

Family, Friend & Carer

A GUIDE



Our focus is your vision

Macular Disease Foundation Australia

Macular Disease Foundation Australia (formerly known as Macular Degeneration Foundation) is a charity with a mission to reduce the incidence and impact of macular disease in Australia. The Foundation is committed to working on behalf of the macular disease community through awareness, education, client services, research and representation.

Macular disease, including macular degeneration, is the leading cause of blindness* and severe vision loss in Australia. The Foundation funds world leading research into macular degeneration, its prevention and treatment and ultimately seeks to find a cure for this chronic disease.

As a charity, the Foundation relies upon donations, bequests and fundraising efforts to support its work. If you would like to donate to support the Foundation or its research grants program, or arrange for a bequest, please contact the Foundation.

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

Macular Disease Foundation Australia

Helpline: 1800 111 709

E: info@mdfoundation.com.au

W: www.mdfoundation.com.au

Resources Available

The Foundation has developed a comprehensive range of publications and resources. Contact the Foundation for a free information kit to help better understand macular degeneration, or other macular diseases, and to learn more about living well with low vision.



*Legal blindness

Introduction

Family, Friend and Carer - A Guide provides information and advice for family members, friends and carers of a person who is blind* or has low vision.

Providing care to a person who is blind or has low vision aims to maintain quality of life and independence. When independent living is no longer possible, it may be the role of the carer** to undertake activities that can no longer be performed by the person who has low vision.

Providing care requires time and attention so it is important to have the right tools to approach the role, to feel confident and to maintain personal health and well being.

One way of viewing the carer role is as part of a larger support team. When viewed in this way all aspects of the caring process become more manageable for everyone involved.

The team players who may make up this support team are centred around the person who has low vision and can include family, friends, eye care professionals, low vision service providers, support workers, counsellors, carer associations and other service providers.

Together team members can provide support and assistance for each other and the person in need of care. This will ensure the best outcomes are achieved.

This guide supports family, friends and carers with information, coping strategies and pathways for assistance in order to help with the care of those with low vision.

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* Legal blindness

** In this booklet the word carer will be used as a general term to refer to unpaid family and friends.

What is Low Vision?

A person has low vision when their eyesight is limited or impaired and cannot be corrected by surgery, conventional glasses or contact lenses. When someone has low vision their eye ceases to function normally.

Low vision can affect people of all ages and can have an impact on many aspects of a person's life. It may affect reading, being able to use and access technology, identifying faces and undertaking daily living activities such as cooking and driving.

Low vision is measured by distance visual acuity. When a person has normal vision their visual acuity is rated 6/6 or 20/20. This rating indicates that a person can read all of the letters on an eye chart designed to be seen at six metres or twenty feet away. A person is said to have low vision when they see fewer letters on the eye chart from this distance. Low vision is often experienced as loss of sharpness in vision, loss of visual field, light sensitivity, distorted vision or loss of contrast.

Low vision occurs as a result of birth defects, injury, a medical condition or an eye disease. The most common causes of low vision in western countries are macular degeneration, glaucoma, cataract, diabetic retinopathy, retinitis pigmentosa and other retina dystrophies. These eye diseases affect vision in different ways. The impact of each disease is connected to the amount of loss in visual acuity, visual field and contrast and this will vary from person to person.

Eye Health

Understanding the symptoms and impact of the eye disease is important because early detection and diagnosis can make a difference and lead to more positive outcomes. It also highlights the importance of having regular eye checks and taking a proactive approach to maintaining good eye health.

Macular Degeneration

Macular degeneration (MD) is Australia's leading cause of blindness*. It affects one in seven Australians over the age of 50 and the incidence increases with age. The disease causes progressive damage to the macula resulting in central vision loss. Macular degeneration is frequently referred to as age-related macular degeneration or AMD.

There are two types of MD. The dry form results in gradual loss of central vision. The wet form is characterised by a sudden loss of vision and is caused by abnormal blood vessels growing into the retina. It is possible to have MD in its early stages without knowing. Immediate medical treatment is essential if symptoms occur in order to save sight.

How a person sees the world when they have:

1. Macular degeneration
2. Glaucoma
3. Cataract
4. Diabetic retinopathy
5. Retinitis pigmentosa



Glaucoma

Glaucoma is the name given to a group of eye diseases in which the optic nerve at the back of the eye is slowly destroyed. More often than not this damage is due to a blockage of the circulation of the water (aqueous fluid) in the eye or its drainage.

In other cases, it can be caused by poor blood supply to the nerve fibres, a weakness in the optic nerve or a problem in the health of the nerve fibres.

Glaucoma destroys a person's vision gradually, starting with the peripheral (side) vision. People can have glaucoma and be completely unaware, as there is usually no pain or early warning signs associated with the most common form of glaucoma. Early detection is critical as any sight lost is irreversible.

Cataracts

A cataract is a clouding of the normally clear and transparent lens of the eye.

When a cataract develops the lens becomes as cloudy as a frosted window and light cannot be properly focused on the retina, resulting in an unclear image.

Diabetic Retinopathy

The most prevalent cause of visual impairment in people who have diabetes is diabetic retinopathy, a condition in which changes occur in the tiny blood vessels that nourish the retina. In the early stages of diabetic retinopathy small blood vessels weaken and leak fluid or tiny amounts of blood which distort the retina. In the more advanced stage blood vessels in the retina are blocked or closed completely and areas of the retina die.

Retinitis Pigmentosa

Retinitis pigmentosa is a degenerative, hereditary disorder that is often first characterised by night blindness, followed by loss of peripheral vision. It can eventually lead to total blindness. Retinitis pigmentosa is one of many retinal dystrophies and is the leading cause of youth blindness in Australia. It is second only to diabetes as a cause of blindness for those in their twenties and thirties. Retinitis pigmentosa in most cases is hereditary.

If more information is required about one of these diseases, contact the Macular Disease Foundation Australia or one of the organisations listed in the National Service Directory section at the rear of this guide.



What is the Impact of Low Vision?

Low vision can affect quality of life and independence. The impact may be small and manageable or it may be difficult and require more time, support and patience. The amount of vision lost will determine to what extent quality of life is affected. The impact of low vision will vary from person to person and can depend on the following factors:

Vision: symptoms and conditions

The type of eye condition will determine how vision is affected. The extent of the loss of vision is determined by visual acuity, visual field and contrast sensitivity.

Social: interpersonal relationships and social contact

The social impact of low vision lies in the possible social isolation that can occur because of loss of mobility or depression.

Psychological: cognitive function, emotional status and wellbeing

Blindness and low vision do have an emotional impact. For the newly diagnosed it can bring about feelings of helplessness, confusion and anxiety and there is a risk of developing depression.

Functional: self care, mobility and activity level

Low vision can affect a person's level of functioning in everyday life. A person's level of mobility and independence may also be affected.

Economic: financial costs

There are financial implications associated with low vision. If a person is required to leave paid employment this can have a significant impact on the individual and their family.

Low vision can affect many areas of a person's life, however, the overall impact depends on the interplay of various factors outlined above. Understanding the ways in which low vision can affect a person provides a good starting point in determining possible areas of assistance.



Challenges of Low Vision

Everyone meets challenges in life differently. The impact low vision has on quality of life has direct consequences for the amount of assistance required. Some of the challenges after the initial diagnosis may include:

- Working through decisions regarding current employment, future plans and lifestyle
- Working out what advice is needed and seeking the right assistance
- Working through the critical issues in a calm and supportive environment
- Staying engaged with social and recreational networks
- Maintaining confidence in the ability to continue doing everyday activities
- Maintaining feelings of autonomy and independence
- Learning new skills and utilising adaptive technology in a variety of ways
- No longer being able to drive and having to find new forms of transport
- Re-organising the home by adapting an old environment to a new set of needs

When a person is affected by low vision the need to maintain quality of life and independence is the main outcome of services and support. People who are blind or have low vision can maintain their quality of life and independence with the help of family, friends and carers.



When Does a Person Become a Carer?

At some stage many people who are blind or who have low vision will seek and receive some form of support from a family member, friend, volunteer or community service to assist them in everyday living.

A carer is usually an unpaid family member or friend who provides support to children or adults who have a disability, mental illness, chronic condition or who are frail and aged.

The time a person cares for another can vary from a few hours a week to every day of the week.

In certain circumstances a person may be considered a carer before as well as after the person requiring care is officially diagnosed with blindness or low vision.

What Types of Tasks do Carers do?

There are many roles for a carer and these can change over time. Activities associated with being a carer for a person who is blind or has low vision include:

- Helping to access 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

“My Mum was fine on her own until two years ago when her vision deteriorated because of age-related macular degeneration. Now I visit her three times a week after I finish work and on the weekends. I read her mail and make sure that she has what she needs, and when we go food shopping I help her to read the labels on jars, cans and packets.” Sue

What can be the Impact of Providing Care?

It is important for a carer to consider the possible impacts before adopting a longer term commitment to provide care.

Many people, especially family, take on this responsibility because they are the only person available and it can feel like there is little choice. In this situation it is important to consider the social, economic and emotional impact so that a realistic care plan can be developed.

Thinking through the process and developing a workable plan will provide for a smooth transition in a changed and perhaps challenging personal environment.

Questions that may arise for the carer are:

- What does becoming a carer mean for me?
- What impact is this going to have on me?
- Do I have to give up my job?
- Do I have to provide all of the care on my own?
- Who can help me?
- Who can I talk to?
- What does a person with low vision need?
- What impact will it have on other members of my family, my social life and my health?

Asking questions is a natural and healthy part of the process of becoming a carer.

Answers will come with time by seeking relevant advice, support and information.

There are support services which can provide opportunities for carers to talk about issues and the possible social, economic, and emotional impacts.

Social Impact

The social impact of providing care will depend on how much care is required and whether there are multiple carers who share the responsibility. Providing care in any circumstance requires time and energy and can have an impact on family life and social activities.

The level of care to be provided by the carer should be considered carefully. The possible impact on family and social life should be assessed and discussed, with those that it may impact upon, before proceeding to offer a level of care that may not be sustainable in the longer term.

Key considerations for carers are the age and size of the carer's family, the family support team surrounding the carer as well as the needs of the person requiring care. If the person requiring care has a young family the assistance to be provided is obviously different to that of an elderly person.

Economic Impact

In some circumstances, carers may be entitled to a carer's benefit. However, this is not always the case and some carers may not be adequately financially supported for their time in the role. This can have an impact on a carer's financial status. It can also present a very difficult choice when finances, emotions, loyalties and duty collide.

Limits to finances can place a strain upon the carer. It is important to be aware of the financial implications of being a carer as well as the financial assistance and support that may be available before final decisions and long term commitments are made.

Further information on entitlements and concessions for carers is provided in the Entitlements for the Carer section of this guide.

Emotional Impact

When care is first required the carer may experience a range of feelings. A carer may feel confident, supported, informed and prepared or they may feel overwhelmed and ill-equipped.

The initial diagnosis along with being asked to provide care may provoke a period of intense activity where questions are being asked by all involved and information, understanding and solutions are being sought.

Many feelings can arise as a result of the initial experience of the diagnosis of a friend or family member. Negative feelings can also arise as a result of being asked or feeling obliged to provide care and support. In many cases, with careful planning and as practical solutions are found these feelings will be resolved as time passes.

It is critical to be aware of any unresolved negative feelings and to seek advice and support if the situation becomes unduly worrying. It is never too late to consider issues that may have been left unresolved at the beginning of the carer relationship.

When considering the carer role it may be useful to:

- Avoid making any quick decisions regarding employment, future plans or lifestyle
- Seek advice from all available sources
- Remain in contact with social and recreational networks
- Access counselling if necessary
- Develop new coping skills
- Acknowledge and allow time for feelings that may arise
- Take time out to think calmly and quietly

A Guide for Care

Providing care is not always a simple or step-by-step process. Knowing how to proceed when there may not be a clear road to follow may be challenging. When creating a plan to provide care, consider who will be the primary carer, what types of care are required, who makes up the support team and what the members of the support team can offer.

The Carer

When care is first required it may be initially organised by a family member or friend. This may be a temporary role that requires initial action or an ongoing commitment, or a role which ebbs and flows. Initially, a family member or friend may step into the role because they feel obliged to do so, because they are available or because it suits everyone involved at the time. However, the initial carer may not continue in this role on a permanent basis.

When a person becomes the primary carer temporarily or permanently it is helpful to know how to identify a starting point. Identifying what types of care are required as well as knowing who can assist the carer in their role are two of the actions that will need to be considered.

Care Required

A good starting point is identifying the tasks and activities that can no longer be performed independently by the person who has low vision. When approaching the person to assess their needs consider the following:

- Acknowledge that they are the authority on their own experience
- Allow them to make their own decisions unless they request assistance
- Avoid being overprotective
- Remain positive in tone and manner

After an initial assessment, areas that require assistance could include access to financial or social services, low vision aids, support for cleaning, shopping, cooking or a replacement meal service such as Meals on Wheels or help looking after finances and bills.

If the person who is blind or has low vision is unable to identify what they need, the carer can work with the appropriate specialised members of the support team to help find pathways to meet these needs.

There may also be other issues, apart from low vision, that need to be considered for the person under care including physical and medical conditions or other diseases.

Once the individual needs of the person under care have been assessed it is a matter of identifying what types of care are available to meet these needs and where to go to access care.

Identifying the types of care required is a process that involves the person who has low vision, the primary carer and other professionals and service providers.

Creating a Care Plan

The following table is a simple example of how you could set out your care plan.

Example – NSW

Issue	Need	Service Provider	Contact	Notes
Difficulty reading small text on bank statement.	Low vision aids, e.g. magnifier	Your relevant low vision service provider (see directories p28)	Phone no. of relevant provider	2/4/2013 Spoke to Lisa, arranged appointment.
Preparing meals difficult, but can still use microwave.	Meals Service	Meals on Wheels	02 8219 4200	15/4/2013 Follow-up call on Tuesday.
Can no longer drive to the shops and has difficulty with using public transport.	Help with shopping and transport	Local Council	Phone no. of local council	10/3/2013 Spoke to Ben, waiting for a call back.

Knowing how to begin to provide support is important for carers. It helps the carer remain in control and makes the care process more manageable. To receive a Carer Support Kit call the Carer Advisory Service on 1800 242 636.



Caring for the Carer

When caring for someone else it is easy to forget to care for yourself. It is important for all carers to have a positive experience whilst in a supportive role and ensure their own health and well being is maintained. The following activities should be considered essential in order for the carer to maintain good health and well being:

○ Eating well

It is not always easy to have regular, healthy meals but it is essential for long term health. Planning meals ahead of time and cooking meals and freezing them for later use can help to save time. Eating foods such as fresh fruit and vegetables will also ensure a carer maintains a healthy diet.

○ Exercise

Regular exercise is an excellent way to relieve stress and helps a person to remain fit and healthy. Going for a short walk, attending an exercise class or even using an exercise DVD at home can all help with fitness.

○ Sleep and Rest

Tiredness can often add to stress. Be aware of tiredness, take short periods of rest during the day, and seek some support for night relief if the care required involves losing sleep.

○ Take a Break

Regular breaks from caring can help to prevent burnout and exhaustion. Taking a break is an important part of being a carer because it is an essential part of maintaining wellbeing. Avoid feeling guilty about having regular breaks. Everyone needs a break from time to time whether they are a carer, a full-time professional or both. Breaks can be short or long and can be organised by accessing local respite services or by asking another member of the support team to help.

○ Talk to Someone

It is important to have a person who is there for the carer. Family, friends and support groups can all play their role in providing support. Professional counselling should be sought if support is not available and/or feelings of anxiety, stress or depression are present.

Caring for the Carer Checklist

- ☐ I have someone to talk to about how I am feeling
- ☐ I am getting regular exercise
- ☐ I am getting enough rest and sleep
- ☐ I ensure I have enough regular breaks from my role as a carer
- ☐ I have regular times in which I can relax and take time out

Entitlements for the Carer

There are a range of formal services available for carers that include financial entitlements and benefits. Entitlements change and the following serves as a guide only. Check with the relevant authority for current information.

Financial Assistance

Carers can receive benefits and entitlements for their time. As a carer, benefits and entitlements may include:

A Carer Payment (means tested) may provide a carer with:

- A fortnightly payment from Centrelink
- A pensioner concession card
- A pensioner education supplement (if studying)
- Access to a Centrelink jobs, education and training advisor
- Pharmaceutical allowance
- Telephone allowance
- Rent assistance
- Remote area allowance
- Utility allowance
- GST supplement

A Carer Allowance (non means tested) may provide a carer with:

- A fortnightly payment from Centrelink

A Pensioner Concession Card may provide a carer with:

- A reduction in council rates and charges
- Electricity and gas rebate
- Water bill rebate
- Dog and cat registration rebates
- Free drivers licence renewal
- Discounted travel on public transport
- Countrylink train travel

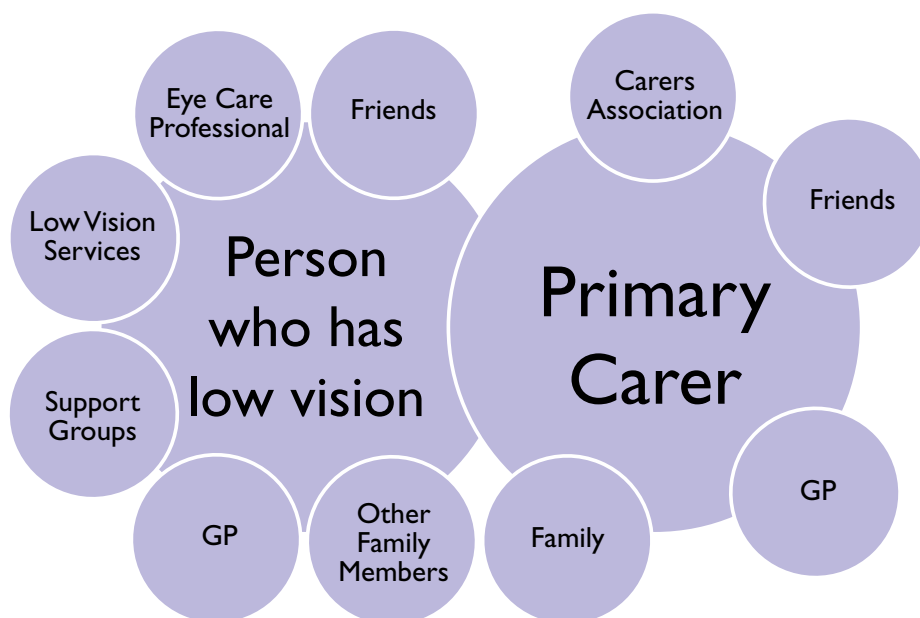
To obtain information on eligibility for a carer payment or a carer allowance contact Centrelink on 13 27 17 or visit www.humanservices.gov.au



The Support Team

It is important for a carer to recognise that they are part of a support team. The team is centred on the person who requires care in partnership with the primary carer and further supported by the family, health care professionals, low vision services, support groups and other community services.

A simple model which can help identify the support team may look like this:



A carer is never alone in providing assistance to their family member, friend or client. A carer is part of an extended support team.

Eye Health Care Professionals

Eye health care professionals are responsible for helping to diagnose and manage eye disease and low vision. The following provides a description of the tasks undertaken by each type of eye professional.

○ Ophthalmologist

An ophthalmologist is a medical doctor who has completed extra training in eyes. Ophthalmologists perform eye exams, treat disease, prescribe medication and perform surgery. They may also write prescriptions for spectacles and contact lenses. Some ophthalmologists have further specialisation as a retinal specialist.

○ Optometrist

An optometrist performs eye exams for both vision and health problems, prescribes spectacles and fits contact lenses. Some optometrists have further specialisation in low vision rehabilitation. They can diagnose eye diseases and refer patients to ophthalmologists for treatment. For people with low vision, the optometrist can provide practical advice on how to maintain quality of life and independence.

○ Orthoptist

An orthoptist is an allied health professional who assists in the diagnosis and treatment of vision problems. An orthoptist may work in an ophthalmologist's surgery, a hospital/community eye clinic or in a rehabilitation setting.

Rehabilitation Professionals

Rehabilitation is essential for supporting independence and quality of life. The following professionals can help to teach new skills to people who have low vision for ongoing independence and confidence in everyday activities.

○ Occupational Therapists

An occupational therapist (OT) is a health professional who assists people with vision impairment perform practical everyday tasks by providing them with the skills and strategies to maintain their quality of life. Occupational therapists show people with low vision how they can make the most of their remaining vision as well as using other senses like touch, hearing and smell to perform daily activities. This may include everyday tasks such as cooking, personal care, housework, making a cup of tea or using the telephone.

○ Orientation and Mobility Instructors

Orientation and mobility instructors help a person with low vision to move about independently, confidently and safely. A mobility instructor can visit a person's home and give advice and training regarding common challenges such as stairs, public transport, crossing roads and finding the way to different places.

Blindness and Low Vision Agencies

A carer can assist a person who has low vision to access the right services and aids by contacting a local low vision agency and requesting information on the best course of action to follow.

One of the most important services that blindness and low vision agencies offer is a low vision assessment. This assessment will help determine the amount of vision remaining and how to make the most of that vision.

Some blindness and low vision agencies also provide daily living aids, low vision aids and adaptive technology. This equipment can help a person who has low vision maintain quality of life and independence.

Carers Associations

In every State and Territory of Australia there is a Carers Association which oversees all of the services and support available to carers. Depending on the State or Territory, the Carers Association can connect carers to services such as counselling, respite care, information and advice. These services are all designed to help carers in their care giving role.

A list of low vision and blindness agencies is provided in the Service Directory at the back of this guide. For further information on low vision and blindness agencies for all States and Territories, please refer to the Foundation's publication *Low Vision - A Guide*.

Communicating Effectively

The key to a successful relationship is good communication. Establishing clear and open communication between a carer and the person who has low vision will aid independence.

The following communication skills and techniques are useful when communicating with a person who has low vision:

- Let the person know that you have entered the room or joined the group and if appropriate who else is there
- Identify yourself by name
- Always make it clear to whom you are talking by using the person's name
- Let the person know when you are leaving the room so that he or she is aware you are no longer there
- It is not necessary to raise your voice or slow your speech simply because someone has vision impairment. Speak as you would normally
- Use the language that you usually use in conversation
- Advise if there are animals in the room or house
- Check if the person is more comfortable with the lights on or off
- Check that when seated the person is not facing the window
- Always address the person directly and never in the third person
- Never assume that a person will need or want your help
- If you are unsure, ask "Do you need help?" or "How may I help you?"
- Use supportive language and assure the person that they are not a burden
- Demonstrate empathy, not sympathy

When communicating with a person who has low vision it may be necessary to use small verbalisations because the person will not automatically be able to see a head nodding or other body language.

Active listening is also an important part of communicating with a person who has low vision. Active listening is when someone listens to the person who is talking to them with their full attention.

Active listening also means waiting for the other person to conclude speaking before the listener begins to talk. This communicates to the other person that there is interest in the person and what they have to say.

Living with low vision can at times be challenging. Sometimes just having someone there to listen makes all the difference. Take time to listen to the person who requires care. Let them know that they are important and that they are supported.

Strategies for Independent Living

A carer can help a person who has low vision remain as independent as possible. This section of the guide examines what types of strategies might be put in place in order for independence to be enhanced.

Maintaining independence and quality of life once a person has lost vision is about using remaining vision to continue to undertake everyday activities.

Maintaining Independent Mobility

Mobility is the activity of moving or getting around. When a person has low vision their mobility can be affected by:

- Darkness or dim light
- Changing light conditions
- Unfamiliar places
- Crowded situations
- Visually complex environments such as supermarkets
- Uneven footpaths

A person who has low vision may have feelings of anxiety and helplessness about moving around independently. They may also have a greater risk of slips, trips and falls.

To help maintain independent mobility a carer can encourage the family member, friend or client to seek orientation and mobility training. This helps to restore confidence by teaching a person to use existing vision and remaining senses to move around independently. Making adjustments around the home can also make it easier for the person to move around confidently.

If independent mobility is lost and cannot be regained it is important for the carer to know how to guide the person.



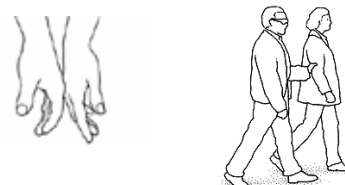
Guiding

Guiding techniques are designed to enable a person who has low vision to move through the environment safely and efficiently with the assistance of a guide.

Good communication is the key to being a good guide. A responsible guide will let the person know what is happening around them by using precise language, avoiding potential hazards and walking at a comfortable pace.

Initial Contact and Grip

If guiding is required, the guide can make contact with the person by touching the back of the person's hand with the back of their own hand. The person will hold the guide's arm just above the elbow.



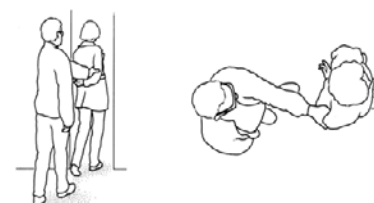
Position

The guide should hold their arm relaxed at their side. The person being guided should not stand beside the guide. They should stay one step behind the guide, keeping their own arm close to their side.



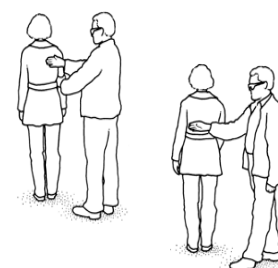
Narrow Spaces

Be sure to tell the person being guided if you are approaching a narrow space. The person being guided will step behind in single file. In this case it may be easier for the person to grip the guide's wrist.



Changing Sides

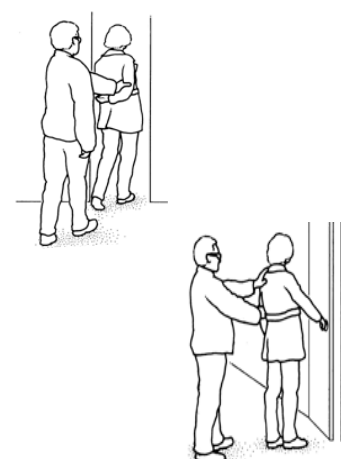
Sometimes it is necessary to change sides. After informing the person of the need to change sides, it may be safest to stop. The person being guided will place their free hand on the guide's back, releasing their original grip. The person being guided then trails their hand across the guide's back until reaching the guide's other arm.



Doors

Let the person being guided know when you are approaching a closed door and explain which way it opens. Where possible, it will be easier to place the person on the same side as the door hinges.

The guide opens the door with their free hand. Walking forward, the guide grips the door handle. The person slides their free hand down the guide's arm to locate the handle and closes the door.

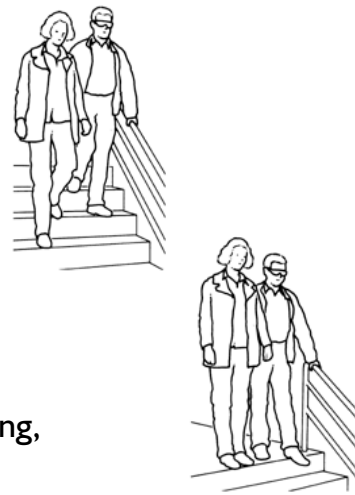


Stairs and Kerbs

Inform the person when you reach the kerb or stairs and also whether they go up or down. If there is a handrail and the person wishes to use it, you may need to change sides.

The guide stops at the edge. The person moves forward to find the edge of the first step. When both are ready, the guide goes one step ahead. The guide walks at the pace most comfortable for the person they are guiding.

The guide lets the person know when they have reached the landing, the top or the bottom of the stairs.



Getting into a car

Ask the person if they need help with getting into the car. Explain which way the car is facing and find out where they would like to sit.

If help is needed, the guide places their hand on the door handle and the person runs their hand down the guide's arm to locate the handle. The person opens the door and may use their free hand to touch the edge of the car roof. This may help the person avoid bumping his or her head. Alternatively, the guide may open the door and show the person the top of the door frame and the car roof.

Getting into a chair

Start by letting the person know about the chair, the position and the type of chair and its relation to the surroundings such as a table. Tell them which part of the chair they will contact first.

The guide places their guiding hand on the chair. The person slides their grip hand down the guide's arm on the chair. With their other hand, the person can feel the chair and seat themselves.

Giving Directions

Use accurate directions such as right or left. Use the clock face positioning such as "your drink is at 10 o'clock" or the direction 'in front of' or 'behind'.

For more information on orientation and mobility, please refer to the Foundation's publication *Low Vision – A Guide*.



Preventing Slips, Trips and Falls

Slips, trips and falls can happen to anyone, although the likelihood of having a fall is increased as a person ages or if they have low vision. To reduce the risk of slips, trips and falls and to help reduce feelings of fear and anxiety there are a number of things that can be undertaken to help the person who is in care. More detailed information is available from the Foundation's publication *Slips, Trips and Falls – A Guide*.

Safety in the home:

- Remove all loose mats and rugs or ensure they are firmly secured and have slip-resistant backing
 - Keep floors free of clutter
 - Always wipe up spills as soon as they occur
 - Coil or tape cords and cables next to the wall
 - Place lighting in dark areas
 - At night turn on the main room light and/or the passage light
 - Install and use handrails when walking up stairs
 - Keep frequently used items in the same place so they are easy to reach
 - Attach slip-resistant rubber tread on stairs
 - Use a slip-resistant mat in the shower and bath
 - Handrails in the bath, the shower and the toilet are also recommended
 - Avoid placing fans and heaters in walkways or in the middle of the room
 - It is easier to get in and out of higher chairs and chairs with solid armrests
 - Have a light within reach of the bed
 - Purchase shoes and slippers with slip-resistant soles and patterned tread with rounded, low, broad heels
 - Paint a contrasting non-slip strip on the front edge of the steps
-

It is also recommended that a person who has low vision:

- Allows time for eyes to adjust when walking from light to dark areas and vice versa
- Wears sunglasses and a hat when outside to reduce glare
- Places a chair near the back door so when entering from outside there is somewhere to wait until the eyes adjust to the light
- Avoids rushing and allow plenty of time to get to a destination
- Keeps active as physical activity maintains health and helps to improve balance, muscle strength and flexibility

New Lifestyle and Leisure Activities

When a person has low vision they may stop doing the activities they once enjoyed or their approach to a task may be very different. Helping them to continue doing the things they enjoy and adjusting the way they undertake the activity will help preserve quality of life.

Carers can help a person to continue doing what they enjoy by introducing the person to new ways of doing activities. To help maintain activities a carer can:

- Suggest the use of adaptive technology for reading or doing the crossword
- Utilise the radio
- Utilise audio technology that can deliver books and newspapers in audio form
- Suggest or arrange a walking group to maintain an active lifestyle
- Develop strategies for exercise such as going to the gym
- Conduct a search for low vision activity groups
- Use computer programs such as Zoomtext or Jaws to continue to use the computer and access the internet
- Help teach a person how to use the internet, write letters and stay in touch with others
- Undertake computer training
- Find a travel agent who can help plan trips for those with low vision
- Network with social clubs for support



Daily Living Aids, Low Vision Aids and Technology

Using daily living aids, low vision aids and technology can make all the difference to a person who is blind or vision impaired. The following is a brief description of the use and purpose of these types of aids. More detailed information is available from the Foundation's publication *Low Vision Aids & Technology - A Guide*

- Daily living aids can include liquid level indicators, coin sorters and large button telephones. These aids can help in and around the home with daily activities
- Low vision aids can include hand-held magnifiers and lamps. These aids can help with reading labels, books, newspapers and letters
- Technology can include closed circuit televisions (CCTV) (also known as electronic magnifiers). These are used to magnify text up to fifty times and for reading text when hand-held magnifiers are no longer effective
- Audio technology can include talking books, and is useful when reading aids are no longer effective

As a carer it is important to encourage the use of equipment that will help to maintain independence.

A positive and encouraging environment is important and will facilitate the use of daily living aids, low vision aids and adaptive technology. When the person who has low vision begins to use new equipment the carer may need to keep in mind the following:

- Be patient, as it takes time to master the use of new equipment
- Ensure the equipment is being used properly
- Exchange equipment if it does not appear to be of help to the person

Exploring options for independent living helps the family member, friend or client who is blind or has low vision to remain in control of their own rehabilitation process.



Services and Information for Carers

There are a range of services available to carers. These services can be accessed by contacting the Carers Association in each State and Territory, the Carer Advisory Service or the Commonwealth Carelink Centre.

- **Aged Care Assessment Teams (ACAT):** Help older people who are no longer able to manage at home without assistance, as well as their carers, ascertain the care which will best meet the client's needs. These teams provide information on suitable care options and help arrange access for referral to appropriate residential or community care.
- **Carer Support Groups:** A support group offers carers the opportunity to come together and share their experiences. Some support groups are for all carers while others are specific to a type of illness or disability.
- **Commonwealth Home Care Packages:** Provide individually planned and co-ordinated packages of care. They are tailored to help older Australians remain living at home. They help provide for the complex care needs of older people.
- **Commonwealth Home Support Programme (HACC in VIC and WA):** This program provides a range of basic maintenance and support services for older people, people with disabilities and their carers. Services include domestic assistance, home modifications and maintenance, personal care, community nursing, food services, assessment and referral services, carer support, transport and some allied health services.
- **Community Health Centres:** These centres offer services which include child health, counselling, speech therapy, physiotherapy, community nursing and mental health care.
- **Counselling:** Counselling services are available to carers and patients alike. Counselling involves talking to someone who has appropriate expertise and skills to help with a range of issues, feelings and difficulties and can be conducted face-to-face or over the telephone. Counselling offers an opportunity to talk about issues which may be sensitive or private and require specific expertise.
- **Food Services:** When a person can no longer prepare their own meals at home there are home food services available which can cater to the dietary needs of the individual.
- **Home Help:** Home help services can assist with practical tasks in the home such as cleaning, shopping, laundry and personal care.
- **Home Maintenance and Modification:** Assistance can be provided for essential home repairs and modification, such as safety ramps and support rails.
- **Home Nursing:** A trained nurse can visit a person in their home and assist with tasks such as hygiene and medication.
- **Respite:** Respite care provides support for carers by providing a break from the caring role. Respite may be provided informally by friends and family or by formal services which supply a trained person either in the home or at a day centre.

- **The Aged Care Rights Service (TARS):** This is a community legal centre that provides advocacy for the residents of Commonwealth funded hostels and nursing homes, self-care retirement villages and recipients of in-home aged care. They also give information on the costs associated with entering an aged care facility and advice on retirement village contracts. All calls to TARS are confidential.
- **The Age Page:** The Age Page is a listing at the front of most telephone directories. It provides the listing and contact details for aged care services in the local area.
- **Translating and Interpreting Service (TIS):** This service can arrange for a pre-booked telephone interpreter or a face-to-face interpreter. There is a charge for this service.
- **Transport:** Transport services can assist people who are unable to use or have no access to regular transport. Help can be provided to get to and from appointments, shopping or social activities.
- **Volunteer Programs:** Volunteers can carry out home visits and help with shopping and transport to aid carers.

For more help and information, call the Carer Advisory Service on 1800 242 636, or My Aged Care on 1800 200 422. See the Service Directory section of this guide for more information.

Talking to Service Providers

When contacting a service provider to request a service consider the following suggestions:

- Write down the key points of the issue
- Ask yourself “What is the problem?”
- Ask yourself “Have I checked that this is the appropriate service provider?”
- Ask yourself “What do I need from the service provider?”
- Ensure all the important information you may need such as pension numbers are in front of you before making the call
- Communicate the points as clearly as possible
- Provide only relevant and important information to the service provider
- Document the important points, phone numbers and the name of the person to whom you are speaking and their direct contact phone number as part of the care plan
- Ask questions such as “When will the service be available?” “Is there a cost?” and “What forms are required to be completed?”
- Be polite but firm. Do not finish the conversation without feeling confident that your questions have been answered

Easy Reference Guide

This guide relates to services provided specifically to carers. For services for those with low

Organisation	Information and/or Helpline	Counselling
National		
Carers Australia	✓	✓
Centrelink	✓	-
My Aged Care	✓	-
Australian Capital Territory		
Carers ACT	✓	✓
Guide Dogs NSW/ACT	✓	-
The Royal Society for the Blind (Canberra)	✓	✓
Vision Australia	✓	-
New South Wales		
Carers NSW	✓	✓
Guide Dogs NSW/ACT	✓	-
The Royal Society for the Blind (Hunter region)	✓	✓
Vision Australia	✓	-
Northern Territory		
Carers NT	✓	✓
Guide Dogs SA/NT	✓	-

All efforts have been made by the Macular Degeneration Foundation to verify the accuracy of the information in this reference guide.

vision, please refer to the Foundation's publication *Low Vision - A Guide*.

Support Groups	Respite Care	Home Care	Financial Assistance
✓	-	-	-
-	-	-	✓
-	✓	✓	-
✓	✓	-	-
-	-	-	-
-	-	-	-
✓	-	-	-
✓	-	-	-
-	-	-	-
-	-	-	-
✓	-	-	-
✓	✓	-	-
-	-	-	-

Easy Reference Guide

This guide relates to services provided specifically to carers. For services for those with low

Organisation	Information and/or Helpline	Counselling
Queensland		
Carers QLD	✓	✓
Guide Dogs QLD	✓	✓
Vision Australia	✓	-
South Australia		
Carers SA	✓	✓
Guide Dogs SA/NT	✓	-
The Royal Society for the Blind	✓	-
Tasmania		
Carers TAS	✓	✓
Lions Low Vision Clinic	✓	✓
Guide Dogs Tasmania	✓	-
Victoria		
Carers VIC	✓	✓
Guide Dogs VIC	✓	-
Vision Australia	✓	-
Western Australia		
VisAbility (formerly Association for the Blind of WA)	✓	✓
Carers WA	✓	✓

All efforts have been made by the Macular Degeneration Foundation to verify the accuracy of the information in this reference guide.

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Support Groups	Respite Care	Home Care	Financial Assistance
✓	-	-	-
✓	-	-	-
✓	-	-	-
✓	-	-	-
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✓	-	-	-
✓	-	-	-
✓	-	-	-

National – Service Directory

Aged Care Assessment Team Phone: 1800 052 222	Glaucoma Australia Phone: 1800 500 880 Website: www.glaucoma.org.au Email: glaucoma@glaucoma.org.au
My Aged Care Phone: 1800 200 422 Website: www.myagedcare.gov.au	
beyondblue Phone: 1300 224 636 Website: www.beyondblue.org.au Email: infoline@beyondblue.org.au	Lifeline Phone: 131 114 Website: www.lifeline.org.au Email: national@lifeline.org.au
Carers Australia Phone: 1800 242 636 Website: www.carersaustralia.com.au Email: caa@carersaustralia.com.au	Macular Disease Foundation Australia Phone: 1800 111 709 Website: www.md.foundation.com.au Email: info@mdfoundation.com.au
Centrelink Phone: 13 27 17 Website: www.humanservices.gov.au	Meals on Wheels Website: www.mealsonwheels.org.au NSW (02) 8219 4200 QLD 1300 909 790 ACT (02) 6234 7634 SA (08) 8271 8700 NT (08) 8920 3700 TAS (03) 6228 4546 VIC/WA – contact your local council
Department of Veterans' Affairs Phone: 133 254 Website: www.dva.gov.au Email: generalenquiries@dva.gov.au	Optometry Australia Phone: (03) 9668 8500 Website: www.optometrists.asn.au Email: oaanat@optometry.org.au
Diabetes Australia Phone: 1300 136 588 Website: www.diabetesaustralia.com.au Email: admin@diabetesaustralia.com.au	Retina Australia Phone: 1800 999 870 Website: www.retinaaustralia.com.au Email: ransw@retinaaustralia.com.au
The Genetic Eye Foundation Phone: (02) 9382 2493 Website: www.gef.org.au Email: enquiries@gef.org.au	The Royal Australian and New Zealand College of Ophthalmologists Phone: (02) 9690 1001 Website: www.ranzco.edu Email: ranzco@ranzco.edu

Australian Capital Territory – Service Directory

ACT Health

Phone: 132 281

Website: www.health.act.gov.au

Email: HealthACT@act.gov.au

Guide Dogs NSW/ACT

Phone: (02) 6285 2988

Address: Suite 4, Mungga-Iri House
18 Napier Close
Deakin ACT 2600

Website: www.guidedogs.com.au

Email: ACToffice@guidedogs.com.au

The Royal Society for the Blind (Canberra)

Phone: (02) 6247 4580

Address: Room G06, New Griffin Centre
20 Genge Street
Canberra City ACT 2601

Website: www.rsb.org.au

Email: rsbcanberra@rsb.org.au

Vision Australia

Phone: 1300 847 466

Address: Level 2, 22 East Row
Canberra ACT 2601

Website: www.visionaustralia.org

Email: info@visionaustralia.org

Carers ACT

Phone: (02) 6296 9900

Address: 2/80 Beaurepaire Crescent
Holt ACT 2615

Website: www.carersact.asn.au

Email: carers@carersact.asn.au

New South Wales - Service Directory

Carers NSW

Phone: 1800 242 636

Address: Level 18, Roden Cutler House
24 Campbell Street
Sydney NSW 2000

Website: www.carersnsw.asn.au

Email: contact@carersnsw.asn.au

Guide Dogs NSW/ACT

**Phone: 1800 804 805
02 9412 9300**

Address: 2-4 Thomas Street
Chatswood NSW 2067

Website: www.guidedogs.com.au

Department of Family and Community Services. Ageing, Disability and Home Care

Phone: (02) 8270 2000

Address: Level 5, 83 Clarence Street
Sydney NSW 2000

Website: www.adhc.nsw.gov.au

Email: infoadhc@facs.nsw.gov.au

Vision Australia

Phone: 1300 84 74 66

Address: 4 Mitchell Street
Enfield NSW 2136

Website: www.visionaustralia.org

Email: info@visionaustralia.org

The Royal Society for the Blind (Hunter region)

Phone: (02) 4956 2282

Address: 151 Lambton Road, Broadmeadow NSW 2292

Website: www.rsb.org.au Email: rsbhunter@rsb.org.au

Northern Territory – Service Directory

Carers NT

Phone: 1800 242 636

(08) 8944 4888

Address: 59 Bayview Boulevard
Bayview NT 0800

Website: www.carersaustralia.com.au

Email: carersnt@carersnt.asn.au

Guide Dogs SA/NT

Phone: (08) 8995 2222

Address: Shop 4, 5 Keith Lane
Fannie Bay NT 0820

Website: www.guidedogs.org.au

Email: info@guidedogs.org.au

Department of Health

Phone: (08) 8999 2400

Address: Health House, 87 Mitchell Street,
Darwin NT 0800

Website: www.health.nt.gov.au

Queensland – Service Directory

Carers Queensland

Phone: 1800 242 636

(07) 3900 8100

Address: 15 Abbott Street
Camp Hill QLD 4152

Website: www.carersqld.asn.au

Email: cas@carersqld.asn.au

Queensland Health

Phone: (07) 3234 0111

Address: Queensland Health Building
147-163 Charlotte Street
Brisbane QLD 4000

Website: www.health.qld.gov.au

Guide Dogs Queensland

Phone: 1800 810 122

Address: 1978 Gympie Road
Bald Hills QLD 4036

Website: www.guidedogsqld.com.au

Email: admin@guidedogsqld.com.au

Vision Australia

Phone: 1300 847 466

Address: 373 Old Cleveland Road
Coorparoo QLD 4151

Website: www.visionaustralia.org

Email: info@visionaustralia.org

Queensland Blind Association

Phone: (07) 3848 8888

Address: 26 Warwick Street
Annerley QLD 4103

Website: www.qba.asn.au

Email: qba@qba.asn.au

South Australia – Service Directory

Carers SA

Phone: 1800 242 636
(08) 8291 5600

Address: 66 Greenhill Road
Wayville SA 5034

Website: www.carers-sa.asn.au

Email: info@carers-sa.asn.au

Guide Dogs SA/NT

Phone: 1800 738 855
(08) 8203 8333

Address: 251 Morphett Street
Adelaide SA 5000

Website: www.guidedogs.org.au

Email: info@guidedogs.org.au

SA Health

Phone: (08) 8226 6000

Address: Citi Centre Building
11 Hindmarsh Square
Adelaide SA 5000

Website: www.sahealth.sa.gov.au

The Royal Society for the Blind (RSB)

Phone: (08) 8417 5599
1800 675 554

Address: Knapman House
230 Pirie Street
Adelaide SA 5000

Website: www.rsb.org.au

Email: mail@rsb.org.au

Tasmania – Service Directory

Carers TAS

Phone: 1800 242 636
(03) 6231 5507

Address: 64 Burnett Street
North Hobart TAS 7000

Website: www.carerstas.org

Email: catinc@carerstas.org

Guide Dogs Tasmania

Phone: (03) 6232 1222

Address: 164 Elizabeth Street
Hobart TAS 7000

Website: www.guidedogstas.com.au

Email: admin@guidedogstas.com.au

Lions Low Vision Clinic

Phone: (03) 6222 8310

Address: Eye Clinic, RHH
Cnr Argle & Liverpool Streets
Hobart TAS 7000

Website: www.dhhs.tas.gov.au/services

Email: llvc@dhhs.tas.gov.au

Department of Health and Human Services

Phone: 1300 135 513

Website: www.dhhs.tas.gov.au

Victoria – Service Directory

Carers Victoria

Phone: 1800 242 636
(03) 9396 9500

Address: 37 Albert Street
Footscray VIC 3011

Website: www.carersvic.org.au

Email: reception@carersvictoria.org.au

Guide Dogs Victoria

Phone: (03) 9854 4444

Address: Chandler Highway
Kew VIC 3101

Website: www.guidedogsvictoria.com.au

Email: referrals@guidedogsvictoria.com.au

Department of Human Services

Phone: 1300 650 172

Address: 50 Lonsdale Street
Melbourne VIC 3000

Website: www.dhs.vic.gov.au

Vision Australia

Phone: 1300 847 466

Address: 454 Glenferrie Road
Kooyong VIC 3144

Website: www.visionaustralia.org

Email: info@visionaustralia.org

Western Australia – Service Directory

VisAbility

(formerly Association for the Blind of WA)

Phone: (08) 9311 8202
1800 847 466

Address: 61 Kitchener Avenue
Victoria Park WA 6100

Website: www.visibility.com.au

Email: info@visibility.com.au

Department of Local

Government and Communities

Phone: (08) 6551 8700

Address: Gordon Stephenson House
140 William Street
Perth WA 6005

Website: www.communities.wa.gov.au

Email: info@dlgc.wa.gov.au

Carers WA

Phone: 1800 242 636

Address: 182 Lord Street
Perth WA 6000

Website: www.carerswa.asn.au

Email: info@carerswa.asn.au



Notes

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Family, Friend & Carer

A GUIDE

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For further information
and support please contact:

**Macular Disease
Foundation Australia**

1800 111 709

www.mdfoundation.com.au



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Our focus is your vision

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Canadian National Blindness Institute. 1929 Bayview Avenue Toronto Ontario M4G 3E8

Carers Australia. Deakin West ACT 2600 Australia.

Guide Dogs NSW/ACT. 2-4 Thomas Street Chatswood NSW 2067 Australia.

Lighthouse International, The Sol and Lillian Goldman Building, 111 East 59th Street New York, NY 10022-1202 USA.

National Eye Institute, National Institutes of Health, 2020 Vision Place, Bethesda, MD 20892-3655

NSW Department of Health, Stay on your feet (2004) 73 Miller Street North Sydney NSW 2060

O'Connor, PM., & Keffe, JE (2007). Focus on Low Vision. Melbourne: Centre for Eye Research Australia.

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