

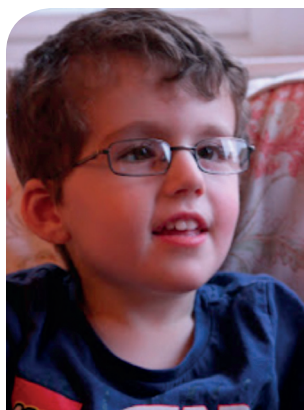
# Radioactive plaque therapy



This leaflet has been written to complement the medical information you have been given about radioactive plaque therapy (plaque) 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.

Below is one member's story about his son's plaque therapy.

**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.**



## James Morley-Smith's story

Fintan has bilateral retinoblastoma, for this he has received a number of treatments. When a new suspicious area was detected in Fintan's right eye, it was monitored for a while but our consultant decided he needed radioactive plaque treatment.

The plaque was inserted on a Wednesday. We had been warned prior to the start of this treatment that the plaque would have to remain in place until the following Saturday, however, once it was inserted we were informed it only needed to stay in until Friday lunchtime. This was welcome news, as I thought Fintan might really struggle with the isolation, as he is always so keen to get outside, insisting on putting his wellies on, or 'toots' as he called them, at every opportunity! Not only did Fintan have to stay in a hospital room for the whole period but my wife Fiona couldn't visit at all as she was pregnant at the time.

As it happens, Fintan coped extraordinarily well with everything. He kept himself busy playing with his cars and watching 'Big Cook Little Cook'. In fact, it was me who cracked first by only about midday on the Thursday. However, relief was at hand from some friendly faces from the Childhood Eye Cancer Trust and the retinoblastoma play specialist who came over to give Fintan a break from his grumpy Daddy.



The Friday morning was a bit tougher as Fintan had to be starved in preparation for the operation to remove the plaque - he couldn't even have water due to the timing. Fintan devised a crafty way to get a few drops and ease his thirst, but after he asked me to clean his teeth for the third time, I cottoned on to the ruse and the toothbrush was packed away!

The plaque was safely removed and after a nap and some well-deserved crisps, Fintan was ready for Mummy and his brothers, Archie and Barnaby.

There were no problems after the treatment; he had to have some basic eye care which wasn't really an issue for Fintan or us. There was a little redness from all the poking about but nothing more than that.

In the following year, Fintan had another round of plaque treatment, this time in his left eye.

Fintan was admitted on a Wednesday and went down to theatre at about 4pm for the plaque to be inserted and was back in recovery just before 6pm. Fiona and Fintan's brothers set off home leaving me to deal with Fintan coming round from his anaesthetic and to start the 3-day 15-hour isolation ordeal (the timing for how long the plaque stays in are really quite precise!).

By this time in Fintan's treatment his right eye was not much use to him and he could not see much more than a little light and dark. Despite this and being confined to a small room, he coped admirably. By Friday he had discovered a spot in his right eye (the one not being treated) through which he could see and if he tucked his chin into his chest he was able to watch TV and see what he was eating.

The plaque was removed with no complications on Sunday morning and Fintan was back home by 6pm.

## **We asked our members to tell us what made things easier for them whilst their child had a plaque. Here are some of the things they had to say.**

- Make sure you have a portable DVD player and plenty of DVDs!!!! And lots of munchies help too!
- We brought a huge bag full of toys, books, DVDs and iPod with speakers for our son's favourite music. Lots of food treats and a few toy treats too. It was hard, by the end of day two he didn't want to do anything but watch films. I think he was bored rigid and not feeling great which made him really tired. We expected him to be bouncing off the walls with excess energy but the whole experience made him very subdued and inactive. We also took the time to plan all sorts of lovely things we were going to do as a family when we got home - everything from holidays, visits to the park, seeing friends, to day-to-day stuff. He spent quite a bit of time on the phone too speaking to his sister and grandparents!
- A friend sent us a fab large parrot puppet which squeaked "naughty parrot". It lived in the room and was used to lighten the atmosphere and distract us from everything that was going on. Don't forget DVDs for grown ups for the evenings too!

## **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 plaque therapy 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. If you want to speak directly to someone out of office hours **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 everyday between 8pm and 10pm. Telephone: 0845 121 4277 (calls are charged at local rate).