



JUST DIAGNOSED



Hearing your child has retinoblastoma (Rb) will have left you with a mixture of emotions. When you were given the diagnosis, you would also have been told about the treatment your child would have to undergo. All this may have left you feeling completely overwhelmed, but there are people to guide you through this difficult time and helpful information available.

You will receive support and medical information from your Retinoblastoma Team, support from your Childhood Eye Cancer Trust (CHECT) support worker, and can find more information about Rb on the CHECT website. This leaflet has been put together to help you deal with some of the practicalities around a new diagnosis, as well as tips on looking after your family and yourself. You can also read about a family's experience of diagnosis.

On our website you will find stories from other families which may be helpful, and we also provide a closed Facebook group for parents to share experiences.

If you would like to speak to other parents with a similar experience, we can also arrange that for you.

It can feel like there is a lot of information to take on in the beginning but you will be supported through this.

You may have family and friends who are waiting for you to let them know how your child's appointment has gone, what the doctors said to you and what will

happen next. Some parents find it easy and comforting to explain it all to family and want support from them immediately; others need time to digest the information first. There is no right or wrong approach, and how much or little you want to tell people is completely up to you.

You could choose who you want to tell immediately, and use email and social media to let others know, perhaps including a link to the CHECT website. Or you may ask one person to act as an information 'gatekeeper', coordinating telling others. This way you won't need to repeat yourself

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many times, especially if you find yourself getting upset the more times you tell people.

Some people find it helpful to write a blog about their child to let their friends and family know how treatment or check-ups have gone. If you choose to use social media, people can see how you are doing and let you know that they are thinking of you without the constant calls.

You may find that friends or family really want to help you but they don't know how to. It can be hard to

ask for help or accept the help that has been offered but if you can give people practical things to do it can make life a little easier.

Ideas include:

- Doing a supermarket shop for you
- Looking after your child's sibling while you're in hospital
- Picking up siblings from school
- Giving you a lift to hospital appointments

It's really important to look after yourself so that you are able to support your child through this in the best way possible.

Some people find writing down feelings and events in a diary helps.

You will have plenty of people to support you – hospital teams (play specialists, nurses, doctors to name a few), your CHECT support worker, other charities, as well as your family and friends.

Do whatever works for you and your family. Please don't be afraid to ask for help, at whatever stage you are. Our support workers are always happy to listen to any concerns or difficulties you may be having.

For more information about retinoblastoma, treatment and the ways in which CHECT can help, go to www.chect.org.uk

Jude was diagnosed with unilateral Rb at nine months. His mum, Jodie shares their story.

To say that Jude's diagnosis was a shock would be an understatement. We took Jude to a paediatric ophthalmology clinic one Saturday morning for what we believed was a squint and were told that his retina was detached and we were being referred to the hospital. The consultant didn't tell us why. Earlier in the appointment I had mentioned that I was starting a new job that Monday after

eight months on maternity leave and he told me not to worry, to start my new job and let the doctors do the worrying. So I did.

Two days into my new job I got a call from the Rb team at the hospital who told us that they suspected Rb and arranged for Jude to have an EUA (examination under anaesthetic) the following Monday. I don't really remember the next



few days, only how hard it was to telephone my parents and tell them the news, and how determined my husband and I were to stay positive.

The diagnosis was confirmed as retinoblastoma with a tumour in Jude's right eye. Unbeknown to us, Jude had had no vision in this eye for a long time due to the tumour, possibly even since birth. The tumour was large and the damage to the eye was irreparable, irrespective of what treatment he had. Despite our shock, we tried to identify and focus on the positives.

Telling people about Jude's diagnosis was incredibly hard. Our family and friends were extremely supportive, but often people didn't know how to react or what to say. The word 'cancer' makes people scared and feel awkward at the same time. Often we found ourselves comforting those we had told rather than the other way around. So many times we listened to people tell us that they didn't know how we coped so well. Whether or not we coped well is subjective, but ultimately when you



have a child you have no choice but to cope and to carry on. Your love for them is what carries you through as they need their parents to be there for them in every way possible.

Two years on and Jude is doing brilliantly. My advice for anyone going through

the agony of diagnosis now would be to try to find the positives and focus on them, but to also be kind to yourself and allow yourself plenty of time to come to terms with what has happened and for your emotions to catch up with the fast pace at which treatment moves.

“Six years ago today we were told Eliza had bilateral retinoblastoma. Even as a nurse who had worked in oncology it was the first time I had heard the word. Our lives today have been completely changed by the diagnosis, but we have four lovely children and Eliza is thriving. I wish that I could have had a glimpse of the future when times were tough over the last few years. We could never have predicted that Eliza would deal with things with such awesome courage and resilience. We feel so lucky to have her and to have met so many amazing families over the last six years”

Lucy Deakin, mum to Eliza



Remember, everybody deals with bad news in different ways, but many parents who have been through diagnosis and treatment recognise it usually affects them much more deeply than it does their child. It is the parents who bear all the pain, stress and worry and their child amazes them by how resilient and cheerful they can be throughout treatment or operation.

We hope this information pack helps you through the difficult time of diagnosis.

You can always call or email your support worker; visit our website; chat to other parents on the wards; read our newsletter; become a member of the charity; ask to be linked to another family who has been through a similar experience; or join our closed Facebook group for parents if you would like more support or information.

www.chect.org.uk

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