



**Vision  
Australia**

Blindness. Low Vision. Opportunity.

# Family and Supporters Resource Guide



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## Letter from a carer

"I'm terribly sorry, but you've got macular degeneration," said the kind young optometrist. This explained why the edges of the steps we descended a few days earlier had V's cut into their edges! So began my journey as a carer.

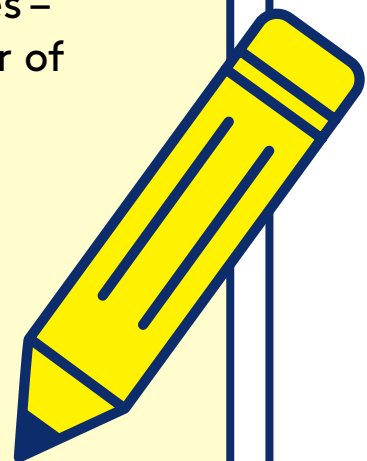
We coped with the initial specialist referrals and their follow-ups, but all too soon it was over to us. We found it wasn't an essential for my husband to drive a car, recognise and greet people from a distance, nor even read the daily paper. The scary challenges came in coping with everyday life – what support we required and how to access it. This is why I am so happy to introduce this wonderful initiative of Vision Australia – Family and Supporters Resource Guide.

The first section has been compiled from input from carers just like you and is full of helpful hints for coping with the challenges of everyday life for you and the person who so much depends on you.

The second section explains in simple terms how and where to find the solutions to more complex issues – financial support, modern technology, all manner of official requirements in our modern world.

Relax, unwind... you will do a fantastic job!

**Val, carer to her husband.**



# I'm supporting someone in their vision loss, what's next?

You might be a parent, a grandparent, a sibling or someone's child. A friend, a neighbour or a community member.

No matter your relationship, supporting someone in their vision loss means you are making a difference.

**From having conversations with carers, Vision Australia has discovered they can often:**

- Feel stress over not knowing how to find the right kind of support.
- Not know where to find and what information is most relevant.
- Feel overscheduled by appointments and caring duties.
- Struggle with fear and panic, especially around the time of a new diagnosis and changes in circumstance.
- Feel guilt around having their own personal needs.

You might think it's impossible to know where to begin, especially when so much change is happening so quickly.

**A great place to start is to build a foundation of knowledge. This can include:**

- Understanding the specific eye condition that is affecting the person you are supporting.
- Understanding the impact a vision loss diagnosis has on their life, confidence and how they navigate their surroundings.
- Knowing how and when you should offer help and support.
- The types of help available.

To help you navigate this change, Vision Australia has created "Family and Supporters Resource Guide".

# Did you know vision loss is a broad spectrum?

It's important for you to understand the diagnosis of the person you are supporting. Quite often, it is the simplest form of care and things like having a shared understanding of what is now happening in your lives that can be the most effective.

**Low vision** is used to describe someone who still has some functional vision but may need to be twice as close to an object as someone with unaffected vision to see it.

**Blindness** is when someone has very little or no sight and needs to rely almost completely on other senses like touch and hearing to understand and navigate their environments safely.

## Signs of vision loss typically include:

- Blurry or cloudy vision
- Difficulty reading and recognising faces
- Decreased peripheral (side) vision
- Increased clumsiness and bumping into things
- Difficulty seeing clearly at night
- Changes in colours
- Seeing halos around lights
- Sensitivity to light and glare
- Eye fatigue
- Difficulty making sense of what you see.

It's important to be aware that the impact vision loss can have extends beyond physical challenges. It can also affect emotional wellbeing and a sense of independence.

# Different kinds of eye conditions

Many different eye conditions can cause blindness and low vision. The most common causes are:



**Age-related macular degeneration** is a degenerative eye condition caused by changes to the macula (a tiny part of the retina at the back of the eye) that can result in a gradual or sudden loss of vision.

**Cataracts** are the clouding of the clear lens in the eye and can appear in one or both eyes.



**Diabetic retinopathy** is a diabetes complication which can damage the tiny blood vessels inside the eye's retina and cause bleeding and swelling, leading to partial or complete blindness.

**Glaucoma** is a group of eye diseases that cause progressive damage to the optic nerve. A gradual loss of sight, beginning with peripheral vision, will occur. If left untreated it can lead to blindness.



## Other common eye conditions include



**Retinitis pigmentosa** is a complex hereditary eye condition that causes cells in the retina to degenerate slowly and progressively.

**Nystagmus** causes rapid, involuntary flickering of the eyes.



Acquired brain injuries such as **strokes** can affect vision. The cause and area of the brain affected will determine the type of vision loss.

Blindness and low vision are more common in older adults because many of the diseases that can cause it present as people age. Noting that aging alone does not cause low vision.

Eye and brain injuries, as well as certain genetic disorders, can also lead to vision loss.

# Supports and services

While you can offer great support in the home, external help can often be needed.

Here are some examples of external supports that can help you and the person you're supporting:

- **Assistive technology** from our Vision Store can help them make the most of their remaining vision. This can include specialised tech like magnifiers, or more mainstream technology like voice-activated personal assistants.
- **Emotional support groups** like Vision Australia's Quality Living Groups, where you can both connect with people in similar situations.
- **Occupational therapists** can help build confidence for them to develop and maintain the skills they need for daily living.
- **Orientation and mobility specialists** can help them stay safe and navigate their environments with confidence.
- **Orthoptists** can assess your remaining function vision and play a crucial role in the management of eye diseases.
- **Ongoing technology training** is a valuable way for you both to stay connected.
- **My Aged Care and NDIS** experts will help to maximise funding, ensuring the best possible care.
- **Specialised children and adolescent's services** are important to become involved with from the beginning if you are caring for a child.
- **Audio books and library services** can open their world to a new way of reading.
- **Seeing Eye Dogs** can help the person you care for move safely around their day-to-day activities.

If you'd like to learn more, please call Vision Australia on 1300 84 74 66, or email us at [info@visionaustralia.org](mailto:info@visionaustralia.org).

# Funding options and bodies

Funding options can be tricky to navigate when looking for the right ones for both you and the person you are supporting.

## Most commonly used funding methods

### NDIS for under 65s

The National Disability Insurance Scheme (NDIS) is one of the ways people who are blind or have low vision can access funding and support, including help with activities in the community and accessing assistive technology.

Find out more at <https://www.ndis.gov.au/>.

### My Aged Care for over 65s

My Aged Care is available to any Australian resident over the age of 65. The two most popular programs are the [Commonwealth Home Support Program \(CHSP\)](#) for entry-level care and [Home Care Packages \(HCP\)](#) for more complex needs.

Find out more at <https://www.myagedcare.gov.au/>.



## Services Australia (formerly Centrelink) payments

**The Carer Payment** is for people who provide constant, daily care to someone with a disability, a medical condition, or an adult who is frail aged. To be eligible you will need to have been a carer for six months. Find out more on the [Services Australia Carer Payment homepage](#).

**The Carer Allowance** is for those who care for someone who needs daily support. To be eligible, the person you care for will have a terminal medical condition or need ongoing daily assistance for at least 12 months. Find out more on the [Services Australia Carer Allowance homepage](#).

**The Carer Supplement** may also be available to you. This is an annual payment that helps to cover the costs when caring for someone with a disability or medical condition. Find out more on the [Services Australia Carer Supplement homepage](#).

**The Age Pension (Blind)** provides financial support for people who are legally blind and over the retirement age. Find out more on the [Services Australia Age Pension homepage](#).

**The Disability Support Pension (Blind)** provides financial support if you are legally blind and under 66 years and 6 months. Find out more on the [Services Australia Disability Support Pension \(Blind\) homepage](#).

To learn more about funding, visit us online at <https://www.visionaustralia.org/services/funding>.

# Communication tips

When you are first faced with a loved one's vision loss diagnosis, it can be confusing to know how to act around them.

We have compiled this list for you to keep on hand and share with your friends and family.

## Do

Identify yourself. Don't assume someone with vision loss will recognise you by your voice.

Speak naturally and clearly. Vision loss does not mean loss of hearing.

Keep using body language. This will affect the tone of your voice and give a lot of extra information to the person with vision loss.

In a group situation like a meeting, do a rollcall and introduce the other people present.

Offer your elbow to help guide.

## Don't

Never channel conversation through a third person.

Don't avoid words like "see" or "look", or talking about everyday activities like watching TV.

Don't put yourselves in situations where there is competing noise.

Don't assume someone needs help. Always ask first.

Don't grab their arm, it will cause surprise and discomfort.

# Being safe at home

Dealing with the number of changes now faced in day-to-day life can be overwhelming. These can include the comfort and safety felt in their own home.

It's important to remember that people adapt to change in their own ways. Allow the person you are supporting to guide you.

You should encourage them to make the necessary adjustments to make sure they are safe, but keep in mind that too much change all at once can be challenging.

## Lower the risk of tripping and falling

Some tips and modifications around the home to help prevent falls can be to:

- Keep clear, level pathways.
- Move the furniture if needed to make it easier to move around.
- Replace low, hard-to-see furniture like side tables and glass tabletops.
- Involve the person you are supporting, making the changes easier to remember.
- Use coloured tape on doorframes and cupboard edges.
- Add tread to stairs.

## Simple solutions

Quite often, it is the easy things that can make a huge difference:

- Using baskets to keep items like remote controls in the same place.
- Storage solutions in the bathroom for toothbrushes and toothpaste.
- Keep shower caddies organised and products full.
- Make sure keys remain in the same place on the bench, or on a hook.
- Phone chargers remain plugged into the same outlet.

If something is used every day, try to keep it in the same place so everyone knows where to find it.



# Bigger, Bolder, Brighter

Making things bigger, bolder and brighter is a simple way to help make the transition through this new way of living smoother.

## Bigger

- Magnifiers are available in a wide range of sizes, strengths and models to suit the task at hand, like:
- Reading and writing.
- Looking at photographs.
- Craft hobbies including sewing, knitting and painting.

If reading is their passion, encourage the person you are supporting to make some adjustments to the way they read. Large print options are available in books, newspapers and magazines. Audio books are also easily accessible and available via the [Vision Australia Library](#), or apps like [Audible](#) and [Spotify](#).

There is also the option of household products with large buttons, such as:

- [Telephones](#)
- [Remote controls](#)
- [Computer keyboards](#)

## Bolder

Changing colour and contrast is a simple yet effective way to make the home safer to navigate. If something becomes bolder, it becomes easier for someone with low vision to find the things they need.

Some simple ways to increase the contrast in your home can include:

- Hanging bright towels in a light bathroom.
- Serving food on white plates.
- Using different coloured containers for similar looking ingredients.

## Brighter

While everyone's eyes are different and some might not benefit from making things brighter, it's important to experiment and find the right lighting conditions for the person you are supporting.

Some ways you can do this include:

- Always keep surroundings well-lit.
- Use specialised [lamps](#) and bulbs to increase contrast and reduce glare.
- Cover reflective surfaces where possible.
- Use direct task lighting, such as the [Daylight Foldi Glo Lamp](#) for activities like reading.
- Under-the-counter lighting for illuminating the kitchen and other large areas.
- Use nightlights around the home to reduce the risk of falling.
- Use lamps in combination with the room's available lighting.
- Try not to switch the lights off during the day, to avoid a change in lighting as it becomes darker.

## What's next?

Not all home modifications need to be huge. Simple changes and additions like those listed above will go a long way to help the person you are supporting feel comfortable and safe in their own home.



# Getting out and about

Enjoying some time out and about as someone recently diagnosed with vision loss can be daunting. We have put together a series of tips to help you and your loved one navigate external environments safely.

Remember to describe the layout of the room or outdoor space when you are visiting somewhere new. If you can visit where you are going alone beforehand to get a good feel of the area, or even bring a torch along with you for low-light areas, it can make the outing easier.

## Dining

Some ideas to improve the experience enjoying a meal in a restaurant include:

- Suggest a well-lit table, or a table near a window.
- Check if the person you are supporting for would like to read the menu themselves. [A portable magnifier](#) is perfect for this.
- Ask if they would like non-essential items removed, such as lit candles.
- Keep the water jug closer to you to avoid accidental spills.
- Let them know if you're moving things on the table.



## Transport

Travelling as someone who is blind or has low vision can be challenging. Ways to make the journey more comfortable can include:

- They will not have a driver's licence, so make sure you have other forms of identification available.
- Let transport operators know you are travelling with someone who is blind or has low vision, so they can offer assistance if needed.
- Make sure they know boarding times and how to get to their boarding gate in advance.
- Plane departure boards, bus and train timetables are not accessible, so make sure to read them out loud.
- Airports and train stations are often busy and loud, so make sure to guide them around these areas carefully.

## Entertainment

Art and cultural events are an important part of Australian society. Some tips to make going to an event easier can include:

- Describing in detail what each art piece is and looks like, so you both feel involved in the experience.
- Check if the gallery has headsets with audio description of the exhibition you are visiting.
- Use any resources that are accessible for people who are blind or have low vision, such as virtual guides.

Visiting the theatre and attending sporting events can become a more inclusive excursion by:

- Making sure they know any areas that are off-limits, such as corded-off or staff-only sections.
- Pre-book tickets when possible to ensure there is accessible seating and access for a Seeing Eye Dog, if needed.

# Signs to look out for

When someone is dealing with a new vision loss diagnosis, it's normal for them and for you to experience a wide range of emotions. You may notice the following changes in their behaviour:



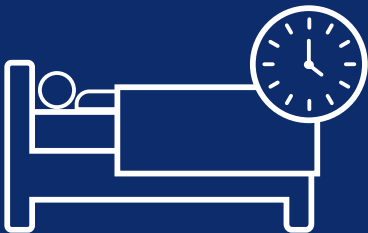
Are often unhappy or worried



Focus on negative topics



Changes in appetite



Altering sleeping patterns



Increased arguments and outbursts



Withdrawing from loved ones



Increased smoking, drinking, or drug use



Lack of hope about the future



Disinterest in usual routines and activities

Remember that these changes are common, however if they continue to present it could be a sign that additional support is needed. This can include:

- Making a plan to understand potential emotional triggers.
- Recognise when someone may be feeling distress.
- Finding ways to de-escalate situations.

It's important to make these changes together for you to both feel that your voices are heard.



# How to ask for help

When it comes to living your lives post-diagnosis , it's more than okay to ask for help. It can be hard to ask, but trying to do things alone can often be even harder.

When someone is first diagnosed, there are often other priorities that come before their emotional wellbeing. Adapting to vision loss is something everyone deals with in their own way, focusing on their own priorities, in their own time.

When you are both ready, some simple ways you can prepare to get the support you need include:

- Prioritise. What is the most important thing to you both right now? What is important but can wait for you to focus on it?
- Take a moment and decide who would be the right person to speak to for your questions.
- Figure out beforehand what you would like to say and how to say it. Be prepared.
- Let them speak when they want to and ask the questions they want to be answered.
- Be proud of yourself once you have taken the first step.



# Specialised vision loss and allied health services

Vision Australia gives you access to a team of specialists and experts, designed to help you navigate your way through your vision loss. It can be hard to remember who you need to contact and for what reason, which is why we have compiled the list below.

Optometrist	Primary eye health care providers who prescribe glasses and contact lenses. They also screen for, diagnose and manage eye disease and prescribe a range of therapeutic medications. They can refer clients directly to an ophthalmologist if more complex treatments are required.
Orthoptists	Allied eye health practitioners who specialise in the assessment, diagnosis and non-surgical management of vision and eye conditions.
Ophthalmologists	Eye doctors with additional specialist training in the diagnosis and management of eye conditions, who can also perform medical and surgical treatments and procedures.
Psychologists and counsellors	Working with you to develop the strategies and confidence you need to help you manage your changing mental and emotional health, also providing you with someone you can talk to about your vision loss.
Orientation and mobility experts	These experts will work with you to develop the skills you need to independently and safely navigate at home and in the community.
Access technology specialists	Assessing your current skill levels and areas that require some help, these specialists will train you to use technology like screen readers, magnifiers and voice-to-text tech.
Occupational therapists	Working with those living with blindness or low vision, occupational therapists are there to help you improve your independence to continue living your everyday life.

# Support for carers, family members and supporters

There are a range of external avenues available for you as a carer to access.

[Carer Gateway](#) - 1800 422 737 (Monday to Friday). Access to supports and services for carers.

[My Aged Care](#) - 1800 200 422 (Monday to Friday, 8.00am to 8.00pm, Saturdays 10.00am to 2.00pm). Access to a range of supports and services for older Australians.

[National Disability Insurance Scheme \(NDIS\)](#) - 1800 800 110 (Monday to Friday, 8.00am to 8.00pm). Funded support for people with significant and permanent disability.

[Seniors Rights Service](#) - 1800 424 079 (Monday to Friday, 9.00am to 4.30pm). Information, support and advocacy for older people, their family members and carers.

[Ageing and Disability Abuse Helpline](#) - 1800 628 221 (Monday to Friday, 9.00am to 5.00pm). Information and support if you are concerned that an older person is being abused, neglected or exploited.

If you and the person you're supporting are ready to take the next steps forward, Vision Australia is here to support you in locations across the country. [Visit us online](#) to begin your journey.

If you're located in Tasmania, you can contact VisAbility on 1800 371 104 or email them at [info@visabilitytas.com.au](mailto:info@visabilitytas.com.au).

If you're located in South Australia, you can contact See Differently with the Royal Society for the Blind on 1300 944 306 or email them at [contact@SeeDifferently.org.au](mailto:contact@SeeDifferently.org.au).

If you are in South Australia or the Northern Territory, you can contact Guide Dogs on (08) 8203 8333 or email them at [info@guidedogs.org.au](mailto:info@guidedogs.org.au).

# More informational resources

Vision Australia understands the responsibility and time it takes to support someone as they adjust to a life with vision loss, and as such is developing dedicated tools and supports to help make your job easier.

## Navigating the emotional impact of a diagnosis

Read more: <https://www.visionaustralia.org/community/news/2023-10-20/navigating-emotional-impact-diagnosis>.

## Having conversations around a diagnosis

Read more: <https://www.visionaustralia.org/community/news/2024-09-16/having-conversations-around-diagnosis>.

## Learning from people with lived experience

Read more: <https://www.visionaustralia.org/community/news/2023-10-11/learning-from-people-with-lived-experience-supporter>.

## The right kinds of questions to ask

Read more: <https://www.visionaustralia.org/community/news/2024-02-22/asking-right-kinds-questions>.

## Other helpful information

Read more: <https://www.visionaustralia.org/services/helpful-resources/carers>.

# Contact us

Find out more about how our services and support can help you and your family today.

**Call us on 1300 84 74 66**

Vision Australia has metro and regional centres around Australia. Call us or visit our website at [visionaustralia.org](https://visionaustralia.org) to find out the one closest to you.



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