredibly weak. He was in a wheelchair and we didn't know whether he would ever be able to walk again. We ended up being in St George's for about three and a half months while

Jake needed a wheelchair when he finally came out of St George's Hospital.

Jake now, showing off his new hair.

the fantastic doctors and nurses managed to get this infection under control. However, despite all this that Jake went through, he still managed to get into remission from the Leukaemia and he was placed on low level risk, which was a big relief. This actually put Jake's prognosis for the Leukaemia at 95%.

Once we were home Jake was on one IV antibiotics each day for a further six months, but we were so grateful that the Ellenor nurses could come out to do this or we could go to Queen Elizabeth Hospital each day. Jake's treatment does not end until 16th September 2019, but the progress he has made since he fell so ill has been amazing. He has had to learn to walk again, learn how to hold a pen again and his talking is amazing. He still has some complications from the infection and has quite a way to go with his treatment for the Leukaemia, but his strength and resolve are immovable. He continues to amaze us each day.

Tiger Ward have been amazing with Jake, our daughter and us (Mum and Dad). They are there for us whenever we need them and we thank them for doing such a fantastic job. They are unafraid to make real emotional connections, an incredibly brave thing to do when they face situations filled with such despair. I am not a religious man, but they are as close to living angels as I can imagine a person can be.

"Thoughts and prayers for the amazing kids fighting for their lives, and for the amazing parents and families who fight right next to them – through the good and the bad, while their hearts are breaking.
And for the amazing doctors and nurses who fight to cure these kids of this brutal disease.
Never give up!"

"Until you see Childhood Cancer first hand, it's hard to conceive how brutal it really is."

Sophie's Story...

As told by her Mum, Karen

Dates are etched so clearly in our minds. Our world came crashing down on Tuesday 3rd March 2015, when Sophie was 9 years old, and exactly four weeks after my surgery to remove a rugby-ball sized cancerous Tumour on my left kidney.

Sophie first complained of a pain in her right hip on Monday 16th February. She was fine for the next two weeks – going to school, swimming and gymnastics. On Monday 2nd March she was at Brownies with her twin sister, Emma, when we received a call to collect her as she wasn't feeling too well. Sophie was sick when we got home and went to bed. Later she complained of a pain on her right side and I suspected a grumbling appendix. I could hardly walk post-surgery so my Mum drove us to the Urgent Care Centre just before midnight. The Doctor indicated Sophie would need an Ultrasound scan so we took her to A&E at the PRUH. Sophie had various blood tests and was admitted to the children's ward about 6am.

Karen with her twin daughters Sophie and Emma.

Sophie was incredibly brave throughout her treatment.

I clearly recall Sophie getting out of bed and doing star jumps for the Doctor before she went for her Ultrasound. It was during that examination that I knew it was something bad – it was *déjà vu* of my Ultrasound just a few weeks before. I could see the Sonographer measuring Sophie's kidney and once Sophie had left the room I asked what she had seen. She advised me she couldn't rule out a kidney Tumour. We were dumbfounded.

On 4th March, Sophie's CT scan confirmed a suspected Wilms' Tumour on her right kidney. We were told Wilms' usually presents itself in children under age five and is thought to be embryonic. By now Sophie's blood pressure was sky high and she was constantly being sick, although she'd eaten nothing. We were transferred to the High Dependency Unit at St George's Hospital in Tooting on 5th March. Sophie was very unwell – her blood pressure wouldn't settle and she didn't want to take medication as she was being so sick. We made the decision to sedate her so that a Nasogastric (NG) tube could be

inserted – at least we could administer medication without her having to swallow it. We sat with her 24/7. I was constantly told to go and rest to aid my recovery but I refused. I was never going to leave Sophie as she was so ill.

The CT had shown a shadow around Sophie's Tumour and the Consultants did not want to risk a biopsy for fear of rupture, so she had an upfront Nephrectomy (removal of her kidney) on Thursday 12th March. We received confirmation of a Wilms' Tumour the following week and Sophie had her Portacath fitted on 20th March. Post surgery Sophie continued to vomit – she couldn't keep anything down. It was delaying the start of her Chemotherapy and a further CT scan diagnosed Ileus (a condition which prevents food from passing through the intestines). Sophie was kept totally 'nil by mouth' for five days. She weighed just 20kg and was fed intravenously by TPN (Total Parenteral Nutrition).

Sophie had her first cycle of Chemotherapy on 9th April and we went home on 17th April (almost seven weeks from admission). Desperate to see friends, she went to school that afternoon! Sophie started Radiotherapy alongside Chemotherapy at the end of May 2015. She was admitted into The Royal Marsden Hospital in Sutton in June by the Symptom Care Team and Dietician to get her sickness under control as she was still very under-weight despite being fed by NG tube at home.

After a turbulent six months Sophie finished her treatment and we were very optimistic. We rang the End of Treatment bell at our local hospital on 4th January 2016. Everyone cheered but I remember having an element of 'what if' in my mind.

In March 2016 Sophie, her twin sister Emma, Steve and I spent an amazing week in Florida. Sophie had bundles of energy and we had a fantastic time. Emma and Sophie then did a charity fun run on 17th April. On 18th April she had a check-up with her Consultant at our local POSCU at the Queen Elizabeth Hospital in Woolwich. "I did a fun run yesterday which I was determined to finish. I had a slight pain in my chest at the end and I thought 'oh is it a relapse?' but then figured it's just because I'm not used to exercising" – Sophie's exact words to her Consultant!

That week Sophie complained of a pain in her back. We thought she'd maybe pulled a muscle during the run. We called the hospital and supplied a urine sample to check for a water infection. By 27th April, Sophie was 'under the weather' and a bit off her food. I didn't want to be a neurotic mum but took her back to the Queen Elizabeth Hospital. A Consultant examined her and requested a chest X-ray. Her right lung had collapsed and the Doctors were surprised she'd managed to walk onto the ward. Please just let it be Pneumonia, I thought! A CT scan that evening showed Sophie had relapsed to her right lung with one large Tumour and multiple small Tumours. Our nightmare was starting all over again.

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Sophie's first question to her Consultant was: "Why didn't they get it right the first time?.". Even I didn't think to ask that!

Sophie was transferred to St George's on 28th April. She had a PICC line inserted whilst awake and started Chemotherapy all over again. We gave her lots of anti-sickness medication and, despite the usual side-effects, she seemed to be doing well.

In June she had a Hickman line inserted and had her Stem Cells harvested at The Royal Marsden Hospital on 4th July, ready for her high-dose Chemotherapy which was scheduled for the end of September. On Monday 11th July we were at The RMH for Chemotherapy when I mentionedI thought Sophie's breathing seemed a little different the night before. All her observations were good and two Doctors checked her over. They finally decided to request an X-ray, which showed her lung had collapsed again. Another CT scan showed her Tumours had started to grow again. We were transferred to St George's in case she needed a chest drain inserted.

Sophie was put on another Chemotherapy drug which made her feel rough. She was very Neutropenic (no immune system) and required lots of blood and platelet transfusions. A CT scan after two cycles showed her Tumours were responding to the new Chemotherapy which was good news. It was decided she would have four cycles of Chemotherapy so there was as little residual disease as possible before her high dose Chemotherapy, which was now due early October. Just before that, on 30th September, a CT scan unfortunately showed that the Tumours had again increased in size. Sophie commenced another Chemotherapy drug which she did initially respond to, but on 11th November 2016 we found out that her Tumours were growing yet again, despite being on active Chemotherapy. The decision was made for her to commence Radiotherapy earlier than planned as an alternative.

Steve with his beautiful daughter, Sophie.

On 13th November Sophie was unwell at home and admitted to our local hospital. Her right lung had collapsed again. She was in agony and was blue-lighted to St George's where a chest drain was inserted. The amount of fluid that was drained from her lung over the next 10 weeks was incredible. She started Radiotherapy to her entire right lung with the chest drain in situ and was once again fed intravenously by TPN.

Because Sophie was spending more time in bed, she suffered with Foot Drop which required Physiotherapy. It was whilst she was out of bed doing her strengthening exercises on 26th December 2016 that her foot gave way underneath her. She told the Doctors she had broken her leg but there were no immediately obvious signs. On 2nd January 2017, when she could still not bear weight on her leg, she had an X-ray which showed she had a broken leg. I've never seen anyone so happy to say "I told you so" and have their leg put in plaster – purple of course!
A week later Sophie was experiencing more pain. She was on Morphine, Fentanyl and other pain relief medica-

tion. She had another CT scan on 7th January and on the 8th January we heard the news we never, ever thought we'd hear. We were always so positive and hopeful, but Sophie passed away, thankfully peacefully, on Saturday 21st January 2017 with the three of us and her Nan by her side. She was 11 years old and we are truly devastated and broken-hearted. We never believed she would ever die.

We're blessed to have a wonderful network of family and friends around us and we tried to keep as much normality in our life as possible. Sophie went to school whenever she could. She was brave and never wallowed in self pity – she just got on with it. Sophie was also incredibly smart – she needed to trust us and those who cared for her so we were as honest as we could be (without scaring her) throughout her treatment.

Sophie raised £3,000 for charity when she was first diagnosed. She was very passionate about helping other children who were poorly like her and wanted to set up her own charity. At Sophie's funeral we set up a fundraising page in her memory for donations rather than flowers to support four charities close to her heart. In 16 months we have raised over £104,000 and CCT Tiger Ward is planning to fulfil Sophie's dream and wish to buy a holiday home on the Isle of Wight (a place she loved) for use by children suffering from and battling Cancer. It is impossible to plan holidays when you have such a poorly child – the holiday home will give others the opportunity to create some special memories, enjoy a much-needed break and have some respite. For Sophie – so smart, brave, beautiful, kind and loving – and our inspiration.

FACT: Relapse

In simple terms, relapse means that the Cancer has returned. • Sometimes children can 'relapse' during the course of treatment, soon after or even months or years after treatment has ended. • After treatment, children attend regular follow up appointments for many years, to check and test that there is no sign of the Cancer returning. The fear of relapse is always there. It never goes. • Often further treatment can be offered, sometimes involving stem cell transplant. • Sadly, not all Cancers can be cured.

"My heart hurts, dreading this possibility, but God is watching over our son and family and I know he hears all the prayers from family and friends, and wonderful people we don't even know."

Blue's Story...

As told by his Mum, Francesca

Blue (two years old) was at nursery five days a week as I worked full time, he had never been a good sleeper but was otherwise healthy and ate and played well. I started to notice that his nose bled intermittently and that he had small light coloured bruises springing up mainly on the torso area. I thought the nosebleeds were due to him being a boy and discovering how to pick his nose (how naïve of me) and because my Mum, my daughter and I bruised easily, I thought perhaps he was having a bit too much 'rough and tumble' at school.

I mentioned this to the nursery and they said they would keep an eye on it as they had noticed his nose bled too. We body mapped and I took him to see my Doctor on Tuesday 29th March 2011, who referred me to a Paediatrician for the following Friday to check him out. Unbeknown to me my lovely doctor had suspicions but didn't want to panic me (as I subsequently found out), so he made an urgent referral.

On Wednesday 30th March, I was called to the nursery from work, where Social Services and the Police were waiting for me! I was under suspicion of child abuse. We went in the police car to the hospital instantly – a day I will never ever forget – and at 16.40 with Social Services and the Police still present, Blue was seen by Dr Parkes, who could see how upset and terrified I was. By 16.44 she had diagnosed a blood disorder and told both parties to "do one" – God, how I loved that doctor!

We were blue-lighted to William Harvey Hospital in Ashford where further tests confirmed it was a form of Leukaemia. From there, we were immediately transferred to Addenbrooke's in Cambridge, where on the 1st April (ironic isn't it) his Hickman line was inserted and it was confirmed he had Acute Myeloid Leukaemia (AML) Mk 4, a very aggressive form of Leukaemia.

Blue's parents were wrongly accused of 'Child Abuse' prior to his diagnosis. Right, 'Ringing the Bell' in the Tiger Ward, at the end of his treatment.

Today after his Bone Marrow Transplant in May 2012 and finally leaving hospital in July 2013, after a two-years plus stay mainly in isolation, Blue is a normal healthy nine year-old boy enjoying a normal life after finally achieving six years' remission on May 10th 2018. He is what every nine year old should be, pushing the boundaries and testing the water. We have lovingly nicknamed him "Asbo". He continues to amaze everyone and endeavours to raise as much money as possible to help "The other poorly children" his words. We certainly couldn't be prouder.

I have tried to keep this brief but I wanted to make people aware of how an awful disease and its symptoms can be so misleading and make people cry "Child Abuse". I hope our story might help others.

FACT: **Brain & Spine Tumours**

The brain is the control centre of your body and is responsible for thoughts feelings and actions. It is part of the central nervous system (CNS), along with the spinal cord. Brain Tumours can develop anywhere in the brain. • CNS tumours are abnormal growths of tissue in the brain and spine. This type of Cancer occurs when the growth of cells gets out of control, developing a lump known as a Tumour. • Cancerous Tumours that start in the brain and spine do not often spread to other parts of the body, but can increase in size and take over surrounding tissue.

"75.7% of families fighting childhood cancer will have a parent reduce hours or leave their job altogether."

CANCER FOR CHILDREN IS A LIFELONG DIAGNOSIS. FIRST THEY HAVE TO SURVIVE THE CANCER TREATMENT, THEN A LIFETIME OF LATE EFFECTS.

"With 80% of kids with Cancer, the Cancer has already spead to other parts of the body by the time they are diagnosed. There are no screening tests for children!"

"I was told I was an over-concerned parent and to stop googling! My son was Stage 4b Hodgkin's and fighting for his life by the time he was diagnosed. I feel I really let my son down by not kicking up a fuss."

"That's why all parents should read the signs."

ALWAYS LISTEN TO YOUR INNER VOICE... AS A PARENT, YOU JUST KNOW!

Ollie's Story...

As told by his Mum, Emma

On a Saturday morning Ollie asked if he could get in the bath with me, he was aged three-years, 10-months at the time. While he was playing, I noticed his testicle was really swollen. He said it didn't hurt, but I was concerned so took him to the out-of-hours Doctor. As it was a Saturday, there was no one available to do bloods, the Doctor didn't really indicate what it may be, but said the Children's Ward would contact me with an appointment to run some blood tests and a scan.

I had a call on Monday morning, with an appointment for lunchtime on Tuesday. Ollie went to nursery as normal and I took him to the ward at around 1pm. He had magic cream and the blood test was done, we had to wait ages for the scan. We went back to wait on the ward and Ollie was happily watching a Power Rangers dvd, whilst I was taken to one side and told that they had found Blast Cells in Ollie's blood sample and that Ollie had Leukaemia. We were blue-lighted in an ambulance that evening to The Royal Marsden Hospital in Sutton. He was diagnosed within 24-hours with having both Acute Lymphoblastic Leukaemia and a marker of Acute Myeloid Leukaemia. His only sign had been the swollen testicle, an unusual symptom and diagnosis, more common at relapse. I am so thankful he got in the bath with me that day.

WHAT CAN WE ALL DO?

Be aware and help raise awareness by talking with others about the facts, symptoms and statistics.

Make donations to children's cancer charities when you can, to help fund research, trials, medicines and get closer to a cure.

Give blood and/or platelets – they really do save lives!

To find out more and visit www.chartwellcancertrust.co.uk

The Magic of AV1: The No Isolation Robot

Pioneering technology keeping young Cancer and Leukaemia patients connected to school life, education, friendship and normality as they undergo greatment.

An estimated 35,000 children in the UK are battling long-term illness and the traumatic upheaval to their lives and inevitable absences from school can be as devastating as the illness itself. For educators and parents, there has been a frustrating lack of solutions to alleviate the isolation and disruption that these children suffer from as a result of their illness – until now.

Introducing the AV1 Robot

Norwegian company No Isolation have developed an ingeniously simple answer in the form of a compact, portable robot. Equipped with microphone, loud-speaker and camera, the AV1 robot acts as the child's eyes, ears and voice, and livestreams direct to a phone or tablet via an app offering a seamless, interactive connection with school wherever the child is. Its handy portability allows the child to participate in every aspect of school life - all being so important for their wellbeing and social development.

Our commitment

As part of our ongoing commitment to improving and enhancing cancer care for young people in London and the South East, The Chartwell Cancer Trust are working with No Isolation to expand the use of this technology in the UK and introduce these life-changing robots in hospitals and schools across South London and Kent.

To date, we have raised funds and built partnerships to support up to 12 trials with young patients with resoundingly successful outcomes reported by the children, medical staff and teachers alike.

Our fundraising challenge

We have a vision – to extend the provision of this transformational technology within our community and eliminate isolation and exclusion amongst our children with long-term illnesses.

With tried and tested results, we are now looking for partners and sponsors to help us raise the funds and realise our ambitions to bring these life-changing robots to more young people who are desperately in need of a life-line back to their education, peer groups and everyday lives.

Grateful thanks to our first "Robot Sponsors" – partners and staff of Messrs. Clarkson Wright & Jacques, Solicitors and VINCI spearheaded by Paulette West.

"There is a real buzz of excitement at the prospect of our latest addition to the classroom. It will be a fantastic opportunity for one of our class members to continue their education I am grateful that this will allow me to continue to chat and often laugh with my student, and being able to give the normality this bright, brave child really deserves."
Daniel Brown, class teacher at South-East London Primary School.

You have just changed a young child's life.

If you are interested in supporting this pioneering project using technical innovation to change children's lives, please get in touch to discuss sponsorship opportunities with us.

Contact: Michael Douglas, Hon. Trustee, The Chartwell Cancer Trust
Email: michael607douglas@btinternet.com
Call: 07760 786 881

Healthy Living

PLANT-BASED Health Professionals UK

Plant-Based Health Professionals UK Ltd is a non-profit organisation dedicated to the promotion of plant-based nutrition and other lifestyle interventions for optimal health and well-being. Their website – www.plantbasedhealthprofessionals.com – has a wealth of information about how a healthy lifestyle for all ages can help prevent and reverse many of today's common diseases. The chart below is from their website.

Useful Addresses

ADDENBROOKE'S HOSPITAL
Hills Road, Cambridge CB2 0QQ
Tel: 01223 245151
Email: contactcentre@addenbrookes.nhs.uk
Website: www.cuh.nhs.uk/addenbrookes-hospital

CANCER RESEARCH UK
PO Box 1561, Oxford OX4 9GZ
Tel: 0300 123 1022 (general enquiries)
(Open Mon-Fri 8am-5pm – closed Wed 11am-11.30am, weekends and bank holidays.)
Cancer related questions, please call our cancer nurses on **0800 800 4040** – Mon-Fri 9am-5pm (UK residents only).
Email: supporter.services@cancer.org.uk
Website: www.cancerresearchuk.org

CHELSEA AND WESTMINSTER HOSPITAL
369 Fulham Road, Chelsea, London SW10 9NH
Tel: 020 8560 2121 (Switchboard)
Email: appointmentenquiries@chelwest.nhs.uk
(for outpatient appointment enquiries only).
Website: www.chelwest.nhs.uk

CROYDON UNIVERSITY HOSPITAL
530 London Road, Croydon CR7 7YE
Tel: 020 8401 3000 **Email:** None given.
Website: www.croydonhealthservices.nhs.uk

DARENT VALLEY HOSPITAL
Darenth Wood Road, Dartford, Kent DA2 8DA
Tel: 01322 428100
Email: dgn-tr.enquiries@nhs.net
Website: www.dvh.nhs.uk

GUY'S HOSPITAL
Great Maze pond, London SE1 9RT
Tel: 0207188 7188
Email: pals@gstt.nhs.uk (for Patient Advice and Liaison Service).
Website: www.guysandstthomas.nhs.uk

KING'S COLLEGE HOSPITAL
Denmark Hill, London SE5 9RS
Tel: 020 3299 9000 **Email:** None given.
Website: www.kch.nhs.uk

LEWISHAM HOSPITAL
Lewisham High Street, London SE13 6LH
Tel: 020 8333 3000 **Email:** None given.
Website: www.lewishamandgreenwich.nhs.uk

MARIE CURIE CANCER CARE
89 Albert Embankment, London SE1 7TP
Tel: 0800 716 146 (general enquiries), 0800 090 2309 (support line).
Email: supporter.relations@mariecurie.org.uk
Website: www.mariecurie.org.uk

MACMILLAN CANCER SUPPORT
89 Albert Embankment, London SE1
Tel: 020 7840 7840 **Email:** Through website.
Webiste: www.macmillan.org.uk

PRINCESS ROYAL UNIVERSITY HOSPITAL
Farnborough Common, Orpington, Kent BR6 8ND
Tel: 01689 863000 **Email:** None given.
Website: www.pruh.kch.nhs.uk

QUEEN ELIZABETH HOSPITAL
Stadium Road, Woolwich, London SE18 4QH
Tel: 020 8836 6000 **Email:** None given.
Website: www.lewishamandgreenqich.nhs.uk

QUEEN MARY'S HOSPITAL
Frognal Avenue, Sidcup, Kent DA14 6LT
Tel: 0208 302 2678
Email: dgn-tr.enquiries@nhs.net
Website: www.qmh.oxleas.nhs.uk

ST GEORGE'S HOSPITAL
Brackshaw Road, Tooting, London SW17 0QT
Tel: 020 8672 1255 **Email:** None given.
Website: www.stgeorges.nhs.uk

ST THOMAS' HOSPITAL
Westminster Bridge Road, London SE1 7EH
Tel: 0207188 7188 **Email:** None given.
Website: www.guysandstthomas.nhs.uk

SLOANE HOSPITAL
125 Albermarle Road, Beckenham, Kent BR3 5HS
Tel: 020 8466 4000 or free on 0808 101 0337
Email: Through website plus live chat available.
Website: www.bmihealthcare.co.uk

STARLIGHT
Third Floor, 227 Shepherds Bush Road, Hammersmith, London W6 7AU
Tel: 020 7262 2881 **Email:** None given.
Website: www.starlight.org.uk

THE NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE – NICE
10 Spring Gardens, London SW1A 2BU
Tel: 0300 323 0140 **Email:** nice@nice.org.uk
Website: www.nice.org.uk/

THE ROYAL MARSDEN HOSPITAL
Downs Road, Sutton, Surrey SM2 5PT
Tel: 020 8642 6011
Email: patientcentre@rmh.nhs.uk
Website: www.rmh.nhs.uk

WILLIAM HARVEY HOSPITAL
Kennington Road, Willesborough, Ashford, Kent TN24 0LZ
Tel: 01233 633331 **Email:** None given.
Website: www.ekhuft.nhs.uk

Glossary

BMT, bone marrow transplant. (*Ref. p41*)
Benign, not recurrent, favourable to recovery with appropriate treatment.
Biopsy, *n* (*pl* **-ies**) the removal and examination of tissue, cells, or fluids from the living body.
Blast Cells, name given to immature white blood cells, which do not have the infection-fighting properties of healthy white blood cells. (*Ref. pp12,32 & 42.*)
Bone marrow aspirate (aspiration), the removal of a small amount of bone marrow (soft tissue found inside bones) in liquid form for examination. A bone marrow aspiration is not the same as a **bone marrow biopsy**,which removes actual marrow for examination. (*Ref. p32.*)
Cancer, malignat tumour that develops when cells multiply in an unlimited way – the medical condition that is characterised by the presence of tumours.
Cannulars, (from the Latin "little reed") is a tube that can be inserted into the body, often for the delivery or removal of fluid or the gathering of data.(*Ref. pp15 & 26.*)
Carcinoma, a cancerous tumour originating in the EPITHELIUM (tissue covering an external surface or lining a body cavity). (*Ref. p16*)
Catheter, in medicine, a catheter is a thin tube made from medical grade materials serving a broad range of functions. Catheters are medical devices that can be inserted into the body to treat diseases or perform a surgical procedure.
Chemotherapy, (often abbreviated to chemo and sometimes CTX or CTx) is a category of cancer treatment that uses chemical substances, especially one or more anti-cancer drugs (chemotherapeutic agents) that are given as part of a standardised chemotherapy regimen.
CT scan, computerised tomography is a technique that uses advanced X-ray technology to build up a detailed picture of a patient's insides.
ECHO (Echocardiogram) is a **scan** used to look at the heart and nearby blood vessels. It's a type of **ultra-sound scan**, which means a small probe is used to send out high-frequency sound waves that create echoes when they bounce off different parts of the body. (*Ref. p29.*)
Embryonal rhabdomyosarcoma, (ERMS) is a rare histological form of cancer of connective tissue wherein the mesenchymally-derived malignant cells resemble the primitive developing skeletal muscle of the embyo. It is the most common soft tissue sarcoma occurring in children. (*Ref. p9.*)
Fentanyl (also spelled **fentanil**) is an opioid used as a pain medication and tegether with other medications for anesthesia. (*Ref. p38.*)
Fits, sometimes called a **Seizure**, is a sudden, uncontrolled electrical disturbance in the brain. It can cause changes in your behaviour, movements or feelings, and in levels of consciousness. (*Ref. p34.*)
Foot Drop, is a gait abnormality in which the **dropping** of the forefoot happens due to weakness, irritation or damage to the common fibular nerve including the sciatic nerve, or paralysis of the muscles in the anterior portion of the lower leg. It is usually a symptom of a greater problem, not a disease in itself. (*Ref. p38.*)
The **"good"** leukaemia, often used to describe ALL (Acute Lymphocytic Leukaemia) because the outlook for children is usually good. (*Ref. p15.*)
Haemaglobin, red blood cells contain haemaglobin (Hb), which gives the blood its red colour and transports oxygen from the lungs to all parts of the body. The body uses this oxygen to create energy. (*Ref. p25.*)
Hickman line, a type of catheter (see Catheter above).
IVs, an apparatus used to administer a fluid (as of medication, blood, or nutrients) intravenously; also, a fluid administered by IV.
Leukaemia, a type of cncer that is characterised by an abnormal increase in the number of white blood cells in the body tissues, especially the blood.
Lymph Nodes (or **Glands**), any of the rounded masses of lymphoid tissue in the lymphatic system where lymphocytes are formed.
Malignant, (*opp. to benign*), tending to become progressively worse; having the properties of anaplasia, invasiveness, and metastasis; said of Tumors.
Meningitis, inflamation of the meninges (membranes enveloping the brain and spinal cord), usually caused by bacterial, fungal or viral infection. (*Ref. p25.*)
Metastasised, cancer cells that spread to other parts of the body via the blood. (*Ref. p17*)
MRI scan, magnetic resonance imaging is a type of scan that uses strong magnetic fields and radio waves to produce detailed images of the inside of the body.
Morphine is a strong painkiller used to treat severe pain, for example, after an operation or a serious injury, or pain from Cancer or a heart attack. (*Ref. p38.*)
Mucositis is the painful inflammation and ulceration of the mucous membranes lining the digestive tract, usually as an adverse effect of Chemotherapy and Radiotherapy treatment for cancer. (*Ref. p29*)
Nasogastric (NG) tube, is a medical process involving the insertion of a plastic tube through the nose, past the throat and down into the stomach. (*Ref. pp29 & 36.*)
Neutropenic, little or no white blood cells (neutrophils) in the blood, causing the patient to be vulnerable to bacterial and fungal infections. (*Ref. p28.*)

Oncology, the study and treatment of cancer and malignant tumours.
PICC, a peripherally inserted central catheter (PICC or PIC line), less commonly called a percutaneous indwelling central catheter, is a form of intravenous access that can be used for a prolonged period of time (eg, for long chemotherapy regimens, extended antibiotic therapy, or total parenteral nutrition). (*Ref. p38.*)
PICU, Paediatric Intensive Care Unit – an area within a hospital specialising in the care of critically ill infants, children and teenagers. (*Ref. p20.*)
POCU, Paediatric Oncology Secial Care Unit.
Paedriatic(s), medicine dealing with the care and diseases of children.
Platelets, (thrombocytes) are colourless blood cells that help blood clot. Platelets stop bleeding by clumping and forming plugs in blood vessel injuries. **Thrombocytopenia** (low platelet count) often occurs as a result of a separate disorder, such as leukaemia or an immune system problem. (*Ref. pp25,26 & 28.*)
Pneumonia, lung infection that causes the air sacs to fill with pus, so that the lungs change from a soft spongy consistency to become quite solid. (*Ref. p26.*)
Pneumothorax, sudden shortness of breath, or breathing difficulty (dyspnoea). (*Ref. p17*)
Portacath, in medicine, a port (or portacath) is a small medical appliance that is installed beneath the skin. A catheter connects the port to a vein. (*Ref. p26.*)
Prognosis, the prospect of recovery as anticipated from the usual course of disease or peculiarities of a particular case.
Proton Beam Therapy is a different type of **radiotherapy.** It uses a high energy **beam** of **protons** rather than high energy X-rays to deliver a dose of **radiotherapy** for patients with cancer. It works best on some very rare cancers including tumours affecting the base of skull or the spine. (*Ref. p23*)
Radiotherapy, often abbreviated to **RT**, **RTx** or **XRT**, is a treatment used to destroy cancer cells with high-energy radiation. A beam of radiation is targeted on the cancer, which shrinks it. Radiation therapy can be used to control or kill malignant cells.
Rotavirus, is a virus that causes gastroenteritis. Symptoms include severe diarrhea, vomitting, fever and dehydration. (*Ref. p26*)
Sarcoma, a usu cancerous tumour arising espially in connective tissue. (*Ref. p16.)*
Sats, oxygen saturation (SO2), commonly referred to as 'sats', measures the percentage of oxygen-saturated haemoglobin relative to total haemoglobin in the blood. Blood oxygen levels below 80% may compromise organ function.
Scan, medical examination of a part of the body using a scanner; an image produced by a medical scanner.
Shingles, severe short-lasting inflamation of certain ganglia of the nerves that leave the brain and spinal cord, caused by a virus and associated with a rash of blisters and often intense neuralgic pain. (*Ref. p26*)
Slapped Cheek,(also known as fifth disease or erythemia infeciosum) is so-called because of the distinctive bright red rash that appears on the cheeks. It is a mild infection that looks much worse than it is. (*Ref. p26.*)
Sleep apnoea, is a common disorder in which you have one or more pauses in breathing or shallow breaths while you sleep. Breathing pauses can last from a few seconds to minutes. They may occur 30 times or more an hour. Typically, normal breathing then starts again, sometimes with a loud snort or choking sound. Sleep apnoea usually is a chronic (ongoing) condition that disrupts your sleep, causing you to move from deep sleep into light sleep. As a result, the quality of your sleep is poor, making you tired during the day. (*Ref. p21*)
Sonographer, is a preferred term for the specialised healthcare worker who performs diagnostic medical **sonography,** or diagnostic ultrasound. (*Ref. p36.*)
Steroid(**s**), also called corticosteroids, are anti-inflammatory medicines used to treat a range of conditions. They are different from the anabolic steroids used by athletes and body builders to improve their performance.
Stroke, is a serious life-threatening medical condition that occurs when the blood supply to part of the brain is cut off. (*Ref. p34.*)
T-Cell Non-Hodgkin Lymphoma, lymphoma is the most common blood cancer. The two main forms of lymphoma are Hodgkin lymphoma and non-Hodgkin lymphoma (NHL). Lymphoma occurs when cells of the immune system (lymphocytes), a type of white blood cell, grow and multiply uncontrollably. The body has two main types of lymphocytes that can develop into lymphomas: B-lymphocytes (B-cells) and T-lymphocytes (T-cells). (*Ref. p21.*)
Total Parenteral Nutrition (**TPN**) is a method of feeding that bypasses the gastrointestinal tract. Fluids are given into a vein to provide most of the nutrients the body needs. The method is used when a person cannot or should not receive feedings or fluids by mouth. (*Ref. pp37, 38.*)
Tumour, a swelling on or in a part of the body, especially one involving an abnormal growth of tissue that may be benign or malignant.
UCC, Urgent Care Centre. (*Ref. pp24& 36.*)
Ultrasound, (as in scan), the use of ultrasonic waves or vibrations in therapy or diagnostics, e.g. to examine internal bodily structures. (*Ref. pp9, 20, 34 &37.*)
Wilms' Tumour, also known as **nephroblastoma**, is a cancer of the kidneys that typically occurs in children, rarely in adults. It is named after Dr Max **Wilms**, the German surgeon (1867–1918) who first described it. (*Ref. p36.*)
X-ray, to examine, treat or photograph with x-rays.

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