

Radiotherapy – external beam radiotherapy



This leaflet has been written to complement the medical information you have been given about radiotherapy treatment by the retinoblastoma team at your child's hospital. You will also have spoken to your child's consultants about treatment. The information here draws from people's personal experiences of the treatment so we hope this information offers you some idea of what to expect.

Radiotherapy is given at St Bartholomew's Hospital (Barts) in London. It may be given for three to five days a week for five weeks. It is usually booked for the morning. Some people choose to come in every day if they live near enough, others will use hospital accommodation organised by the retinoblastoma team. This accommodation is on the Royal London Hospital site. People using the accommodation will have to travel to and from appointments by public transport or car as there is not any hospital transport for this. A Childhood Eye Cancer Trust support worker may be able to visit you during one of your appointments if you would like them to.

Below is one member's story about her son's radiotherapy treatment.

Please note: Retinoblastoma affects children in different ways. Some children have more aggressive forms than others. Treatment options will vary from child to child and your retinoblastoma team will be able to discuss all the treatment options with you.

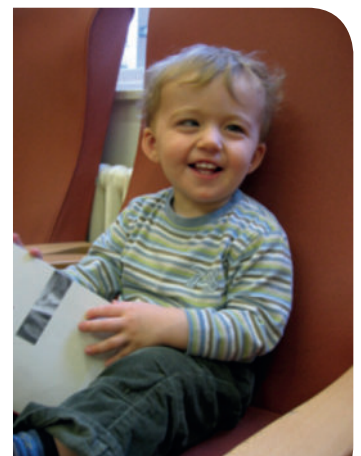
Fiona Morley-Smith's story

Fintan has bilateral retinoblastoma, for this he has received a number of treatments. Almost a year after his initial diagnosis, we were told that things had taken a turn for the worse and radiotherapy was the next step.

One week later, Fintan had an ultrasound of his eyes at Moorfields Eye Hospital, a simple and painless procedure. The following day we met the consultant radiation oncologist and radiotherapy department team at Barts where Fintan would be having his treatment. We were advised that Fintan would be having 'lens sparing' external beam radiation therapy which would reduce the risk of him developing cataracts, a possible side effect of radiotherapy.

We finally got a start date for Fintan's treatment, which would involve a month-long course of radiotherapy – every weekday with a few extra days off for machine servicing. We had already been advised that Fintan would require a general anaesthetic for each dose, but the application of the radiotherapy does not take long and it was anticipated that we would only have to spend the morning at the hospital and could return home each day. The treatment involved directing a beam of radiation to the eyes, with the entry point at the side of Fintan's head at eye level and exit point at eye level the other side. As both of his eyes were being treated, the procedure was repeated with the radiation beam entering the opposite side of his head. It was at the exit points that the skin could become red, sore and dry, but 'eye care' was carried out whilst Fintan was anaesthetised; this involved the application of lots of cream which we also repeated at home.

When you discover that your child requires major treatment, you just want it to get started and any time waiting is spent worrying and speculating about the unknown. Once treatment starts, you can appreciate how much



organisation is required in getting a team together – time slots at Barts, anaesthetist and nurse from the Royal London Hospital and the radiotherapy team at Barts.

The day finally arrived and it was an early start, having to be at Barts by 9.00am and a two-hour peak time drive into London. Fintan had to be starved due to requiring a general anaesthetic; the treatment is not painful, but he had to stay perfectly still. Fintan took it all in his stride, as normal; he did have a little cry when he was taken down to the treatment room, which was not particularly welcoming and the radiotherapy machine was huge! The staff briefly explained the equipment and what would happen, Fintan was then anaesthetised and Fintan's dad, James and I returned to the waiting room.

The treatment did not take long at all, in fact he was only away from us for about 40 minutes, and this was longer on the first day as they needed to create a mould for his head (so that he lay in the same position each day). When Fintan came round from the anaesthetic, he was a little drowsy but was drinking his milk and playing with toys again in no time and we were able to leave the hospital around lunchtime.

Recovery took place in the waiting room, it was pretty basic with chairs and a few toys, but didn't normally take long. There were a couple of mornings when Fintan struggled to come round from the anaesthetic, but the nurse and anaesthetist stayed with him until he was more settled.

Fintan's 2nd and 3rd doses, which also went very smoothly, took us to the end of the first week. Doses four, five and six were carried out in week 2 and Fintan was coping so well, I started taking him to the hospital alone, whilst James was able to work from home and make sure Fintan's older brothers got to school.

Fintan soon got used to the routine; being starved in the morning and setting off for the hospital when it was still dark. At the hospital, he liked to walk around and around the waiting area - out one doorway and in another, making friends with some of the other patients on his way!

We had been warned that by about week three Fintan might start to feel more tired and may develop sores on the sides of his head, but he was still coping very well at this stage. He had four doses in week three and was now used to the daily anaesthetics. The end of week four with four doses and Fintan was still smiling; small red patches had appeared on both sides of his face by his eyes, similar to sunburn, but it didn't seem to bother him.

Week five with five doses passed without event! At last, just before Christmas, Fintan had his final dose of radiotherapy. By this stage, the redness around the eyes was more obvious, though it didn't seem to cause him any discomfort - he just got a few funny looks when we were out and about!

Fintan's older brothers, Archie and Barnaby, came to the hospital with us for the final treatment. We took them for a pizza and admired the Christmas lights; despite the previous five weeks of treatment, Fintan was well enough to thoroughly enjoy himself.



Although we were glad the radiotherapy had finished, the intensity of the treatment means you soon get used to the hospital routine and you almost forget life pre-treatment, so it took a few days to adjust back to normal life. However, we were delighted to have completed treatment in time for Christmas!



Support

Please get in touch with one of our support workers if you would like to discuss any of the information in this leaflet or visit our website for information on treatments and stories from other families affected by retinoblastoma.

If you would like to speak to others who have been through radiotherapy you can ask our support worker to link you to someone via email or phone. You can also post on our Facebook page asking for someone with experience to message you privately.

The CHECT Support Team will also be available via email at support@chect.org.uk