Macular Disease Foundation AUSTRALIA

UNDERSTANDING VISION LOSS

Contents

Macular Disease Foundation Australia

MDFA is the national peak body for the macular disease community. Its mission is to reduce the incidence and impact of macular disease in Australia. MDFA is committed to working on behalf of the macular disease community through awareness, education, guidance and support, research and representation.

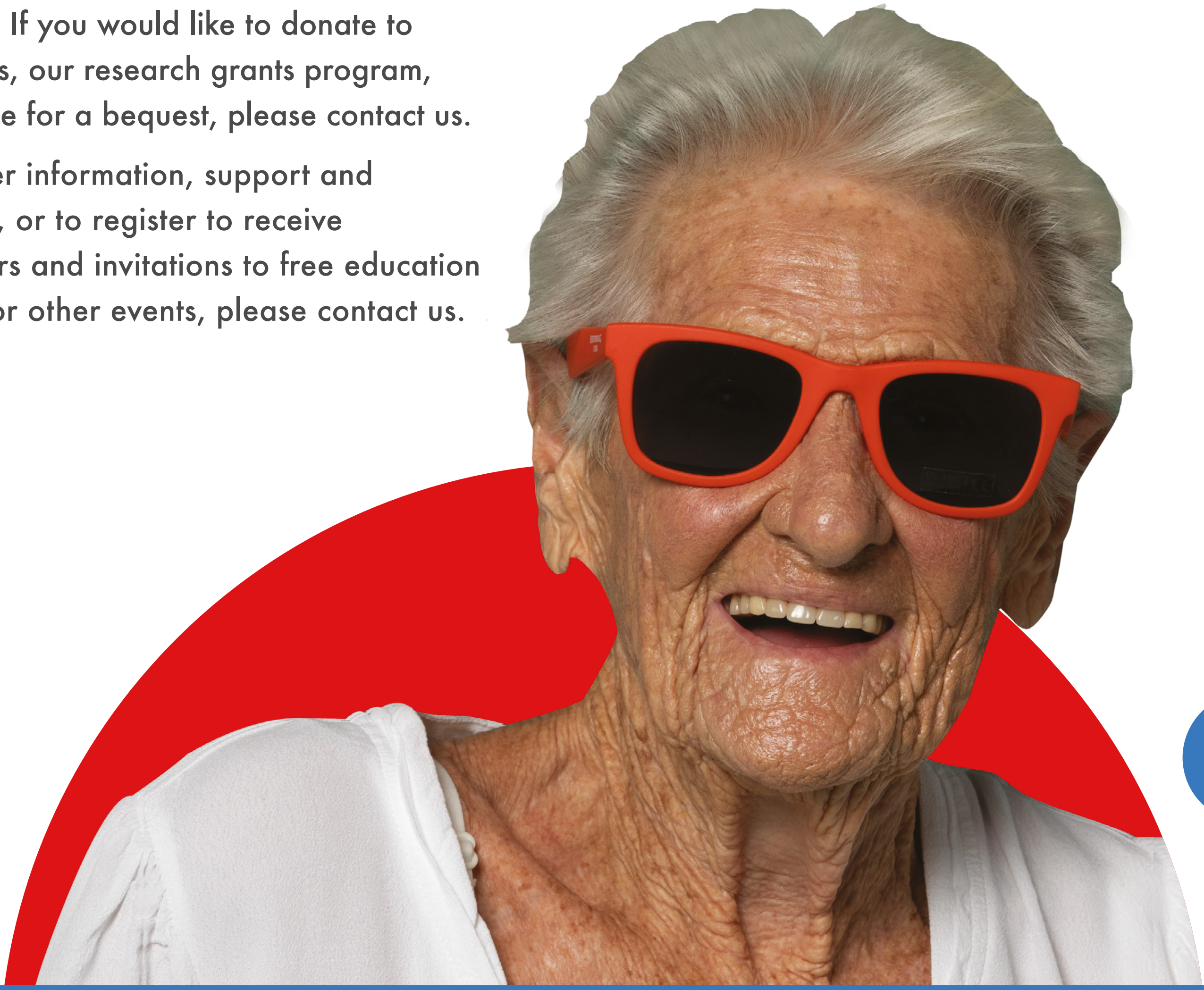
Macular disease covers a range of painless conditions that affect the central retina (the macula) at the back of the eye. It's the leading cause of blindness and severe vision loss in Australia. MDFA funds world leading research into macular disease ultimately seeking to find cures.

As a charity we rely upon donations, bequests and fundraising efforts to support our work. If you would like to donate to support us, our research grants program, or arrange for a bequest, please contact us.

For further information, support and guidance, or to register to receive newsletters and invitations to free education sessions or other events, please contact us.

Macular Disease Foundation Australia

National Helpline: 1800 111 709
E: info@mdfoundation.com.au
W: www.mdfoundation.com.au
W: www.CheckMyMacula.com.au



Introduction

This booklet is designed to answer some of the questions you may have as you begin navigating the journey of living with impaired vision. It covers all degrees of vision loss including low vision and legal blindness.

Understanding what impaired vision is, how it can impact you and your loved ones, and the support available, can help you face the challenges of living with vision loss.

Being aware, and seeking the right advice and support, can help you continue to maintain quality of life and independence at work, at home and socially.

What is vision loss

Vision loss is limited or impaired eyesight that can't be corrected with surgery, conventional glasses or contact lenses.

Loss of vision is often dismissed as just a natural consequence of getting older. It's not.

In fact, vision loss and low vision can happen at any age. For a younger person at school or work, vision loss caused by eye disease or injury can be especially challenging.

What is low vision?

There are several definitions of low vision. The most commonly used in Australia defines a person as having low vision when they are unable to see at six metres (with spectacles if required) what someone with normal vision can see at 12 metres.

Low vision often involves a loss of sharpness but may also involve loss of field of vision, light sensitivity, distorted vision, or a loss of contrast. The greater the vision loss, the greater the impact on independence and quality of life.

Low vision can affect anyone and can impact life at home, in the workplace and in society. People with low vision may have trouble reading and using the computer, using a phone, watching TV, recognising faces, and doing daily activities such as cooking.

A number of conditions can lead to vision loss, low vision, and blindness. Age-related macular degeneration (AMD) and other macular diseases impact central vision, leaving peripheral vision intact. Glaucoma affects peripheral vision, while cataract causes cloudy vision.

Low vision services are essential in helping anyone with vision loss, regardless of age, cope with the associated challenges.

> "One of the most difficult things about being diagnosed was the uncertainty. How much vision would I lose and how long would it take? I made some decisions about life and work that were probably more reactive than positive. Since then I think I've learnt that I'm in control. I'm vision-impaired, not life-impaired."
>
> - Sam

What is legal blindness?

Legal blindness is not 'black blindness'.

Rather, you are considered legally blind if you can't see at six metres with both eyes (with spectacles if required) what someone with normal vision can see at 60 metres, and/or if your field of vision is less than 20 degrees in diameter in your eye with better vision.

If you are legally blind, you are also entitled to certain government programs and benefits, including the 'blind pension' and public transport subsidies. To access them, you must undergo vision tests with an eye health professional, who then signs a normal declaration.

Taking control of your situation

Learning to adapt with vision loss can be overwhelming. You may feel many emotions ranging from disbelief, apprehension and even depression. Try not to let your emotions get the better of you. With the right support, it's possible to live happily and remain independent.

1. Take a deep breath, pause, and take time to calmly sort out the pathway that will lead to the best outcomes.
2. Don't make any quick decisions regarding current employment, activities, plans or your lifestyle.
3. Seek advice from your eye health professional and low vision agencies.
4. Stay engaged with social and recreational networks, especially if you're recently diagnosed. This is when networks may be at greater risk of breaking down.

If you feel withdrawn, anxious or depressed, make sure you seek help.

It's important to remain in control. Things you can do to help your situation include:

- talking through the diagnosis with friends and family
- staying active
- learning new skills and adapting old ones to new circumstances
- explaining to your friends how they can help you
- maintaining existing social activities and seeking support from friends and family
- exploring new options for friends and fun
- linking with peer support groups.

Low vision assessment

Vision loss can affect your mobility and your ability to do everyday tasks such as reading, cooking and other household chores.

You can start maintaining your independence and quality of life by undertaking a low vision assessment.

Providers of low vision services perform these assessments, which include tests to determine how much of your vision remains. The result of these assessments will help you gain a better understanding of vision impairment and how to make the most of your remaining sight. It will also include valuable advice and support for your individual circumstances.

A low vision assessment may include:

- testing your current vision
- assessing the effect your eye condition has on your vision
- learning techniques to enhance your remaining vision and maximising the use of your other senses
- discussion on the psychological and social impacts of vision loss
- referral to counselling and support
- comprehensive information and practical demonstrations on the use of low vision aids and technologies best suited to your needs and which help you with daily activities
- information on modifications you can make in the home or workplace
- a visit to your home for advice on living well and home safety
- orientation and mobility training to help you get out and about
- information on subsidies or entitlements you may be eligible for, and how to access them.

A low vision assessment is an essential way to regain control of your situation and get started to ensure you can live well with vision loss. You can undergo an assessment at low vision clinics, and sometimes in a major hospital or university. Some eye health professionals also provide low vision assessments. We recommend you contact Macular Disease Foundation Australia so we can direct you to the appropriate low vision services for your needs.

> "An occupational therapist came out to my home and gave me lots of handy hints about ways to deal with things I was finding difficult. Simple things that mean I am less likely to cut or burn myself while preparing dinner."
>
> - Amanda

Checklist

- Seek guidance and support
- Learn about vision aids and adaptive technology
- Understand your condition
- Make an emergency plan

Moving forward with vision loss

Being able to live well with vision loss starts with you taking control of the situation. The more you understand your eye condition, its effects and the options you have for dealing with the challenges presented by loss of vision, the more positive you'll feel. Different eye conditions affect vision in different ways, so it's important you understand the kind of support services, aids and equipment that will best help you.

Seek guidance and support

There is a lot of advice, help, information and practical solutions for managing everyday tasks. You can find more information about these by contacting MDFA's National Helpline on **1800 111 709.**

Learn about vision aids and adaptive technology

There are many low vision aids and technologies designed to help you with daily tasks to maintain independence. You can find more information about these by contacting MDFA.

Understand your condition

Having an eye condition that will lead to vision loss can leave you feeling confused and upset. Sometimes this can make it difficult for you to remember what your eye health professional is telling you. This is quite normal. However, understanding your condition will help you manage it more effectively. When you visit your eye health professional:

- take notes
- get a friend or family member to go with you
- ask your friend or family member to take notes and be available later for discussion
- ask your eye care professional to write down instructions
- request further information if you need it
- ask for printed information if possible
- contact MDFA for further information or suggested questions to ask your eye health professional.

Make an emergency plan

Vision loss may put you at a higher risk of slips, trips and falls. For this reason, it's important to make a plan to help you feel safer, more confident and in control. This will also reassure your family and friends.

The aim of the emergency plan is to get help as soon as possible to reduce the impact of the accident and to minimise any distress. Share your plan with your family and friends, so that they know how they can help, and what they may need to do for you in the event of an emergency. If you live alone, or are alone for long periods, it's even more important to have your plan organised to get help quickly.

There are many types of devices to raise the alarm in the event of an emergency such as a mobile phone or a personal alarm that initiates a call for help when activated. If you live alone, consider asking a person or special service to call and check on you at the same time every day. Remember the person who comes to help you needs to be able to get into your home, so think carefully about who you'd be happy to give a spare key to.

You should also make a list of people or organisations you can call in case of an emergency. Understand which number you would call in different circumstances to get the right type of help. Keep this list in key areas such as your mobile phone, wallet, on the refrigerator, or next to the phone at home. Always have your 'in case of an emergency' contact clearly marked.

You can get further information on reducing your risk of slips, trips and falls by calling our National Helpline on **1800 111 709.**

Charles Bonnet Syndrome

Mentally healthy people with significant vision loss may experience visual hallucinations - this is known as Charles Bonnet Syndrome (CBS). These hallucinations can be vivid and complex, however they are not real. For example, a person may see detailed images of people, buildings, plants or animals.

CBS typically affects people who experience significant visual loss later in life, but can affect people of any age. They may worry about their mental wellbeing and can be reassured to hear that this is commonly associated with loss of vision.

If you have vision loss and experience hallucinations, it's important to tell your GP or eye health professional. For further information on CBS, please refer to our fact sheet or call our National Helpline on **1800 111 709.**

> "I was diagnosed with macular degeneration at 39 years of age. I sought professional help and looked at what I could do, not what I couldn't do. I believe a 'can do' attitude will improve your quality of life."
>
> - Barry

Caring for someone with vision loss

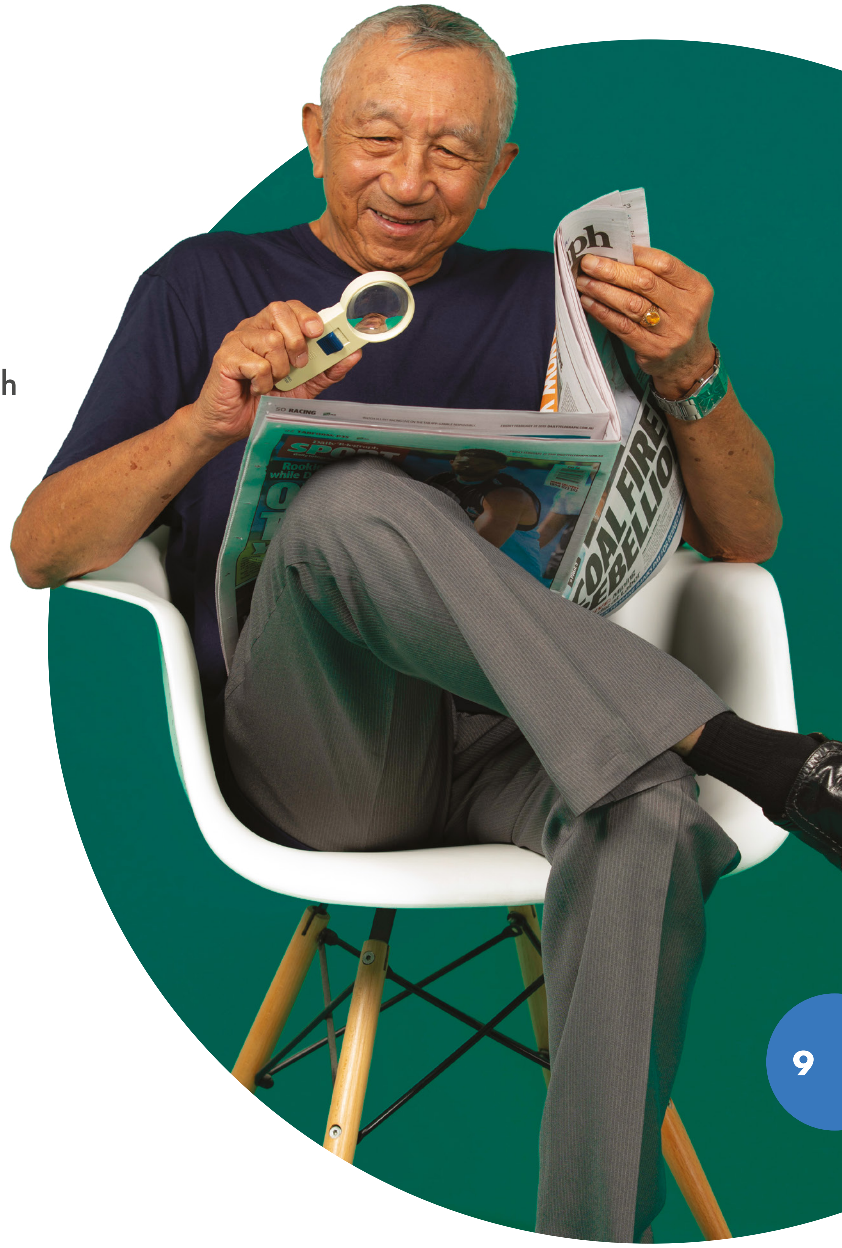
At some stage many people with vision loss will require care and support from a family member, friend, volunteer or community service to assist them in everyday living. Caring for someone with vision loss can be challenging. It's important to understand the level of care required, how this is likely to change over time and how this will impact the carer socially, emotionally and financially. The amount of time spent caring for someone can range from a few hours a week to every day of the week.

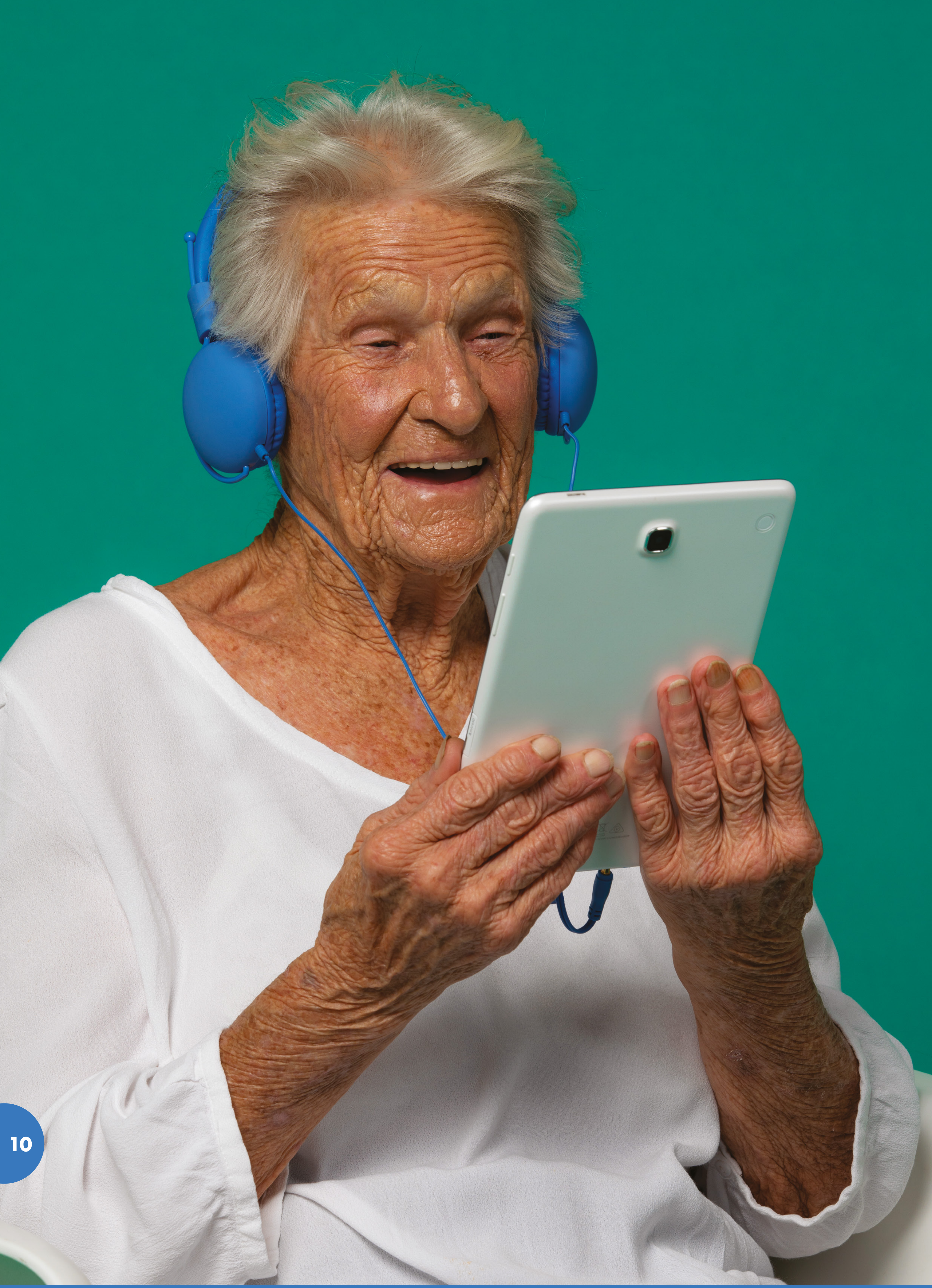
What carers do

Things that a carer may do for someone with vision loss include:

- assisting with accessing community services
- helping to maintain hobbies and leisure activities
- reading bills and mail
- cooking, cleaning or other forms of help within the home
- driving
- shopping
- using the telephone
- helping to use the computer or adaptive technology for reading
- guiding the person when in the home and the community.

Support services are available to help carers navigate this part of the journey and to develop an appropriate care plan. Contact us on our National Helpline **1800 111 709** for further information.





Need more information?

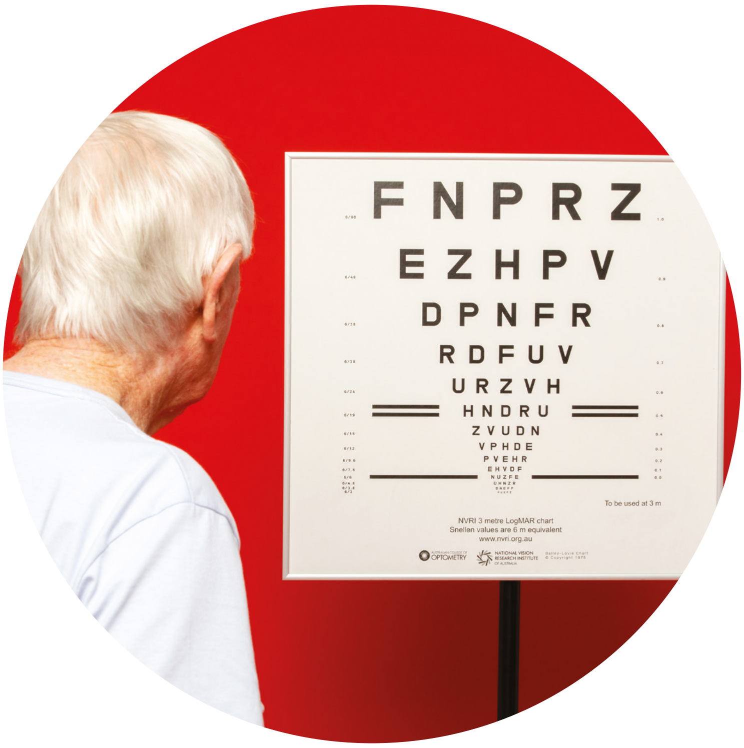
Learn more about macular disease at **www.mdfoundation.com.au.**

How's your macula? Take the quiz at **www.CheckMyMacula.com.au.**

You can also access our free, personalised support services and order information kits and Amsler grids by calling our National Helpline on **1800 111 709.**

MDFA has a free newsletter and you can sign up to receive invitations to education sessions and events in your area.

Macular Disease Foundation Australia is committed to reducing the incidence and impact of macular disease, by providing up-to-date information, advice and support.



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