

CHEMOTHERAPY



We understand it is shocking news to hear your child has cancer and that they need chemotherapy, especially as treatment can start very quickly. However the whole family will be supported throughout the entire process by your treatment team and your Childhood Eye Cancer Trust (CHECT) support worker.

This leaflet is not about the treatment itself, but about how families have coped with it. We know that it can be helpful and often uplifting to read other people's retinoblastoma (Rb) stories. We have two extracts below. You will find the full versions, as well as other stories, at www.chect.org.uk.

Amber was diagnosed with unilateral Rb at 21 months. Her mum Pippa shares their experience of chemotherapy

The first chemo session was a huge learning curve. We soon realised that allowing Amber to walk around was not going to be easy with the trolley full of drugs attached to her port, as she was still charging around at toddler pace. So we settled for six to seven hours in her cot or high chair watching tv or dvds. We always hoped for her to sleep in this time too but it wasn't the easiest, again with tubes attached and the regular alarms on the chemo machine, which the nurses explained, and became easier to handle as the sessions went on.

Amber needed platelet and blood transfusions during her treatment. As with everything, the first of each were worrying. However by cycle six we could recognise the benefits they brought. Our local hospital were fantastic, and we had an isolation room at each transfusion. She also had two 48 hour stays when her temperature spiked. The isolation room was great, but you need imagination and great play room staff to keep a toddler entertained in one space for all that time.

During treatment we were given very specific advice about what to do if Amber got a high temperature and when to take her to hospital. The community nursing

Email -
support@chect.org.uk

Lena - London
07706 919 996

Sarah - Birmingham
07526 594 762

Office -
020 7377 5578

team soon became our social life and new best friends. I looked forward to their company as they arrived to do blood tests. We soon got ourselves into a routine for putting on the numbing cream before they arrived and using the iPad for distraction as the port

was accessed, although after a few weeks Amber actually wanted to see the needle go in. We know that not all children will be like this, but, as we learnt, it was right for Amber. We explained what was happening each time and she began to know the routine. We realised by the end of her treatment that, what at the beginning was a major hurdle, was now a regular event, which we took in our stride.

From diagnosis we were worried about her hair falling out. Once it started coming out in handfuls when we brushed it, and it was covering her cot, we realised it needed to be cut so that it didn't irritate her as much. Her hair continued to fall out after each cycle, until by the end she had lost it all. Ironically, the day she was diagnosed she was supposed to have her first hair cut. Instead she had one at home after her second chemotherapy with two very emotional parents, but as with most things, it wasn't as bad as we thought it may be.

By keeping track of Amber's blood results and also the food she was eating as each new cycle started, we began to see a pattern of her less hungry days and days when she started eating other

foods again. We were told that calories were all that was important, so if she ate Weetabix and plain pasta throughout treatment I learnt not to worry.

Amber's sleep was disrupted by her treatment. Friends would say that she was just being a toddler, but we knew she just didn't feel quite right and now she is recovered her sleep has returned to a more normal pattern.

We are now nearly five months on since Amber's final chemo. So what have we learned?

It was a hard few months which challenged our ideals as parents (such as not watching tv and eating a balanced diet) in addition to the pain of watching our little girl feel more and more tired as the weeks went on. I hear certain children's programmes songs now and I am instantly taken back to those days we sat in front of the tv together snuggling, as that is all she wanted to do. Now, she has all her energy back she's into everything again.

To hear more from families whose children have gone through chemotherapy you can visit the CHECT website, join our closed Facebook group for parents, or ask your support worker to link you with another family.

Matthew was diagnosed with retinoblastoma at almost three years of age. Here his mum Michelle describes their experience of chemotherapy.

Ever since Matthew's retinoblastoma diagnosis we were half expecting he would need chemotherapy, but to get the confirmation was shocking and sad. We moved into our local hospital's care with a call from a lovely calm doctor who told us where to come, explained what would happen and that we would speak in more detail the next day.

Chemotherapy was not what I was expecting. Matthew didn't ever lose his hair (we hadn't cut his hair thinking he would lose it, but he never did, so it was a right mop by the end!). There was no sickness with the first cycle. After the second cycle Matthew was sick at the end of the day and a bit more tired, so the hospital wanted to keep him in to get antisickness meds in.

Later in the process Matthew wouldn't take oral medication anymore, so from then on he would have intravenous anti-sickness meds in hospital before the chemotherapy, go home, and then be sick around 11pm. After that he would go straight back to sleep, and the next day be like nothing

had happened. We managed it with cuddles and lots of changes of bedding!

We had two episodes fairly late in the process when we were in our local hospital for 48 hours with high temperatures. Neither of these episodes delayed the next round of chemo.

We deliberately didn't do much reading around, and took Matthew's experience as the only experience. We were lucky to be surrounded with lots of support. We knew one other family who had a child with Rb, and adults who had had other cancers who were very sympathetic, saying we know it can be tough as we've been there. Both our employers were really supportive, and Matthew's nursery was very sympathetic, organising presents for Matthew and fundraising for CHECT. It was really lovely, not too much, just recognising that Matthew had gone through something tough.

Our home care team were really nice, and Matthew loved both nurses. They came on weekly basis to change dressing and flush his Hickman line.

What is strange is when the chemotherapy ends. We had been so immersed in the process and the

regular contact with doctors and nurses that once that had gone I had a feeling of 'Oh gosh, we're on our own now'.

What would I say to parents starting their chemo journey? Be aware of things but don't expect them (sickness, hair loss). Everyone's situation is different. If you are aware of something you can be ready, but try not to worry in advance as you will put added pressure on yourself.

Give lots of cuddles! If you need to be upset, be upset, don't be afraid of being sad in front of your child. You can let them know you feel really sad about what is happening to them, and this might even encourage them to tell you how they are feeling.

Be aware that your child going through this may put pressure on your relationship, even a strong one, so be more understanding of each other. My husband and I reacted differently to the whole process. Ed took it hard, whereas I largely took it in my stride. Maybe it will hit me at a later stage.

We celebrated the end of chemo in July, and since then have been enjoying life gradually going back to normal.

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:

- Our son was too young to have a 'wiggly' bag for his Hickman line, but a piece of tubular stretchy gauze bandage kept his line in place – he wore it like a boob tube!
- Lots of vests / bodysuits with poppers to hide the line (wiggly) from baby/toddler hands, also Fruit Shoots, iPad with programmes / films for us and our son, and Twitter for communicating with friends and family.
- Our community nurse, disability living allowance, my friends and jam doughnuts (all my daughter would eat!).
- My emergency bag(s) always packed with overnight stuff and toys, the Hippychick hipseat, fruit puree pouches (this was one

of the few things my child would eat), and free parking permits from our local hospital.

- Mum and hubby were great. Just having the house clean and some shopping done when we got home was a blessing.
- Our local hospital: we had quite a few hospital admissions due to line infections. Family and friends helping with siblings.
- Support from friends and school, helpful employers.
- A cleaner was a really good investment. Snacks, 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.
- Being able to talk regularly to somebody with experience of their child having chemo, and seeing that, for the most part, my daughter's spirit was undiminished.

- Starting a blog for all our family and friends to read so that we didn't have to say it all over and over again. It was quite cathartic to read too.
- Friends and family offering to make meals for our freezer, as there were days when we just needed easy food.
- A single sheet from home and a pillow case made the nights in the parent hospital bed a little more appealing.
- Disposable mattress liners for the car seat in case of sickness.
- Talking to other parents on the ward was good for me.
- As parents you still know your child best, and it's okay to tell medical staff what you know.
- Bring an element of play to the appointments: make the journey to hospital more fun by spotting landmarks; turn finding a parking spot into a game.

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☎ 020 7377 5578

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