

# GUIDE FOR FRIENDS OF THE NEWLY DIAGNOSED



## Understanding your friend's condition

Inherited Retinal Diseases (IRD) are genetic conditions that are caused by a variation in one or more genes. These variations result in the retina not functioning as it should, resulting in loss of vision over time. 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 IRD previously.



IRDs are the leading cause of blindness in working age adults and although they are genetic conditions, your friend may be the only person in their family with the condition depending on the inheritance pattern. There are around 300 different genes that can cause IRD and the symptoms can present very differently in each person.

Vision loss progression will vary from person to person. For some, the loss of sight is slow and there may be only a small decline over many years. Others may have periods of rapid loss, but with years of no apparent deterioration in between. There are many online resources where you can learn more about your friend's specific condition. You can find more information on our Inherited Retinal Diseases page.

## Supporting your friend

The most helpful way people can assist those dealing with vision loss, is to listen attentively and communicate openly. Learning how to listen involves concentrating on both verbal and non-verbal cues, without judgement and interrupting. Everyone reacts differently to the experience of living with an IRD and there may be peaks and troughs over time as the vision loss progresses. You shouldn't expect the journey to be linear and nor should you put a time limit on your friend coming to terms with their diagnosis. Patience and empathy will be key.

If you are unsure about how best to support your friend, you can always ask them. They may be unsure at first how you can help them but if you continue the offer of practical and emotional support, they may begin to open up, share their experience and suggest ways you can help them.

## **Practical support**

If you want to be proactive in your support, observe what your friend can do without help and where they may be struggling. If you see them struggling with a task, ask if help is wanted. In time you will learn when you can proactively assist and when you should allow them time to complete a task themselves.

Other ways you can provide practical support are:

- Listen to any suggestions such as how to arrange the house so they can navigate the space freely. This could include: keeping the floor clear of objects, not moving the furniture, shutting doors, clearing clutter, pushing in chairs and adjusting lighting.
- When out, try to give warning of unexpected hazards such as steps, sloping pathways, uneven surfaces and doorways.
- Learn the correct technique for being a 'sighted guide'. There are many tutorials (including videos) online but it is also important to ask your friend how they like to be guided as it may differ.
- Offer to help with organising transport options and solving other mobility challenges. Be mindful of these challenges when planning events or hang outs.
- A lot of people with an IRD will struggle with vision at night or in low lighting. If you are catching up with your friend in the evening, be conscious of the venue lighting, paths to the bathrooms, any stairs or low lying furniture.
- Encourage them to try out the various tools, devices and technology.
- Support their involvement in activities they are interested in.







## Emotional Support

As mentioned earlier, the journey for your friend is not likely to be linear and their needs and type of support they want may change even day to day. Be attentive to both verbal and non-verbal cues.

Here are some things to keep in mind:

- Try not to be overprotective or patronising. The loss of independence through vision loss can be a difficult thing for a person to process. Allowing them to maintain independence is important for them to feel empowered and not helpless.
- Listen when your friend needs someone to talk to. Try to gauge when your friend is seeking advice or solutions or when they just need to vent.
- Ensure you involve the person in decision making about anything that will affect them.
- Sometimes your support won't be enough, if you feel your friend is struggling and may need some professional help, encourage them to talk to their GP about a mental health plan and referral to a counsellor.

## Helpful guide of Do's and Don'ts

<p><b>Do's</b></p> <ul style="list-style-type: none"> <li>• Listen actively without judgement</li> <li>• Be present, keep eye contact and provide your full attention</li> <li>• Notice cues from the person, and respond to these</li> <li>• Acknowledge what has been said</li> <li>• Offer specific practical support such as transport, running errands or offering to be a sighted guide</li> <li>• Ask permission to raise sensitive topics</li> <li>• Don't make assumptions</li> </ul>	<p><b>Helpful phrases</b></p> <ul style="list-style-type: none"> <li>• I care for you and I'm here for you</li> <li>• If you feel like talking I'm here to listen</li> <li>• Many people in a situation like yours would have that reaction</li> <li>• It seems reasonable to me to be feeling sad</li> <li>• I can hear it has been really hard for you to share, thank you for sharing</li> <li>• You've been going through a really tough time</li> <li>• I'm always here if you'd like to talk</li> </ul>
<p><b>Don'ts</b></p> <ul style="list-style-type: none"> <li>• Appear too positive or make light of the situation</li> <li>• Make comparisons with other experiences by sharing stories of others</li> <li>• Share the latest research or treatments you've heard about</li> <li>• It's ok to show your emotions, but don't overwhelm or burden them with your feelings or grief</li> <li>• Withdraw, avoid contact or stay away for fear of burdening them</li> </ul>	<p><b>Unhelpful phrases</b></p> <ul style="list-style-type: none"> <li>• I know just how you feel</li> <li>• I know just what you should do</li> <li>• I know someone who had the same diagnosis</li> <li>• Don't worry</li> <li>• I'm sure you'll be fine</li> <li>• Try not to think about it</li> </ul>