

# Chemotherapy



**We understand it is shocking news to hear your child has cancer and that they need chemotherapy. Many parents feel this way, especially as treatment can start very quickly. The duration of this treatment can be extremely hard on the whole family but it does come to an end. Though treatment cycles are usually set at three-weekly intervals, it is common for there to be delays along the way, and your team of professionals will be around to talk to about this.**

**This leaflet is not about the treatment itself but about how families have coped with it. We asked our members what they felt they could not have lived without during chemo. Here are some of the things they shared with us:**

- I couldn't have done without the little material 'wiggly line' (Hickman line) bag given to us at the hospital. The children wear them around their necks attached to a ribbon. It kept the end of the line safe from being played with and wee! And have lots of help on hand for siblings.
- Our son was too young to have a 'wiggly' bag, but a piece of tubular stretchy gauze bandage (Tubigrip) kept his line in place - he wore it like a boob tube!
- We couldn't have lived without lots of vests/bodysuits with poppers to hide the line (wiggly) from baby/toddler hands, fruit shoots and maxi joule (the only way to get calories into our son), portable DVD player and DVDs for us and our son, using Twitter on our phones to communicate with friends and family.
- Couldn't have done without our community nurse, disability living allowance, my friends (true) and jam doughnuts (all my daughter would eat!!!).
- Sudoku to keep my brain occupied whilst going through the endless hanging around in hospitals. My emergency bag(s) always packed with overnight stuff and toys. The Hippychick hipseat, fruit puree pouches as this was one of the few things my child would eat. Free parking permits from the hospital and being able to use the private/cancer patient's room in our local hospital. (CHECT: These may not be available at every hospital so ask the ward staff)
- Mum and hubby were great. Just having the house clean when we got home was a blessing, mum would do a bit of shopping too when my two were neutropenic.
- We couldn't have done without our community nurses and local hospital - We had quite a few hospital admissions due to line infections. Family and friends helping with siblings.
- Lego for my son, travel chess for myself and partner.

“Seeing that, for the most part, my daughter’s spirit was undiminished helped me get through chemo.”



- Fantastic parents to care for sibling and give us endless emotional support, support from friends and school, brilliant employers (my work allowed me months off with no sacrifice to my salary, etc and were so supportive). This is the time we invested in a DS - a great distraction!
- Invest in a really good under arm thermometer, a cleaner, snacks and your community nurse. A bag full of toys to take into hospital and huge amounts of strength and courage that will get you through it and out the other side!
- Telling other people has been one of the most tricky and exhausting parts. Sending a mass email to parents in both my son and his brother’s class was the most effective way to let people know what was happening.
- Being able to talk regularly to somebody with experience of their child having chemo... the community nurses... seeing that, for the most part, my daughter’s spirit was undiminished.
- Starting a blog for all our family and friends to read so we didn’t have to say it all over and over again. It was quite cathartic to write too.

## My Story

CHECT has always asked people to share their stories. We know that it can be helpful and sometimes uplifting to read people’s Rb stories. We have two extracts below. You can find the full ‘My Story’ on our website.

### Christina Rozeik’s story

Alexander had a Hickman line put in his chest, so the doctors could deliver the chemo drugs and take bloods without continually sticking needles into him. The operation for the Hickman line was carried out under general anaesthetic and was quite quick - Alexander didn’t seem to be bothered by the operation or the line and recovered rapidly.

The chemo drugs were given via a pump connected to Alexander’s Hickman line. The chemo itself seemed painless and Alexander was totally unbothered by the whole process – the biggest drawback was that his movements were restricted and every time he rolled over he squashed the connecting line and triggered the blockage alarm on the pump so one of the

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nurses had to come and reset it. Each cycle began with a dose of chemo and after that we were at home, trying to get on with everyday life, while Alexander’s blood counts fell and then recovered. We were told each cycle would take three weeks. In practice, this didn’t always happen: sometimes Alexander’s blood counts hadn’t recovered enough, and other times he had an infection that delayed the next cycle of chemo. It was hard not to feel impatient and anxious when this happened - you want to get it all over and done with and you also worry a delay will mean the chemotherapy is less effective - but once we realised delays were normal and there was nothing we could do, we were able to relax a bit more.

Three or four times the platelets or haemoglobin fell below a certain level so Alexander had to go into hospital for a platelet transfusion – this only took about half an hour using his Hickman line and was surprisingly undramatic.

We had to take his temperature frequently and any time it was over 38 degrees, we had to go straight back to hospital. This was usually at night, when it was tempting to stay in our warm beds rather than pack everything up and go to hospital. However, an infection is potentially life-threatening so you just have to be prepared to drop everything and go when this happens.

The chemo can make children quite sick and can also suppress their appetite. Unfortunately, Alexander suffered from both of these things, so we had to give him anti-emetic (anti-sickness) drugs for the first few days after each chemo dose to stop him from vomiting



all the time. Halfway through the course, he was prescribed a different anti-emetic which seemed to be much more effective, so it is worth persevering until you find something that works. We were delighted when his feeding returned to normal about five weeks after the last chemo cycle. I can’t believe how much he now eats and how much he’s enjoying his food!

We expected Alexander’s hair to fall out immediately and were quite surprised when it didn’t. In fact, his hair just got thinner and thinner until he was practically bald by the end of the course – but the loss was so gradual we didn’t really notice.

It was an intensive five months and we were slightly taken aback not to feel more elated when it was finished – we felt rather flat and at a loose end. I think we became so focused on getting through the chemo and on all the practical issues that we forgot about why it was happening.

**To read Christina’s story in full, including how they coped with a feeding tube and life after chemo, visit the My Story section on our website [www.chect.org.uk](http://www.chect.org.uk) under [Parents](#).**

“I could see friends and family as long as they were well.”



## Jane Harrison's story

Olivia underwent surgery at Sheffield Children's Hospital to have a Portacath fitted under her skin in readiness for administration of chemotherapy and antibiotics or other medicines needed along the way. Apart from being a little sore where the Portacath now was she had a comfortable night ready for her first cycle starting the following day. The chemo took roughly five hours to administer with the flushes in between and was connected through the Portacath via an IV (Intravenous) line.

The first session felt like the longest day of my life. I remember the alarms on the IV equipment kept going off which made me on edge and on the screen it was saying "resistance alert". All I could think was 'oh no, Olivia's body is resisting!' and then I thought 'Why isn't anyone coming to see why the alarms are sounding?' When I was told it was only because she had moved in her cot and the line had kinked, blocking the flow, I was able to see why no-one was as worried as I was.

I remember Olivia becoming very unsettled and holding her with the IV wire coming up through her vest and worrying I would knock it or make it bleep again, I was anxious as I was not able to comfort her the same as I usually did, I did not want to hurt her as she was still tender from the previous day's surgery.

It was about that time I realised the way I was feeling was making Olivia anxious too, from that moment my whole thoughts and



feelings changed. Within hours of starting chemotherapy I decided I had to forget about how I was feeling or thinking and that had to go away in a little box for another day - my four-month-old little girl who was so happy go lucky needed me to be strong, so I was.

Olivia handled the first session well. The days that followed were no different to normal - none of what I had been told could happen did happen. Olivia blossomed throughout. I successfully introduced food and Olivia put on weight, developed well and none of the side effects came.

Babies and children are resilient and because they do not understand what is happening and having nothing to compare against seem to handle chemotherapy well. Olivia and I attended hospital in between chemotherapy sessions to have her blood counts checked and apart from one infection in her bad eye at the very beginning of treatment where we stayed in hospital on IV antibiotics she was

Our Facebook page, forum and website are resources you can access outside office hours.



infection free for the whole time. I know compared to other children on chemo Olivia was lucky with the way it all went for her. You certainly worry at the start because you know chemo will compromise the immune system but it really is not that bad, I did not need to obsessively clean the house with antibacterial sprays and wipes.

I just carried on as normal. The only part of our routine I changed was that in the middle week when counts are at the lowest I was just mindful of where we went, so I could still see friends and family as long as they were well but could not take Olivia to the supermarket with me exposing her in queues etc.

The chemotherapy days were long and its better someone is there with you even if it's just so you can go for a coffee break. Although the delivery of the chemotherapy was about five hours, we would arrive at the hospital, have Olivia's counts done then see the consultants etc so with travelling and waiting times it soon turned into 10-11 hour days. Olivia is now two-and-a-half and is such a bright, happy and confident little girl who seems to take everything in her stride, it's hard to remember all this was only two years ago.

**Read Jane's story in full in the My Story section on our website [www.chect.org.uk](http://www.chect.org.uk) under [Parents](#).**

### Useful booklets

Visit our website for a list of booklets for families with children who have chemotherapy.

### Out of hours support

Our office hours are 9am - 5pm, Monday to Friday excluding bank holidays. Our forum, website and Facebook page are resources you can use outside office hours but if you really want to speak to someone **gaps:line** is a telephone support line for children, families and others affected by childhood cancer and leukaemia. It is run by a charity called the Bryan Gunn's Appeal. The gaps:line operates every day between 8pm and 10pm. Telephone: 0845 121 4277 (calls are charged at local rate).