



**RETINA**  
australia

## Tips for the newly diagnosed

### Diagnosis

If you have just been diagnosed with vision loss it is likely that you are feeling a mix of emotions including shock, anger, grief and sadness. These emotions are all valid and it is also important to know that there are many ways that you can get help with adjusting to the news.



Some people may experience low vision from childhood or from their teenage years. Others may be diagnosed later in life with little indication they had an inherited retinal disease (IRD) previously.

Progression of vision loss can vary from person to person and it is important to be regularly evaluated by an eye specialist. For some, the loss of sight is slow and there may be only a small loss over many years. Others may have periods of rapid loss, but with years of no apparent decline in between. Some people with IRDs may be able to continue participating in activities such as working, sports, reading and even driving without major change for many years while others may need support to adjust more quickly.

## Communication

It is often helpful for people to be frank with others regarding low vision.

Denial and covering up can hinder your ability to get help. Once aware, people are generally very helpful and will often begin to educate themselves on the vast spectrum of low vision.

It is particularly important to let teachers and employers know so that they can make constructive adjustments to educational and workplace and environments.

If you are unsure how to let an employer know of your condition there are many support organisations you can contact for advice, including Retina Australia.

## Adjusting

One of the hardest steps on your journey towards living positively with a vision impairment is acceptance. Acceptance is not easy, and it is normal to go through periods of despair and of feeling resentful, bewildered or even angry. However, there are many ways that you can get support, and learn to live with vision loss.

Due to sometimes slow process of vision loss involved with IRDs, they can be particularly challenging to adjust to.

Retina Australia can help you find support in the forms of councillors and psychologists or other people in the community going through a similar experience.

## Independence

A common challenge for vision impaired people is being able to move around independently. A mobility instructor is a great way to learn mobility and orientation skills. In recent years, many technological advancements have been made to help assist people with mobility issues. These include devices such as the white cane as well as apps, voice assistants and other software.



## Personal Identification

Unfortunately, loss of driver's license is common for those with progressed vision loss. It can be challenging to prove your age or identity without a driver's licence. Obtaining a Proof of Age card can be useful as well as ensuring you have other proof of identity documents such as your birth certificate or a passport.

## Family support

Families are often concerned about the impact of your IRD on your future, education and career opportunities and your independence. It is common for family worry and want to be overprotective.

Talking to your family about how they can help you to adapt and cope and what supports or help you might need to do the activities you are interested in will allow them to help in ways that are useful to you and relieve concerns they may have if they were left in the dark.

## Peer Support

Talking with people who 'get it' is immensely helpful. There are several forums, networks and opportunities for people to get connected and access support services.

For people in remote areas or with mobility issues there are online groups, several have been started on Facebook including Retina Australia's support group. There are also regular telelink phone calls and face to face meet ups in many Australian cities and towns. Please contact us to be referred to a group meet up near you.

## Orientation and mobility

There are many ways you can make it easier to move around your community independently and safely. Orientation and mobility specialists can help you to learn useful skills through training in:

- How to use your remaining senses to determine where you are.
- Use of residual vision and low vision devices.
- Sighted guide techniques.
- White Cane techniques.
- Route planning.
- Problem-solving skills.
- Techniques for crossing streets.
- The use of public transport.
- Access to assistance dogs.



Some tips for travelling outside of your home are:

- Pre-plan your route by identifying landmarks that are easy for you to detect and use them as reference points.
- If a sighted guide will be required plan to organise this.
- Consider using public transport, taxi or Uber.
- If travelling by bus and you are unable to read the bus timetable, almost all bus companies will have a customer help line. If you let them know you're blind/vision impaired they'll advise you how to get from A to B.

When moving around your community consider:

- Lighting or magnifying signage (carrying a torch, magnifying glass or using a phone app to read print)
- Planning your journey to avoid hours of darkness or adverse lighting conditions such as late afternoon sun.
- Choosing the easiest to navigate route by selecting orientation landmarks that are quickly identified by size, contrast, smell or terrain.
- Controlling glare by wearing appropriate sunglasses or visors.
- Being organised, preparing scenario plans, enlarged route maps, and phone numbers for assistance.

### Leisure, recreation and sport

Participation in recreational activities, whether they are energetic and challenging or quiet and relaxing, is integral to our physical and mental wellbeing. There are several ways in which participation is made possible for people with a vision loss and a wide range of sports and activities can be enjoyed through adaptation, guides and equipment.

For example:

- Tandem Cycling
- Cricket
- Sailing
- Bowls
- Rowing
- Martial arts
- Skiing
- Horse riding
- Yoga



Contact your local sports association or vision support services to discover the range of options available near you.