Macular Disease Foundation AUSTRALIA

CARING FOR SOMEONE WITH MACULAR DISEASE

Carers and macular disease

Macular disease covers a range of conditions that affect the central retina (the macula) at the back of the eye. Macular disease is the leading cause of blindness and severe vision loss in Australia, but it doesn't lead to total ('black') blindness. Severe vision loss can have negative impacts on a person's quality of life and independence.

People with vision loss:

- are more than twice as likely to be at risk of falls
- have a three-fold risk of depression
- are four to eight times more likely to suffer hip fractures
- are admitted to nursing homes three years earlier, on average have significantly decreased social independence.[1]

Caring for someone with vision loss can sometimes be physically and emotionally draining and many carers put their own needs last. It's important to keep yourself healthy, prioritise your own wellbeing, and understand what support is available to help you in your caring role and know that you are not alone.

MDFA is here to explain the clinical and other impacts of macular conditions, how the eye health sector works, Medicare rebates and other practical resources to help you in your caring role.

This fact sheet provides information and advice for family members, friends and carers of a person with vision loss, to support you in this important role.

What is a carer?

A carer is typically a family member or friend who provides unpaid care for people living with a chronic condition, disability or mental illness, or someone who is frail. This could be for as little as a few hours a week, or as often as every day.

Often an unpaid family member or friend takes on the role of carer because they feel obliged to, because no one else can or because it suits everyone involved at the time.

Paid care workers are not defined as carers.

What do carers do?

If you care for someone with vision loss, you may help and support them with daily activities and tasks such as cooking, cleaning, driving, shopping and reading mail. You may also assist with taking them to medical appointments, accessing community services, maintaining hobbies and leisure activities, and guiding them in the home or community.

Other tasks you might help with include using the telephone, computer, or low vision aids and technologies.

How caring may impact you

Caring for someone with vision loss can have a significant impact on you.

Socially: Responsibilities involved in being a carer may mean you don't have as much time or energy to catch up with friends, or to engage in your favourite activities.

Economically: You may be limited in your ability to work or may incur extra expenses. While financial assistance is available, sometimes this is limited.

Emotionally: It's common to feel overwhelmed when caring for a loved one. It's also normal to experience negative feelings, especially if you feel you've had little choice in becoming a carer.

While caring for someone with vision loss can be rewarding, it can also be difficult at times. Understanding macular disease and management of care can be complex.

Call our National Helpline on **1800 111 709** for practical information and resources to assist you.

The Carer Gateway is also a useful resource for anyone acting in the role of a carer. The website – **www.carergateway.gov.au** – provides advice, carer support, respite options, financial help and tips for carers.

Caring for the carer

When caring for someone else, it's easy to forget to look after yourself. However, it's important to ensure you're looking after your own health and wellbeing.

Eating well, exercising regularly, and getting enough sleep will help you keep healthy. It's also important to take regular breaks from caring, and to have people you can talk to. This may be family, friends, support groups, or even a professional counsellor.

Get your own macula checked

Many family carers put their own needs last, but it's important you don't neglect your own eye health.

If the person you're caring for is a relative, your own eye health is a priority, as many macular diseases run in families.

For example, if you have a family history of age-related macular degeneration (AMD), you have a 50 per cent risk of developing it too.

Regular eye exams are recommended every two years. People over 65 years and people living with diabetes should have annual checks. Of course, if your optometrist recommends more (or less) frequent eye exams, follow their advice.

If you notice sudden changes in your vision, get your eyes checked immediately.

Contact our National Helpline on **1800 111 709** for further information.

Developing a care plan

Having a care plan will make it easier to ensure the person with vision loss has the right support and assistance. It also ensures continuity of care, particularly when more than one person acts as a carer, or if respite care is required.

Care plans will vary depending upon the type and extent of vision loss, and the individual circumstances of the person you care for.

However, it should contain:

- personal details of the person you care for
- care needs, including details of tasks the person needs help with
- contact details for all relevant health professionals
- a medicine list, including details of any appointments with an eye care professional
- details of people and/or service providers that can assist
- emergency contact details
- An Amsler grid to monitor any changes in vision between appointments with the eye care professional.
- When developing the care plan, it's important to actively involve the person with vision loss. Try to:
- identify tasks and activities they can no longer do independently
- acknowledge that the person with vision loss is the authority on their own experience
- allow them to make their own decisions, unless they ask for help
- avoid being overprotective
- remain positive.

Low vision assessment

A low vision assessment conducted by a low vision provider is an important element of developing your care plan. It will help determine the extent of vision loss, modifications that can be made to the home, low vision aids and technologies that may assist with independent living, and types of support services available.

If the person with vision loss needs care for other physical and mental conditions, try to identify what this is and how you can access care. This may involve the person with vision loss, as well as other health professionals and service providers.

For further information on developing a care plan, please contact our National Helpline on **1800 111 709**.

The Carer Gateway has templates for care plans, which you can find at **www.carergateway.gov.au.**

Support available

Caring for someone with vision loss requires a support team that's centred around the person who requires care, in partnership with the primary carer.

A support team may consist of:

- your general practitioner
- eye health professionals (optometrist, ophthalmologist, orthoptist)
- rehabilitation professionals (occupational therapists, orientation and mobility instructors)
- low vision service providers
- carers associations and support groups
- community organisations and local councils
- other family members
- friends.

Carer Gateway

The Carer Gateway is an online portal maintained by the Department of Social Services and is the one stop shop and primary resource for Australian carers.

The Carer Gateway provides a range of practical supports including confidential phone counselling, information about eligibility for carer payment, concessions or other financial assistance plus a range of valuable resources to help you in your caring role. Find out more at **www.carergateway.gov.au.**

MDFA

For specific information about caring for someone with low vision, MDFA's National Helpline is a free service providing information, advice and wellbeing support for people with macular disease and their carers. Call **1800 111 709**.

Join Eye Connect today

A macular disease diagnosis is not easy and there may be challenges ahead.

Macular Disease Foundation Australia's Eye Connect support service is free of charge, independent and endorsed by Australia's leading eye health professionals.

It offers tailored support and information that people living with AMD can access in between appointments with their eyecare professional.

Whether you prefer to receive assistance and resources online, in the post, or over the phone, Eye Connect has you covered.

Join Eye Connect via **www.mdfoundation.com.au/join-eye-connect** or call us on **1800 111 709**.

Need more information?

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

You can also order information kits and Amsler grids by calling our National Helpline on **1800 111 709**.

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

Contact us today.

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Reference: 1. 'The Global Economic Cost of Visual Impairment' Access Economics & AMDAI, 2010.

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