Macular Disease Foundation Australia

Saving sight saves money

Addressing treatment access and affordability in macular disease

About Macular Disease Foundation Australia

Macular Disease Foundation Australia is the national peak body representing people living with macular disease.

Our purpose is to reduce the impact of macular disease by:

1. **Supporting people living with macular disease,** their family, and carers, by providing information, education resources, psychosocial support, and practical guidance with navigating the health, aged care, and disability systems.
2. **Being the advocacy voice of the community** to inform government policy makers on the health, economic and social impacts of macular disease to improve access to affordable treatment and low-vision aids.
3. **Investing in macular disease research** that grows the evidence base, and leads to better management, treatments, and cures for macular disease.
4. **Conducting awareness campaigns** to promote early detection of macular disease.

Pillars of work

Advocacy Voice of the Community

Improve national access to affordable eye care services, including treatment and low vision aids nationally.

Healthcare Engagement

Increase engagement with health professionals and health organisations to detect and refer people with macular disease.

Support and Care for People with Macular Disease

Improve the health literacy and quality of life for people living with macular conditions.

Community awareness and early detection

Increase awareness of risk factors of macular disease and the importance of regular eye checks.

Research

Grow the evidence base on effective interventions that lead to improved outcomes for people with macular disease.

"I feel absolutely blessed to live in Australia where we have eye injection treatment. The ophthalmologist often says that it is fortunate to be diagnosed in this decade because the treatment was not available a long time ago. It is just a recent phenomenon, really."

Macular disease community member

About macular disease

Macular disease is the collective term used for eye diseases and conditions affecting the macula, which is the part of the retina at the back of the eye responsible for central vision.

In 2024, it is estimated there are over 1.9 million Australians with some evidence of macular disease, **the leading cause of blindness and severe vision loss in Australia.**[1,2]

Age-related macular degeneration

Age-related Macular Degeneration (AMD) is the leading cause of blindness and irreversible vision loss in older Australians.[3,4]

AMD progresses through early, intermediate, and late stages. The late stage of the disease has the greatest impact on vision and is labelled as neovascular (wet) AMD or geographic atrophy (dry AMD).

There are an estimated 1.5 million Australians living AMD, including 160,000 living with late stage neovascular AMD.[2]

Diabetes-related eye disease

It is estimated that 1.3 million Australians have diabetes, of whom approximately 300,000–400,000 experience diabetic retinopathy, a condition that also affects the retina.[5,8,9]

One in three adults with diabetes aged 40 years and older has diabetic retinopathy, the leading cause of preventable blindness among working-age Australians [5,6] with the number of people affected rising rapidly due to the significant increase in the prevalence of diabetes.[5,7,8]

Diabetic macular oedema is a complication of diabetic retinopathy that can cause the loss of central vision and lead to legal blindness. It is estimated that there are 87,000 Australians living with diabetic macular oedema.[9]

> **"[We need] better government funding for treatments. On a pension I could never afford those injections recommended for macular disease, eat properly and pay my bills."**
>
> **Macular disease community member**

Sight-saving treatments for macular disease

Without treatment, people with neovascular AMD, as well as other treatable macular diseases, will progressively develop severe vision loss and blindness.[10]

Better visual outcomes are linked to prompt referral to an ophthalmologist, timely access to treatment, and persistence with treatment.*

Anti-VEGF (vascular endothelial growth factor) eye injections

The current treatments available for neovascular AMD involve injecting anti-vascular endothelial growth factor .(VEGF) medicines directly into the eye to stop the growth of abnormal blood vessels and fluid leakage into and under the retina.

Anti-VEGF injections have been a game changer since being first being introduced in Australia and listed on the Pharmaceutical Benefits Scheme (PBS) in 2007, saving the sight of tens of thousands of people with macular disease.

Treatment aims to stabilise and maintain vision and reduce the likelihood of further vision loss. However, anti-VEGF eye injections are not a cure. Without this treatment, 76% of people with neovascular AMD will progress to a state of blindness in at least one eye after three years.[10]

Anti-VEGF eye injections are also sight-saving for people with a range of other macular conditions including myopic macular degeneration, retinal vein occlusion, and diabetic macular oedema.

However, unlike neovascular AMD, for people living with diabetic macular oedema and retinal vein occlusion, treatment may safely be stopped in many patients once expected vision outcomes have been achieved.

Barriers to persisting with anti-VEGF eye injections

People with neovascular AMD typically have eye injections every 4 to 12 weeks for an indefinite period – in some cases for the rest of their lives – to maintain their vision.

Consequently, persisting with treatment can be challenging. Reasons for not persisting with treatment include:[11,12,13]

- Treatment burden due to frequent injections and visits to an ophthalmologist, feeling fearful about having an injection in the eye, and pain or discomfort from treatment.
- Perceptions that treatment will not be beneficial.
- Significant ongoing out-of-pocket treatment-related costs.
- Difficulty in attending treatment due to travelling long distances to appointments, needing assistance getting to and from appointments, particularly for people living in regional and remote areas.
- Other medical conditions that impact on managing their macular condition.

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*There are currently no approved treatments for early or intermediate age-related macular disease, nor for geographic atrophy.

What have people living with macular disease told us?

Living with macular disease, and the associated vision loss, can have major impacts on quality of life and adversely affect functional independence. Not to mention the financial burden associated with treatment and care. This can lead to social isolation, decreased independence, anxiety, and depression. It can also impact families and carers.

In 2023, Macular Disease Foundation's second Social Impact Survey of almost 2,000 people living with macular disease, assessed several key health behaviours including attitudes to eye injections and barriers to persisting with these treatments.

Treatment persistence

The survey, carried out in partnership with experts from the University of New South Wales School of Optometry and Vision Science, found that the majority (84%) of all respondents with neovascular AMD reported that they were having eye injections. However, 3% of respondents said they were not having eye injections even though it was recommended for them, and 2% were not having anti-VEGF injections as often as recommended.

Perceived effectiveness of treatment

Whilst 75% of people having anti-VEGF eye injections said they believed anti-VEGF injections are beneficial, 25% said they were unsure or felt the injections were not beneficial, potentially influencing people's decisions not to persist with treatment.

Affordability of treatment

More than 10% of respondents who were having eye injections said that they had issues with affordability. Financial hardship associated with accessing anti-VEGF injections was consistently nominated as an important area of advocacy for Macular Disease Foundation by people with macular disease, particularly by those living in regional and remote areas.

Other eye and health conditions make it even harder to persist

Most people with late-stage disease are in their 70s or older, and often have other co-existing eye and health conditions which require regular monitoring and/or treatment.

Macular Disease Foundation's second Social Impact Survey also found that 34% of respondents had another eye condition that impacts their vision, and 16% reported that they had another health condition (including diabetes, cardiovascular disease, or cancer), which makes it harder to manage their macular disease.

> **"Continue to fight for lower injection costs. Some people can't afford them and in the public system, wait time is more than a year. At the end of the day, when people lose their vision, the government will be required to support them."**
>
> **Macular disease community member**

What needs to change?

Whilst eye injection treatments for neovascular AMD are available, accessing and being able to afford these sight-saving treatments present significant challenges for many Australians living with neovascular AMD and other macular diseases.

Currently only 40% of the estimated 156,000 people living with neovascular AMD in Australia are having anti-VEGF treatment.[14] In January 2023, eye injection treatments were administered nationally to more than 62,000 people living with neovascular AMD and 18,000 people with diabetic macular oedema.[15] Macular Disease Foundation estimates that a further 10,000 people received eye injections for retinal vein occlusion.[16]

The costs of treatment are significant, with out of pocket costs estimated at approximately $1,900 per year based on an average of seven treatments a year, which includes the additional rebates from reaching the Extended Medicare Safety Net Threshold.[16] Many people require treatment to both eyes, further increasing out-of-pocket costs.

Unfortunately, 20% of people with neovascular AMD will stop treatment in their first year, and 50% of people will stop their eye injections within 5 years,[17] putting them at risk of severe vision loss or blindness. **This low persistence with treatment is highly concerning.**

Some of the factors that have contributed to these low numbers of people having eye injections are discussed below.

Access to treatment in Australia is a post-code lottery

Improving access to bulk billed treatment

In Australia, anti-VEGF eye injection treatment is primarily delivered in private ophthalmology clinics with only a minority of treatments being bulk billed, and around 10% of injections performed in public hospitals.

With only a few metropolitan and larger regional public hospitals providing eye injection treatment across the country, the majority of people who require eye injections have no choice but to receive their treatments in the clinics of private ophthalmologists, and often pay out-of-pocket costs for each eye injection visit. The eye injection procedure itself is subsidised through Medicare. The eye injection procedure itself is subsidised through Medicare.

People with neovascular AMD are faced with regular and frequent visits to their ophthalmologist on average, seven visits per year for each eye that requires treatment.[16] However, there is a nationwide lack of ophthalmology services and consequently, limited access to sight-saving treatments in publicly funded healthcare settings across Australia.

Private ophthalmologists set their own fees, with currently only an estimated 18% to 23% of private ophthalmology clinics offering bulk billing.[16] Ophthalmologists need an incentive to encourage them to offer/increase bulk billing for their patients.

Lack of ophthalmologists – particularly in remote areas

There are significant challenges in accessing treatment for people with neovascular AMD who live in rural and remote communities.

Most ophthalmologists are based in major cities (~84%), while the remaining 16% service the 28% of Australians (7 million people) who live in rural and remote communities.[18]

People with macular disease living in rural and remote areas face real struggles in committing to ongoing eye injection treatment and care. Ongoing monthly injections, required in some cases, are particularly challenging for people living in regional, rural and remote areas.

It is therefore vital that access barriers be removed so that more people are enabled to access care and persist with treatment to prevent them going blind.

Inequity of access to anti-VEGF treatment in the public health system

Access to anti-VEGF treatment can be described as a “post code lottery”, with access to treatment being even more problematic in New South Wales (NSW) and the Australian Capital Territory (ACT).

This is because there is currently no access to PBS-subsidised medicines or treatments in public hospital clinics in NSW or the ACT, which have not signed the Australian Government’s Pharmaceutical Reform Agreement. This includes sight-saving anti-VEGF eye injections.

Only a few private ophthalmology clinics offer routine bulk billing to eye injection patients.

> Macular Disease Foundation Australia believes that the key principle of universal healthcare must be upheld. Ensuring the equity of eye injection treatment in the public health system for everyone with neovascular AMD and other treatable macular conditions must be a greater priority.

Increasing treatment persistence will save billions of dollars

Macular Disease Foundation’s research *Investing to Save Sight: Health and Economic Benefits of Improving Macular Disease Treatment Persistence* found that, investing in increasing treatment persistence in just 25% of current treatment recipients could lead to an additional 22,000 people continuing to receive treatment who would otherwise stop therapy.

> Increasing treatment persistence by just 25% would save the Australian Government more than $2 billion, and people living with macular disease more than $1 billion over the next decade.[14]

Increasing access to treatment – and the resulting potential for increased persistence – would mean additional Medicare Benefits Schedule (MBS) and PBS costs in the short term. However, these costs will be vastly outweighed by the net cost benefits to patients, carers, and government associated with helping prevent people from losing their sight.

Deteriorating vision significantly impacts a person's quality of life, including loss of the ability to drive, difficulty maintaining employment, and challenges in living independently. This in turn significantly increases the need for costly health, aged care, and disability support services.[19,20,21]

If left untreated, neovascular AMD and other treatable forms of macular disease will lead to irreversible vision loss or blindness, and cost the government millions of dollars in disability, healthcare, and other related costs. This **CAN** be avoided.

Macular Disease Foundation believes no-one should lose their sight because of where they live or because they cannot afford treatment.

Improved affordability of treatment

Even with the MBS and PBS safety nets, eye injection treatment can be a financial challenge, consuming a considerable proportion of income for the most vulnerable, such as those receiving the age pension.

Unlike some macular diseases where treatment may be safely suspended once the expected outcomes are achieved, people with neovascular AMD need to receive eye injection treatment every 4 to 12 weeks for an indefinite period to maintain vision.

Most people with late-stage disease are in their 70s or beyond and most will be pensioners or self-funded retirees, on limited, fixed incomes.[22] Economic modelling shows that eliminating the out-of-pocket costs for an additional 10% of affected people on low incomes could enable an additional 5,000 people to continue receiving treatment who would otherwise have stopped.[14]

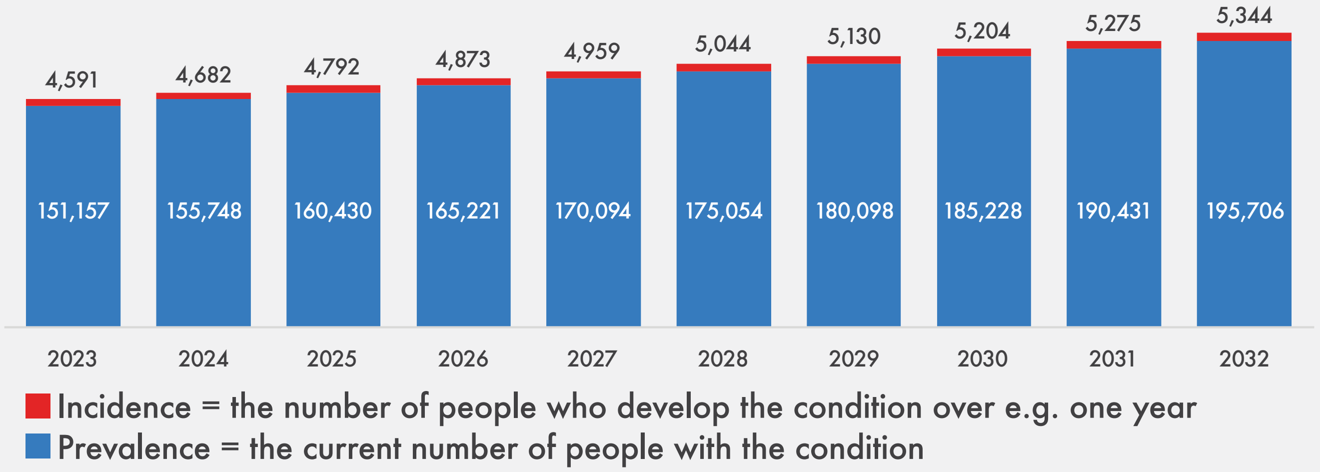
> **"Surely, providing a low cost, preventative service in an accessible location saves public monies in the long term and vastly improves the quality of life of AMD sufferers and their families?"**
>
> **Macular disease community member**

What does the future hold?

The number of people living with AMD is climbing along with the growing ageing population in Australia.[14]

The number of new cases of neovascular AMD in Australia is forecast to increase by approximately 5,000 every year, totalling 50,000 new neovascular AMD patients over the next decade (2023-2032).[14] (See Figure 1).

Figure 1[14]: Estimated prevalence and incidence of neovascular AMD in Australia, 2023-2032



Investing to Save Sight: Health and Economic Benefits of Improving Macular Disease Treatment Persistence.

Furthermore, it is estimated that despite effective treatments, about two in three people who start treatment in the next decade, will stop treatment and develop severe vision loss or blindness.[14] This means that of the estimated 446,000 people with neovascular AMD who start treatment over the next decade, 267,000 will discontinue their eye injections.

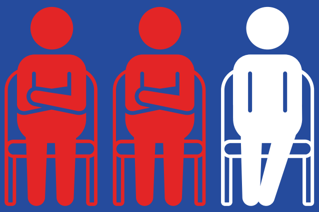
Tragically, more than 160,000 – more than half of those who stop their treatment – will progress to severe vision loss or blindness in a little less than a decade.[14] This will add to the already huge cost burden to individuals and government of treating people with neovascular AMD.

The reality is that, without action, the lives of many thousands of Australians will be devastated over the next decade, due to the increasing rates of avoidable vision loss and blindness from neovascular AMD.

This CAN and MUST be avoided.

2 in 3 people

Almost two in three people who start treatment between 2023-2032 will stop treatment and develop vision loss or blindness.



> **"As a self-funded retiree I am not eligible for financial support to see an ophthalmologist. It would be good to have access to full Medicare cover to allow the recommended follow up. The optometrist has referred me back following episodes of central serous retinopathy but I have not attended due to the cost."**
>
> **Survey respondent**

What can be done?

The total annual economic cost of vision loss in Australia is estimated to be $16.6 billion or $29,000 per person aged over 40 with vision loss.[3]

The total annual economic cost of vision loss associated with AMD has been estimated at $5.15 billion, of which the direct cost was $748.4 million ($6,982 per person).[2] These costs are likely to be an under-estimate, given they are from 2010 and have not been adjusted for inflation.

People with low vision incur significantly higher heath care costs than fully sighted people. These costs are associated with the increased morbidity and mortality from vision loss and include a higher risk of depression, falls and hip fractures, and increased admission to nursing homes or health services.[23] In addition, the loss of wellbeing is the greatest single contributor to the overall cost of vision loss.

This, combined with Australia's ageing population means that without additional investment by government, the significant number of people who become permanently vision impaired and blind will severely impact our health and aged care systems, as well as individuals and their carers in future.

Government investment now will save the sight of thousands of people

Even modest additional investments by the Australian, State and Territory governments that improve affordability and access, to support persistence with treatment for people receiving injections for macular disease, would not only save the sight of tens of thousands of Australians enabling them to lead independent lives, but also save the government billions of dollars in the long term.[14]

Ophthalmologist Treatment Incentive Program

To help alleviate the cost of treatment for the most financially vulnerable people with neovascular AMD, Macular Disease Foundation is recommending the Australian Government establish a targeted financial incentive program, modelled on the Australian Government's Practice Incentives Program for general practitioners.[24]

The purpose of the proposed *Neovascular AMD Treatment Incentive Program* is to increase the number of vulnerable Australians who can access bulk billed eye injection treatment. If this program is implemented, an estimated 15,000 people would be eligible.

The intention is to encourage ophthalmologists to provide – and openly promote – bulk billed neovascular AMD eye injection treatment for Pensioner Concession Card holders, thereby improving the overall access to – and affordability of – treatment.

This incentive could also encourage ophthalmologists to set up new bulk billing eye injection clinics and make it financially more viable for them to do so, which would help with patient demand, particularly in low socioeconomic areas.

The expenditure required from the Australian Government would be limited and controlled at an estimated total of $10.4 million per year, given this program only targets a specific group of people who have the highest financial need.

Economic modelling has shown that providing bulk billed eye injections to just 1 in 10 more people currently receiving treatment, could save 5,000 people from losing their sight. This could save the government nearly $450 million dollars over the next decade (2023-2032) simply by investing in making it easier for people who need eye injections to persist with their treatment.[14]

More investment for research into sight-saving treatments is needed

Researchers across Australia are striving to find new ways to detect, treat and cure macular diseases.

Greater investment in macular disease research that grows the evidence base, and leads to better management of macular diseases, more effective treatments, and cures for macular disease is a necessity.

> Investing in research provides us with hope for a future where no-one goes blind from macular disease.

> **I go to a bulk bill with transport driving me some of the way. I leave home at 5.30am to make the 10.30am appointment.”**
>
> **Macular disease community member**

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Disclaimer

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> **"I would like to see the cost of intravitreal injections reduced to a reasonable level. The rebate from Medicare depends on when/if I reach my threshold, on average my visit to my ophthalmologist for injection costs me $450 after Medicare rebate. (I have injection in one eye only)."**
>
> **Macular disease community member**

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Macular Disease Foundation Australia

Mezzanine, 383 Kent Street
Sydney, NSW, 2000

T 1800 111 709
E info@mdfoundation.com.au
W www.mdfoundation.com.au
W www.CheckMyMacula.com.au
ABN 5209 6255 177

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