



**RETINA**  
australia

## Guide for parents of a child diagnosed with an IRD

### Diagnosis

If you've just learned that your child is (or will become) vision impaired, this is likely a difficult time for you and your family. You may be unsure how to tell family members and friends about your child's vision impairment. You may be wondering how your child's vision impairment is going to impact your family and your child's future. Diagnosis of a child is naturally an overwhelming experience. Feelings can include shock, anger and frustration but there are many options for getting support and assistance.



Many parents will want to learn as much as they can about their child's diagnosis and what the future will look like for their child. Developing an understanding of the diagnosis, of the different eye care professionals your child may be seen by, questions you can ask, and what you can expect at an appointment will empower you and your child to more clearly understand their vision impairment.

### What to tell your child

Telling a child that they have a degenerative eye condition can be challenging. It is important to be honest, positive and not to overload a child with too much information. Ensure the level of information you provide is age appropriate.

Certain pieces of information or activities will be more upsetting than others for your child. It can be difficult to predict what they may react to, so it is helpful to be prepared for these times. For example, visits to the doctor, difficulty with an everyday activity, getting lost and a general fear at losing their sight can be emotional triggers for children. Speaking to people who have experienced what your child is going through as well as professionals such as counsellors and psychologists can help you navigate these occurrences.

### Helping to adjust

There is no single “right” response to a child being diagnosed with an IRD, but it is essential to be realistic, hopeful and positive. You want to help your child to come to terms with the diagnosis without becoming over-protective or stripping them of their independence. Vision loss does not prevent a child from fulfilling their maximum potential – this is something for you and your child to keep in mind.

Support your child becoming involved in sports or activities in which they can develop their confidence and include them in doing things around the home.

Gaining skills in the use of low vision aids, technical equipment, mobility and orientation can also assist with confidence and independence.

It can be helpful to speak with the school or education department to discuss the various options available to support your child both in the classroom and as part of any extra-curricular activities and excursions.



Contact with other vision impaired young people may be beneficial in addressing some of the feelings relating to loss of vision, and in developing an acceptance of their diagnosis. Parents may find it useful to connect with other parents or even speak with a professional themselves. It is normal for a parent to need help adjusting too.

### Adapting the home

Many families of children with vision impairments are concerned about the ability of their child to get around their home safely. There are many relatively simple things that can be done to help your child move safely through your home using their vision (if present) or other senses.

You can make changes to lighting, glare, colours, contrast, textures and labels. You can also give thought to the way things are organised to reduce clutter and improve access to frequently used items.

Many helpful tips can be found from the website of the American Printing House for the Blind:

[familyconnect.org/info/after-the-diagnosis/adapting-your-home](https://familyconnect.org/info/after-the-diagnosis/adapting-your-home)

### Support for the family

It is also important to discuss with other family members what is happening.

They may also have fears or concerns and may need their own support.

Due to the genetic nature of IRD's (IRD's are passed along family lines), your family may want information about potential diagnosis for themselves or their families. You may wish to consider speaking with a Genetic Counselling Service or other support groups in your area. Retina Australia can help you find a service that suits your needs.