



VisionVoice

Autumn Edition 2025

Representing the macular disease community at the federal election

Macular Disease Foundation Australia is advocating for the next Australian Government to make the preservation of sight a national priority.

We have released our Federal Election Agenda, *Fight for Sight*, which proposes clear and practical steps for the next Government to take to save the sight of thousands of people living with macular disease.

Limited access to public hospitals and bulk-billed private treatment has led to many people depending on private treatment with significant out-of-pocket costs, and people living in regional, rural and remote areas having to travel long distances to access public hospital outpatient treatment.

Across Australia, only a few metropolitan and larger regional public hospitals provide eye injection treatment. Treatment is mainly provided by private ophthalmologists, with between 77% to 82% of them charging out-of-pocket fees. Ophthalmologists providing eye injection treatment are extremely limited in regional areas.

Without treatment, people with macular diseases such as neovascular AMD (also known as wet AMD), diabetic macular oedema and retinal vein occlusion will lose their vision.

With the prolonged cost of living crisis, it is little wonder that lack of affordability and access are two main reasons why many

people with macular disease stop treatment, particularly for low-income earners, pensioners and people living in regional Australia.

In response to this, our recommendations to Government centre on driving greater affordability and access to sight-saving treatments, while bringing cost savings to the economy.

A key recommendation in our Election Agenda is for the Australian Government to establish a **Neovascular AMD Treatment Incentive Program** to encourage ophthalmologists to bulk-bill pension card holders having eye injections for neovascular AMD. By targeting the most financially vulnerable people who need sight-saving treatment and encouraging more bulk-billing, this program would cost the government an estimated \$11.1 million a year, and ultimately save government \$140 million a year.

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CEO Update

The lead up to the federal election offers MDFA an opportunity to ask Government to step up and support the macular disease community and commit to changing a system which is letting older and more vulnerable Australians go blind.

We have five key recommendations which we are presenting to Government as our election agenda. These recommendations are bold and require investment, but ultimately, they will save tax-payer funds – and most importantly, they will save sight.

As a result of your generous donations and support, we will award more than \$800,000 for new Research Grants, taking our overall investment tally to over \$6.5 million. The applications we have received are of the highest quality and I look forward to sharing news of the successful researchers as part of our Macula Month celebrations in May.

In exciting news, a new treatment for geographic atrophy, the dry form of AMD, has been approved by the Therapeutic Goods Administration (TGA).

Our newly launched Eye Connect service has hit a milestone of 500 people who are benefiting from this personalised information and care program. Eye Connect is currently available free-of-charge to anyone living with AMD who would like extra support to best manage their condition. In July, we will be extending this service to those who live with diabetes and have been diagnosed with diabetic retinopathy or diabetic macular oedema.

Those currently enrolled in Eye Connect have reported great benefits, including 75% stating that the service is helping them adhere to treatment and maintain a positive approach to living with AMD.



We anticipate 2025 being a year of great opportunity and opportunities to connect.

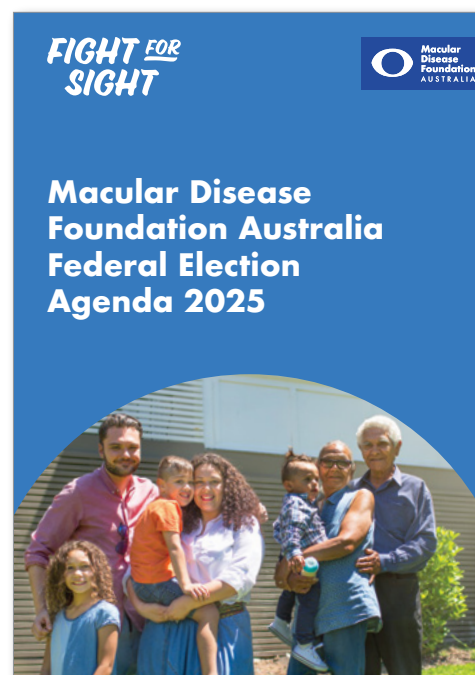
Thank you for your ongoing support. We're here for you.

Dr Kathy Chapman
Chief Executive Officer

Representing you at the federal election

Continued.

Other recommendations include increasing access to eye injection treatment through intergovernmental agreements, and public-private sector partnerships.



The cost of macular disease

- The total annual economic cost of vision loss in Australia is estimated to be \$16.6 billion or \$29,000 per person with vision loss aged over 40.
- Treatment is mainly provided by private ophthalmologists, with between 77% to 82% of them charging out-of-pocket fees.
- Treatment persistence is a significant problem, with about 50% of patients discontinuing treatment within five years of starting eye injections.
- In 2025, it is estimated that there are over 1.9 million Australians with some evidence of macular disease. And this number is growing. By 2030 we estimate it will have reached 2.1 million people.

For MDFA's full recommendations, download our Federal Election Agenda on our website.

First treatment for geographic atrophy approved in Australia

In January this year, a first of its kind treatment for people living with geographic atrophy (GA) was approved by the Therapeutic Goods Administration (TGA) for use in Australia.

It's called SYFOVRE® (pegcetacoplan injection), and it will give many people a treatment option that they've never had before to slow the progression of geographic atrophy, a disease that can cause irreversible and severe loss of central vision.

"This is a long-awaited positive development for people living with geographic atrophy, who to date have had limited treatment options," said Macular Disease Foundation Australia CEO, Dr Kathy Chapman.

"We support thousands of people living with the devastating impacts of geographic atrophy. The TGA's approval of SYFOVRE® is significant as it means the treatment has been independently assessed as being a safe and effective way to reduce the impact of geographic atrophy on people, their families and carers."

"People with geographic atrophy should be aware, however, that this outcome doesn't necessarily mean that they will be eligible for treatment with SYFOVRE®, or that the treatment will be suitable for them. Macular Disease Foundation recommends people consult their ophthalmologist, who will need to weigh-up the benefits and risks to determine if the new treatment is suitable for them."

Macular Disease Foundation advises people with geographic atrophy to continue to have any tests that their eye health professional recommends, to ensure that the progress of their geographic atrophy is regularly monitored.

If you have any questions about geographic atrophy, please call our Helpline on 1800 111 709.



Social Impact Survey 3 reveals alarming cost of living pressures for people with macular disease

Close to 1,500 community members have shared their views on how macular disease impacts their daily life, and the financial cost of living with a macular condition, in MDFA’s third Social Impact Survey.

Developed in partnership with researchers at the University of New South Wales since 2020, these surveys help us identify any unmet support needs, and help ensure our advocacy campaigns, awareness-raising activities, and research priorities are focused on what matters most to people with macular disease.

In the latest survey, people were asked about both their direct and indirect costs associated with living with a macular disease.



Direct costs include	Indirect costs include
Medical out of pocket costs for appointments, treatments and/or medicines, supplements, low vision aids and equipment.	Time commitment and loss of productivity.
Non-medical out of pocket costs related to support services, home modifications and travel (e.g. petrol, parking, ticket fares).	Opportunity costs for unpaid carers and those with macular disease (e.g. working less).
Median total annual direct costs: \$822 (range: \$387 - \$1,939)	Median total annual indirect costs: \$767 (range: \$286 - \$4,411)
Overall total median annual cost for a person living with macular disease: \$2,357 (range \$926-\$7,502)	

The cost of sight saving eye injections

People receiving eye injections face much higher costs than those who don’t. Our survey revealed that almost 1 in 10 people receiving eye injections pay more than \$6,000 in costs directly related to their macular disease every year. These costs include medical appointments, eye injection treatments, low vision aids and equipment, support services, home modifications and travel. This is estimated to consume more than 20% of the Australian aged pension, which is a high cost for some people, particularly as the cost-of-living crisis continues.

Our survey also found that the median total cost for people receiving sight-saving eye injections is \$3,621 (with costs ranging from \$1,899 up to \$9,733 every year), which is 12 percent of the annual pension amount for a single person. This is a huge problem given our research has consistently identified cost and access as the two main reasons people delay or stop treatment.

“Our research underscores the immense financial pressure that people with AMD who solely rely on their pension to get by are facing,” said MDFA’s CEO, Dr Kathy Chapman.

“We know that some people are faced with losing their sight because they can’t afford the treatment needed to save it. The rising cost of living continues to leave more pensioners in poverty, which is why access to affordable treatments is the critical focus of Macular Disease Foundation’s election agenda.”

More results from MDFA’s latest Social Impact Survey will be released during Macula Month this May.

Thanks to those members of our community who participated in the survey. Your insights and feedback are very valuable.

Eye health professionals share how Eye Connect is benefiting their patients

Meri Galoyan, a Senior Staff Optometrist at the Centre for Eye Health, and Associate Professor Fred Chen, a consultant ophthalmologist at the Lions Eye Institute, Royal Perth Hospital and Perth Children's Hospital, have seen firsthand how MDFA's new Eye Connect support service is benefiting people living with AMD.

Launched last year, Eye Connect offers access to free, tailored support and information in between appointments with an eye health professional.

"Eye Connect fills the gap that we as clinicians may not have the expertise or the time to provide," Associate Professor Chen explains. "Our patients appreciate a holistic approach for the management of their macular degeneration. Eye Connect is highly recommended."

"In a clinical setting, patients may not have the chance to think of all the questions they should ask regarding their new diagnosis of macular degeneration. Once the diagnosis sinks in, Eye Connect provides an opportunity for them to ask these questions or help them to clarify what they really want to know so they can articulate the question better when they return to see the clinician at the next clinic follow-up."

Meri says that Eye Connect is "a simple but incredibly effective tool that enhances patient care beyond eye examinations."

"By offering patients these additional resources, we empower them to become more informed about their eye care, helping them not only manage their condition physically but also supporting their emotional and mental well-being," she said.

"I think the work MDFA is doing with Eye Connect and other programs is invaluable. For eye health professionals, it's not just about providing clinical treatment it's about helping patients lead fulfilling lives despite the challenges posed by AMD. Every bit of support counts in improving quality of life for patients with macular disease."

Associate Professor Chen highlighted that it's not only patients who can find value from Eye Connect.

"It is important to note that patients' carers can also benefit from Eye Connect. Carers are essential for the success of medical management of macular degeneration, especially when it comes to bringing patients in for their regular eye injection treatments and for urgent review in case of a sudden change in vision," he said.

Contact MDFA to register or receive more information about how Eye Connect can help you: www.mdfoundation.com.au/join-eye-connect or call MDFA on 1800 111 709.



Meri Galoyan



Fred Chen

Join the 500 people who are already benefiting from Eye Connect.

Whether you prefer to receive information and support online, in the post, or over the phone, we have you covered.

Contact us today.

MDFA is excited to announce that from 1 July 2025, we plan to expand the Eye Connect service to include information and support for people living with diabetic eye disease. Register your interest in joining Eye Connect

by scanning the QR code below, or by calling us on 1800 111 709.



Dr Marianne Coleman, National Centre for Healthy Ageing, on dementia and macular disease

Vision loss can make it harder for people to take part in tailored activities and programs that help them live well with dementia.

The impact of vision loss on daily life can also cause many frustrations, which can, in some types of dementia, trigger behaviour changes if a person's vision support needs aren't looked after.

For carers, looking after someone who has both dementia and vision loss can be really tough. Research shows that carers spend more time on care tasks when a person has vision loss as well as dementia. This doesn't feel good for the person with dementia either, so the impacts of vision loss on wellbeing can be compounded by dementia, and vice versa, for everyone.

People living with dementia are not any more or less likely to develop macular disease,

but they can be more likely to experience vision loss from having age-related eye diseases.

This is because people living with dementia can be less likely to see an eyecare professional regularly, or keep accessing treatments like eye injections.

The central vision loss that happens in macular disease can make it more difficult to use things like calendars and photographs of family members to support memory.

The traditional methods of monitoring macular disease at home, like Amsler grids, can also be trickier to use, if for example the person has a communication difficulty.

This makes regular eye tests very important so macular disease can be monitored by your eyecare team.

It can sometimes be more difficult to get to grips with low vision aids and a person living with dementia may need more support to get in the habit of using them.

But despite these difficulties, every person with dementia is different, so it's important not to make assumptions about a person and their abilities.

For more information visit <https://dementia-org.libguides.com/eye-health-and-dementia>





Evelyn and her Mother.

Living with AMD and Dementia

Evelyn was the carer of her mother who lived with AMD and dementia. She tells her story.

When my mother was diagnosed with dementia I lived over 450 km away and there were no family members in Sydney. Caring from a distance was incredibly challenging, and escalated when COVID hit.

Even when medical appointments were arranged, mum often forgot to attend and would go shopping instead. My number one priority was working towards each eye injection appointment.

My mother's changed behaviours worsened, including hallucinations and wandering away from her home. In the end, mum was too afraid to be on her own, so I moved her to the Mid North Coast to live with me.

Whilst living with me I could see her vision was not great, so I made signs up on my computer in large print and placed them on the door of her bedroom, bathroom and kitchen cupboards. These seemed to help her navigate her new surroundings with less confusion.

We maintained her injections for the next 10 months, and her eyesight remained stable. However, her changed behaviours became harder to manage, and she entered an aged care facility in 2021.

The main advice I would give to carers would be to have your loved one's eyes tested regularly, particularly on entry to an aged care facility, and ensure you have a spare pair of prescription glasses and sunglasses as backup for when your loved one's glasses go missing. Aged care facilities may not cover the cost of replacement of these items (particularly if a resident is in a dementia ward).

After I stopped taking my mother to the eye specialist, there were no further eye tests or specialist eye visits carried out by the aged care facility over the next two and a half years.

This is a matter of great concern and needs urgent attention by the eyecare profession and government. Our eyesight still matters whether you live at home or in aged care facility.

To monitor her vision, I employed creative methods, such as observing her reaction to TV shows like Mr. Bean. She would smile and point to the show, indicating she could still see reasonably well. On another occasion I had placed a note to staff in large print beside the TV stating, "Please do not turn off the TV as the music is lovely," which surprisingly she would read aloud from two metres away, further affirming she still had some vision at 97 years old.

My mother passed away in November 2024 at the age of 97. Her journey highlighted the importance of patience, adaptability, and advocacy for carers navigating the complexities of dementia and AMD care.

Please get in contact with MDFA if you have a story, like Evelyn's, you would like to share, call 1800 111 709 or email info@mdfoundation.com.au.

"I love the energy and supportive environment in the support group" – meet two of our fantastic MDFA volunteers

Our MDFA volunteers play a critical role in enabling us to extend our support services to people across the country. Two of our volunteers, Liz and Christine, share their reasons for volunteering with us and what they've gotten out of it.

Liz – NSW Peer Support Service Facilitator

I retired from the health care arena in 2022, and I was looking for an opportunity for community involvement. When I was diagnosed with macular degeneration, I found MDFA was a valuable source of information, and their information materials were reliable, well-presented and easy to read. I was happy to be able to give back in some way to the organisation.

I also come from a research background, so I was interested in their innovative research, and I value the opportunity to attend their research forums. I have first-hand experience of macular disease so I could appreciate the issues the members of the support group face and the impact macular disease can have on their quality of life.

I love the energy and supportive environment in the support group. The members provide a vital source of support, ideas, and positivity. I have facilitated peer support groups in the past so I appreciate the important role they can play. I enjoy the connection and support from my co-facilitator and MDFA

are always in the background providing resources and administrative support for the running of the group.

MDFA is in the forefront of research and support for people with macular disease. They provide training for their volunteers and support them in their various roles. MDFA volunteers are treated with respect and consideration.

Christine – VIC Peer Support Service Facilitator

My mother had MD for 20 plus years, and I had spent considerable time researching and accessing information and equipment to help her. I didn't know of any support groups when she first was diagnosed, in fact originally she was misdiagnosed and treated for glaucoma. I am aware it can be hereditary.

I have always done some form of volunteer work. If you have a fortunate life, I believe you should give back. I have also instilled this in my children who regularly participate in marathons and Movember. I would suggest to anyone considering volunteering that they do so for a cause or for something they are interested in.

Peer support – places available

If you are interested in receiving support to navigate the challenges of living with macular disease, while fostering a sense of community and connection, then joining one of our peer support groups might be a good fit for you.

There are many benefits to joining including:

- Feeling less alone and better understood
- Sharing experiences and improving self esteem
- Keeping abreast of current medical research, treatment and support services
- Developing new friendships

We currently facilitate peer support groups in Melbourne, Sydney, Brisbane, Perth, Adelaide, Hobart, and Canberra.

Peer support is a great way of connecting with people and sharing lived experience to provide social and emotional support. We have places available. To join or find out more, please get in touch with us via 1800 111 709 or info@mdfoundation.com.au.

Are you interested in giving back to your community and supporting a meaningful cause like Liz and Christine are? Contact us today to find out more about becoming an MDFA volunteer on 1800 111 709 or email info@mdfoundation.com.au.

Mythbusters: What to expect from a macula check at your optometrist

Getting your macula checked regularly by your local optometrist is essential for maintaining your vision and eye health. MDFA asked Specsavers Optometrist, Mengqi Zhang, to give us insights on what to expect when having an eye examination.

There are several tests your optometrist may perform to check the health of your macula.

- **OCT:** Optical Coherence tomography (OCT) is an advanced imaging tool that provides a detailed view of the macula and is one of the most effective ways to check for any macular disease. To perform the OCT scan, you will be asked to place your chin on a machine and focus on a target; then a scan will be taken and assessed.
- **Visual acuity:** This is a measurement of your eyesight. Your optometrist will ask you to read letters of various sizes on a Snellen chart. People with macular disease may notice they struggle to read small letters in their central vision because letters appear hazy or wavy, or they have missing parts.
- **Fundoscopy:** During a fundoscopy examination, your optometrist will use a magnifying lens with a beam of light from the slit lamp machine to view your macula. This checks for any abnormalities including drusen, bleeding and fluids. Your optometrist may also use dilation eye drops to enlarge your pupils, allowing a better view of the macula. If dilation is necessary, it can take up to six hours for your pupils to return to their normal size, so it is recommended you avoid driving home from your appointment and limit time in the sun as much as possible.



Attending eye tests is a proactive step you can take to safeguard your eye health, ensuring any problems are caught even before you notice any symptoms.

Mengqi Zhang is an optometrist at Specsavers Hollywood in South Australia.



Wondering what to do with your unused vision aid?

If you have a vision aid you no longer need or want to keep, there are several online platforms where you may be able to sell or donate it.

These include:

1. Buy, Swap and Sell Blind & Low Vision Equipment & Aids Australia
Facebook Group: <https://www.facebook.com/groups/282042143044172/>
2. Australia's Disabilities & Senior Care Classifieds, Ability Classifieds: <http://www.abilityclassifieds.com/>
3. Classifieds for Second-Hand Equipment: <https://ebility.com.au/en/categories/free-donations.html>

Additionally, you may wish to explore platforms such as Facebook Marketplace, Gumtree, or eBay.

Sadly, MDFA cannot accept or redistribute low vision aids and technology, as we are unable to guarantee warranty or provide user support once these devices are redistributed.

Healthy choices

White bean and kale pasta

As the cooler months approach, this eye-healthy pasta dish is a budget friendly, fast, and meatless meal.



Ingredients

- Spaghetti or pasta of choice; try buckwheat pasta for a healthier option
- 2 tablespoons extra virgin olive oil
- ½ brown onion diced
- 1 teaspoon dried thyme
- ½ teaspoon sea salt
- ½ teaspoon black pepper
- 1 bunch of kale leaves (stem removed); chopped
- 3 cloves garlic minced
- 1 can of Cannellini beans (white beans) drained and rinsed
- Squeeze of fresh lemon to taste
- Fresh parsley to garnish

Instructions

1. Cook the pasta according to packet directions in salted water until al dente.
2. Meanwhile heat the oil in a large frypan over medium heat. Add the onion and sauté 4 to 5 minutes, until soft and translucent.
3. Add the thyme, salt, and pepper, and sauté for 1 minute until fragrant.
4. Add the chopped kale and garlic. Sauté for 3 to 4 minutes until the kale has wilted slightly and is bright green.
5. Add the Cannellini white beans and stir to combine. Sauté 2 to 3 minutes to heat through.
6. Add the cooked pasta to the frypan with some of the pasta water. Stir to combine.
7. Add a squeeze of fresh lemon juice.
8. Garnish with fresh parsley and cracked black pepper.

Have you heard of Speakaboo?

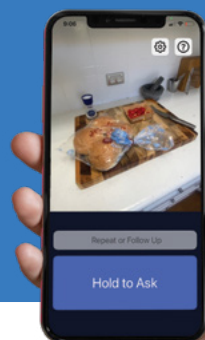
We've come across a great new app that might be handy.

It's called Speakaboo and it has been designed to help people navigate their surroundings by providing real-time audio descriptions via their smartphone or tablet.

Just point the app's camera and tap a button to get an

audio description of spaces around you, like the layout of a room or where the bathroom is. Or it can be used to help identify objects, like when you're cooking, you might ask Speakaboo to help you identify or distinguish between ingredients. Speakaboo is currently only available on iOS devices.

You can download or find out more about the app on the iOS App Store. There is a bit of initial set-up involved, so this app is suitable for people familiar with using a smartphone or tablet.



Our Community



A time for reflection and direction: MDFA's end of year event

2024 was another big year in MDFA's fight for sight. To celebrate the milestones we achieved and share our exciting plans for the future, we closed-out the year with a special event in Sydney attended by the macular disease community. A heartfelt thank you to everyone who joined us.

Our inspiring guest speaker, Dr. Ceecee Britten-Jones from the University of Melbourne, shared her exciting new research which has been funded by MDFA on inherited retinal diseases and how her innovative work is transforming the future of eye health, particularly in improving the diagnosis of age-related macular degeneration (AMD).

Special thanks to our Patron, Ita Buttrose AC OBE, Ambassador The Hon Jillian Skinner AM, and our organisation's Founder Dr. Paul Beaumont for participating in the event with us.

The MDFA team is more motivated than ever to continue reducing the impact of macular disease and supporting those affected. Stay tuned for more exciting developments in 2025.



Celebrating the achievements of MDFA Founder, Dr Paul Beaumont.



Lessons in low vision

MDFA is a big believer in continuous learning and knowledge sharing to advance our support for the macular disease community.

In light of this, our staff were joined by Guide Dogs NSW who provided an interactive workshop, which included hands-on tips and guidance about supporting people living with low vision.

Together, we explored practical strategies to help foster independence and improve daily life for those facing vision challenges, including a practical exercise on how to guide someone with low vision through the environment.

Our organisation is committed to empowering individuals with low vision and providing the all-round support they need. We look forward to continuing our work and sharing our expertise to assist those on their journey toward greater independence.

HELPLINE

Access information and support to complement the care you receive from your eye health professional. Ask us about the latest nutrition recommendations, low vision equipment or what kind of funding you might be eligible for – we are experts in helping you navigate life with macular disease.

Our Helpline is available Monday to Friday 9am to 5pm (NSW, VIC and ACT).



EYE CONNECT

**Holistic service customising
all our offerings to your
diagnosis and your needs.
Delivered regularly in a
format that suits you.**



PEER SUPPORT

Connect with other people living with macular disease in a safe and supportive way. We offer in-person and online groups across the country and we are growing all the time. If accessing our group sessions is not possible, we have a one-on-one telephone service available.



RESOURCES

Our extensive library of resources is approved by Australia's leading retinal specialists. You can view and order these via our website or call to get advice on which ones are right for you. You will find everything you need from information about your specific condition, to eye-friendly menus, and guides that will help you live well with macular disease.

Contact Us:  1800 111 709  info@mdfoundation.com.au  @maculardisease

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