



EARLY YEARS AND VISUAL IMPAIRMENT

A diagnosis of bilateral retinoblastoma (Rb) can sometimes mean that your child may have some problems with their eyesight. This may result in the need for additional help and support as your child is growing up.

We hope you will find the information on this leaflet helpful and supportive. It is not intended as a substitute for medical advice but as a resource to help you and your family.

VISUAL IMPAIRMENT AND YOUR CHILD

The treatment of retinoblastoma aims to save life, and vision where possible. In some children with bilateral retinoblastoma there may be severe visual impairment. However, early treatment can be successful in limiting the degree of sight loss.

Children with more severe visual impairment may have difficulty seeing facial expressions, moving around the home, watching television, interacting with their peers and, when older, experience reading difficulties. Adaptations to the environment can help, and low vision services can

offer assessment for such things as mobility training and low vision aids.

Registering as blind or partially sighted

Your ophthalmologist can make a clinical decision to register your child as sight impaired (partially sighted) or severely sight impaired (significantly limited sight). If this is the case, your child will be issued with a Certificate of Visual Impairment (a CVI.) In Scotland it's called BP1, and in Northern Ireland A655. Often it can be difficult to accurately assess vision in very young children but the ophthalmologist or

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.

orthoptist will be able to give you some indication of the degree of visual impairment.

Once your child has a CVI, you should be contacted by your local social services team about specialist help. The benefits of registration vary in each local authority, but can include the Blue Badge for parking as well as various other concessions.

Referrals can be made by the hospital Rb team for local authority assistance with play, mobility and sensory development (depending on the services available in the area). In many areas there is a visual impairment

or sensory team who visit the home for a needs assessment and follow-up support. Often the local ophthalmology team will know how to access services in your area.

Disability Living Allowance (DLA) for children

This is a non means tested financial benefit that may help with the extra costs of looking after a child.

You can claim DLA if:

- you are the parent of a child under 16 with sight loss
- and your child has had these problems for at least three months
- and your child is expected to have these problems for at least six months.

Details of how to apply and payment rates, as well as other benefits available, can be found on the RNIB website in the Info for everyday living / Benefits and support section.

Visual impairment (VI) / sensory teams

A referral to your local team will be made by the orthoptist / ophthalmologist when they can confirm there is visual impairment in both eyes or the remaining eye.

The VI / sensory teams can begin working with children before nursery age to help the family with play and sensory development. They

can recommend toys and equipment appropriate for the child's development.

The teams provide home visits when children are not in school or nursery and when needed for older children.

They support nurseries and schools with the following:

- Advice on teaching strategies to support access
- Learning support for some pupils
- Functional vision assessments
- Observation in class
- Provision of low vision aids and specialised technology
- Teaching tactile codes like Braille or Moon
- Liaison between families and schools
- Touch typing for children
- Mobility training for all ages

Support at school

The Children & Families Act implemented in September 2014 introduced a new code of practice for the Special Educational Needs (SEN) support process, which your visually impaired child may need when starting school. In particular, the code places an emphasis on working with parents to agree and review the outcomes that the support is intended to achieve rather than counting

the hours or resource given to a child at school.

Education, Health and Care Plans (EHCP) replace SEN statements. Local authorities publish a "Local Offer" listing all the services available to children and parents seeking help with education. Schools acting with these services can make an assessment to meet the educational goals of the child.

The VI / sensory team will contribute to the EHCP which can be started in the nursery years. This process assesses the needs of the child in order to obtain funding from the local authority for educational support throughout the child's time in school and college.

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 with visually impaired children 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.

AIDEN'S STORY

"Our son Aiden has bilateral retinoblastoma and is registered blind. He is now two and a half and for the last 18 months has had a visual support worker to help him and us get the most out of the little sight he has.

The visual support that Aiden has received has been invaluable to Aiden and to us. When he reaches different stages of development the team has been there to offer advice and aids or equipment that would benefit him. For example when Aiden decided to try to feed himself they suggested and loaned us a child's bowl and plate that have suction pads on the bottom to stop them moving about on his high chair tray - ingenious. They have also helped Aiden with his coordination, confidence and strengthening his other senses.

The team helped us identify and assess the different nurseries in the area to find the best one for Aiden. They then advised the nursery on making the area safe for a visually impaired child and continue to advise and support both Aiden and the nursery to meet his needs through regular visits and observations.

Following observations the VI team has set up mobility assessments for Aiden, with a view to him possibly using a cane. They have also started teaching Aiden Braille and are arranging to put us on a Braille course to help support us as well as him.

The support is there for as long as Aiden needs it throughout his school years: finding the best school; sorting out his statement of special needs; and advising the school on how they can best support him. They are and continue to be an invaluable lifeline to the family."



RESOURCES

"Show me what my friends can see" (Sonksen & Stiff, 1991), a developmental guide for parents of babies with severely impaired sight and their professional advisors - available from your support worker.

Your support worker can signpost you to a range of organisations supporting children with visual impairments and their families.

Visit CHECT website www.chect.org.uk/resources for a list of useful resources on a range of topics including:

- reading for parents
- play
- special educational needs
- financial help
- visual impairment

www.chect.org.uk

t 020 7377 5578 e info@chect.org.uk

[@ChectUK](https://twitter.com/ChectUK) [/CHECTUK](https://www.facebook.com/CHECTUK)

Registered charity no. 327493. A company limited by guarantee, registered in England and Wales no. 2143917. Registered Office The Royal London Hospital, Whitechapel Road, London E1 1BB

