Macular Disease Foundation AUSTRALIA

Vision Voice

Spring Edition 2024

Eye Connect community support service now available

Macular Disease Foundation Australia (MDFA) knows that people with macular disease and their carers want more practical and emotional support throughout their treatment and disease journey, beyond what they might receive in their visits with health professionals.

Our new Eye Connect support service has been developed with this in mind, and in collaboration with representatives of the macular disease community.

Support and advice in between appointments

Eye Connect is Australia's first comprehensive free support service for people living with macular disease. People who join Eye Connect will receive tailored health information, including practical and emotional support to help them live well with macular disease.

The service is informed by insights from a neovascular age-related macular degeneration (AMD) pilot program and extensive research involving people with macular disease, their carers, ophthalmologists and optometrists.

Our latest feedback from people who have opted into Eye Connect revealed:

- **85%** found the Eye Connect resources to be helpful
- **74%** said that joining Eye Connect has been positive for their general wellbeing
- **97%** would recommend Eye Connect to others.

> **"It has been a helpful service that strengthened my understanding of the disease during a stressful time of change. The information shared was useful, helpful and informative."**
>
> **– Eye Connect participant.**

CEO Update

I always enjoy sharing good news with our community, particularly when I know people are struggling with the increasing cost of living.

One of the highlights from this year's Federal Budget report was the news that the Pharmaceutical Benefits Scheme (PBS) co-payment for prescription medicines, including anti-VEGF eye injection medicine, will not increase in the next 12 months, and for pensioners, this will not increase for five years.

Macular Disease Foundation also received news that we will continue to receive Government funding to support our education and support programs for the community as part of the Chronic Disease portfolio. As the health budget continues to recover from the global pandemic, any additional funding support we receive to sustain our programs and services is welcomed and thankfully received.

While Government financial support is restricted, we continue to rely on the generosity of our community to provide services like the Eye Connect support program, raising advocacy issues with government on your behalf, and funding leading research.

For those who were able to contribute to our Tax Appeal, thank you so very much for your generosity and trust.

As you read this edition of Vision Voice, I hope you gain a better insight about how and where your contributions are having impact.

Thank you,

Dr Kathy Chapman
Chief Executive Officer

Eye Connect community support service now available Cont.

Eye Connect focuses on three areas of support

- **Health information.** We'll provide you with evidence-based information about macular disease, and support services to help you confidently manage your condition.
- **Practical advice.** Tips and guidance on things like nutrition for healthy eyes, immediate care after your appointment, daily living with reduced or low vision, and even transport advice.
- **Emotional support.** For some, a diagnosis of macular disease – or living with an eye condition – can be a difficult time. Our Eye Connect team can help you manage some of the worries and concerns you may have about your diagnosis and treatment. We can also connect you to peer support, where you can speak with other people with macular disease.

While Eye Connect is currently only available to people living with AMD, the service will be expanded to support other macular conditions in the future.

Joining Eye Connect is easy

Just scan the QR code, head to www.mdfoundation.com.au/eyeconnect or call Macular Disease Foundation Australia on 1800 111 709.

Putting macular disease at the centre of the national news agenda

Patron, Ita Buttrose AC OBE, made an impassioned plea in an opinion editorial piece syndicated across the News Corp Australia Network as part of Macula Month in May.

What kind of country lets its older citizens go blind?

It is estimated that 1.9 million Australians live with some form of macular disease, the leading cause of blindness and vision loss. I've been Patron of Macular Disease Foundation for 18 years and while we have made great inroads in raising awareness and early detection, as well as being a catalyst for ground-breaking research, older Australians, specifically vulnerable age pensioners who require sight-saving eye injection treatment, are going blind because they simply cannot afford treatment.

Australia has an enviable health care system. When anti-VEGF eye injection treatment became available to people diagnosed with neovascular age-related macular degeneration, or wet AMD, in 2007, the implementation of this sight-saving treatment was a major breakthrough.

Thousands of Australians retain their vision today, including my 100-year-old uncle Gerald, because of it, but people living on age pensions, are falling through the gaps because of significant and ongoing out-of-pocket treatment costs.

Access to sight-saving treatment is a postcode lottery. Eye injections are primarily delivered in private ophthalmology clinics in Australia, and only a minority of treatments are bulk billed, with around 10% of injections performed in public outpatient clinics.

Only a few metropolitan and larger regional public hospitals provide bulk-billed eye injection treatment which means that many people who require eye injections have no choice but to receive their treatments in the clinics of private ophthalmologists. They often have to pay out-of-pocket costs for each eye injection visit.

A person living on an age pension receives approximately $29,000 annually. If they require eye injections, their out-of-pocket expenses will be around $1900 each year for one eye and double this amount if they have wet AMD in both eyes.

That's up to 13% of their total income dedicated to keeping their vision, independence, health and mental wellbeing. Coupled with the current cost-of-living expenses, it is becoming more difficult for older Australians to maintain treatment when they must choose between food on the table or treatment to save their sight.

There is a solution that Government and the eyecare health system can work towards. Australia's older citizens need to receive greater access to sight-saving injections in public hospital clinics, as well as bulk billing options for age-care pensioners in private clinics. Bulk billing needs to be at the heart of our medical system and extend beyond general practice.

We need to extend access to affordable treatment, so that older Australians don't go blind. The current situation is unacceptable.

– Ita Buttrose, AC OBE

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Macular Disease Foundation Australia welcomes Federal Government cost increase freeze on PBS medicines

Affording sight-saving treatments and support is a challenge faced by many people in the macular disease community.

A 2020 survey undertaken by MDFA on the barriers to accessing eye injection treatments for neovascular AMD – the findings of which were included in our Federal Pre-Budget Submission 2024-25 – revealed that 29% of people were forced to cut back on expenses such as food and groceries to be able to afford treatment costs. It also showed that 69% of people have some difficulty paying their ophthalmologist fees.

This kind of evidence is a large reason why MDFA is committed to leading advocacy campaigns to spotlight the actions the Federal Government should take to make medicines cheaper. With the release of the Federal Budget 2024-25, MDFA was pleased to see some positive steps in the right direction on this issue.

One of the most significant outcomes was a one-year freeze on increases to the maximum PBS co-payment, meaning the maximum cost of PBS listed medicines for most people will remain at $31.60 until 1 January 2026. This will help the affordability of medicines, including PBS listed intravitreal injection treatments.

A longer indexation freeze has been put in place for pensioners and Commonwealth concession cardholders, meaning there will be no increase to the maximum concession co-payment for prescription medicines for 5 years.

The maximum cost of PBS listed medicines for pensioners and concession cardholders will remain at $7.70 until 1 January 2030.

The Australian Government also announced some changes to MBS items for ophthalmology. The most pleasing announcement was that the Government again confirmed that the MBS rebate for intravitreal injections would not be reduced.

Long-term readers of Vision Voice will recall that a few years ago there was a threat the MBS rebate would be cut, leading to higher out-of-pocket costs for people receiving sight-saving eye injections.

And while most of the healthcare-related Budget announcements were positive, we are aware of proposed changes from 1 July 2025, which may impact people receiving intravitreal eye injections in private hospitals who use their private health insurance to cover the cost of their eye injections.

While this year's Budget has positive cost-saving outcomes, more needs to be done to ensure sight-saving treatments are accessible and affordable to people living with macular conditions. MDFA will continue to make recommendations to the Federal Government on this issue.

Please call our Helpline on 1800 111 709 if you need more information.

Meet our newest Ambassador: The Hon. Jillian Skinner AM

NSW government's former Minister for Health and Minister for Medical Research, the Hon. Jillian Skinner AM, talks about living with AMD and her perspectives on how governments can better support the macular disease community.

When were you diagnosed with AMD and what impact has it had on your life?

I was diagnosed about 12 years ago and it was first of all diagnosed as dry AMD. It was picked up initially when I was at the optometrist getting my glasses upgraded. I was referred to Dr. Paul Beaumont (medical retinal specialist and founding director of Macular Disease Foundation Australia) and he confirmed it was dry AMD. Since then, it has progressed to wet AMD. AMD has changed my daily life in terms of what I eat. When I was first diagnosed, I got the full story from Paul about the importance of diet. I said 'this is going to be easy' but then ended up chucking out half my pantry because when I read the actual labels, I found things contained ingredients that weren't suitable.

You led an impressive 23-year political career. If you were still minister, what steps would you take to improve Australians' eye health?

I'm very mindful of the cost of treatment, particularly for older people – they have to pay for all these eye injections. I would certainly be pushing through the Ministerial Councils the proposition that the Macular Disease Foundation has put to the Commonwealth to extend the provision of treatment for older people and to ensure there are financial incentives to doctors who bulk bill for eye injection treatment.

More than 1.5 million Australians have AMD. It's anticipated that by 2030 it will be 1.7 million. How does the country prepare?

I think by educating people more broadly. I tell everyone that I have macular degeneration. People ask me 'what do you do about it'? and 'how do you detect It'? So much broader education is needed. And maybe, also, through GPs, by letting them know that it is something to worry about.

Would you agree that bulk billing needs to be at the heart of our medical system and extend beyond general practice, so more people can afford and access these treatments?

Yes, 100 percent. It should not be difficult to do. I know that some of the recommendations from the Foundation's economic assessment of the value in terms of money saved for people and government is compelling. At the moment, though, education and health are all feeling the pinch. State and federal governments are really being squeezed, but that doesn't mean you don't keep working towards getting these things done. Maintaining people's sight is so important – and it saves governments money in the long run.

Share your story to help improve policy

As the advocacy voice of the macular disease community, we regularly need up-to-date stories about the life experiences of people with macular disease. This helps us communicate your needs and priorities to politicians and policy makers.

In preparation for the upcoming Federal, State and Territory elections, we would like to hear from you if you are currently finding it challenging to afford eye injection treatment for wet AMD, diabetic macular oedema, and other macular conditions.

If you're interested in sharing your story, please email us at advocacy@mdfoundation.com.au, and include your first name, suburb and state, your treatment experience, how important continuing treatment is for you, how much your out-of-pocket treatment fees cost, and whether you had to make any difficult sacrifices in order to continue paying for treatment.

We would also like to know if you previously received eye injection treatment, but stopped because you could no longer afford it.

We hope to hear from you.

Our new AMD Nutrition Guidelines

We recently launched our new Nutrition Guidelines for age-related macular degeneration (AMD).

As there are no treatments for early and intermediate AMD, or for people with a high risk of developing it, nutrition is a key approach to help delay the onset of the condition and slow its progress.

We consistently find that nutrition is something that helps give people a sense of control over their eye health, but until now, there has been no official evidence-based nutritional advice for them in Australia.

The genesis of the guidelines

In partnership with AMD nutrition expert Professor Vicki Flood and students undertaking their Masters in Nutrition and Dietetics at the University of Sydney, MDFA began the sizable task of investigating the evidence on nutrition and AMD. Using a research technique called a systematic review, the team searched published research databases and identified and appraised the available evidence on how foods and nutrients may help to protect against AMD.

The strength of evidence for alcohol consumption, dietary patterns, food, and nutrition supplements, and their effect on AMD, were investigated. The findings from this systematic review were then used to inform our new Nutrition Guidelines.

Key findings that informed our new nutrition recommendations

Our new guidelines recommend that people focus on their overall eating pattern to help their eye health, rather than on single nutrients and foods.

While people often think that consuming individual nutrients or so-called "super foods" will improve their diet, the reality is that nutrition concerns your long-term, overall diet. It is important to remember that your overall style of eating has more impact on your overall health than single foods.

MDFA also found that Mediterranean and Asian-style diets – defined as a high intake of vegetables, fish and plant-based proteins in traditional eating patterns in Japan and south-east Asia – are the best eating patterns

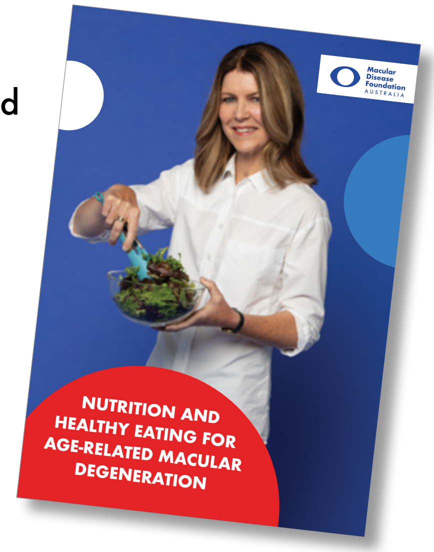
to help lower the risk of early AMD and delay progression to late AMD.

Both eating patterns include a high intake of fish, foods rich in omega-3 fatty acids, and antioxidants, compounds naturally found in fruit and vegetables, which have the strongest protective associations.

Mediterranean and Asian-style diets also have anti-inflammatory benefits. Research has shown that inflammation plays a role in AMD development as eye tissues are vulnerable to oxidative stress. Mediterranean diets have been linked to lower levels of oxidative stress, possibly due to the antioxidant and anti-inflammatory properties found in fruit, vegetables, and fish.

Another new finding was that consuming more than 12g of alcohol a day (a little more than one standard drink) has a detrimental effect on AMD leading to the advice, rethink that second drink.

MDFA's Nutrition Guidelines for AMD are available here: www.mdfoundation.com.au/resources/new-nutrition-guidelines-for-amd



Macular Disease Foundation AUSTRALIA

NUTRITION AND HEALTHY EATING FOR AGE-RELATED MACULAR DEGENERATION

We want to hear from you

Macular Disease Foundation Australia's social impact surveys offer a glimpse into what it's like to live with macular disease in Australia.

Our newest survey is now open. If you have macular disease, we invite you to share your experiences with us so we can learn more about the impact of living with the disease.

The survey mainly focuses on:

- The impact of macular disease on your ability to drive
- Out-of-pocket costs relating to your macular disease
- Your use of low vision aids, assistive technology, and care and support services
- Financial and work concerns.

This is an opportunity for you to share with us how macular disease affects you, and how we can offer support.

You may have received an email or the survey in the mail. If you'd like to participate or need more information, please contact our survey research partners ORIMA on 1800 654 585.

Healthy choices

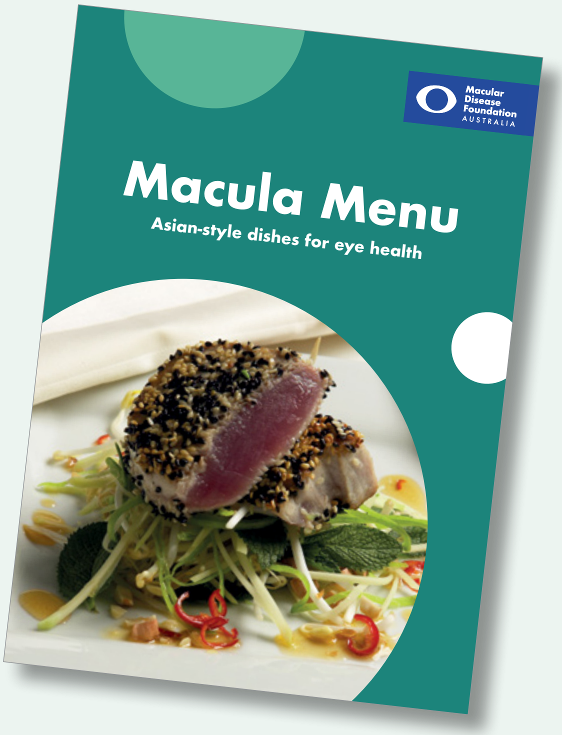
Mouth-watering and wholesome: new Macula Menus free to download

As part of our Macula Month celebration, we launched a new series of Macula Menus which reflect our latest nutrition guidelines.

Our research shows that a Mediterranean diet and an Asian-style eating pattern (defined as a high intake of vegetables, fish and plant-based proteins, in the diet pattern traditional in Japan and south-east Asia) likely reduces the risk of developing late AMD and might reduce the risk of developing early AMD.

Celebrity chef, Luke Mangan, shares his eye healthy recipe with us.

You can download a copy of our latest Macula Menu series www.mdfoundation.com.au/resources/macula-menu-2024/



Pan seared salmon with Asian salad and tamarind dressing

Serves 6

Ingredients

- 6 x 160g salmon fillet, skin on

(if unavailable substitute with a firm white fleshed fish such as snapper)

Asian salad

- ½ cup green papaya, peeled and flesh very finely shredded or cut on a mandolin
- 1 green mango, peeled and flesh very finely shredded or cut on a mandolin
- 1 mango, flesh finely sliced
- ½ cup snow pea shoots, base cut off
- 8 snow peas, finely shredded on an angle
- ½ cup picked Vietnamese mint leaves
- ½ cup picked Thai basil leaves
- ½ cup picked coriander leaves
- 1 mild red chilli, very finely sliced on a slight angle
- ¼ cup peanuts, lightly toasted, oiled and salted and broken up

Combine the above.

Recipe by Luke Mangan

Tamarind dressing

- 90ml tamarind puree
- 2 tablespoons palm sugar, finely chopped or crushed
- 2 tablespoons water
- 2 tablespoons extra Virgin olive oil
- 2 teaspoons fish sauce

Gently warm the palm sugar with the water in a pan until it has fully combined. Whisk the sugar syrup through the tamarind puree. Now slowly add the olive oil into the tamarind puree, whisking through and mix through the fish sauce.

Instructions

Pre warm an oven to 220°C.

Place the seasoned salmon fillet, skin side down, into a non stick pan over a medium heat that had been pre warmed with some olive oil. Fry for approximately 4 minutes until you begin to see the fish's skin lightly browning around the side. Place the pan in the oven for approximately 6-8 minutes depending on the thickness of the fish. Now remove the pan from the oven and gently turn the fish over, to finish cooking.

Place the fish fillet in the centre of a plate, place a large handful of the salad on the fish and spoon the tamarind dressing around and over the salad and fish.

Technology & You

Be My Eyes

The Be My Eyes app connects blind and low-vision users needing sighted assistance with support volunteers and companies. Through live video and artificial intelligence, the app provides real-time support to make navigating everyday life easier for people living with low vision.

How it works

If you're needing help with a task – it might be reading a letter or the label on a grocery item, or finding a product on a supermarket shelf – you can use the Be My Eyes app to call a sighted volunteer for assistance.

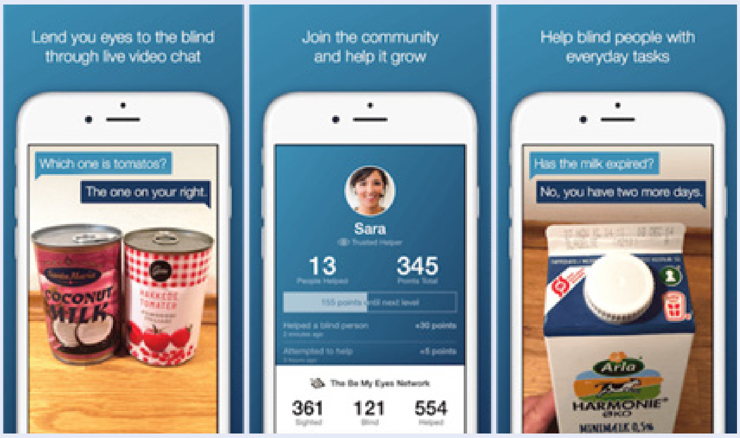
The app will activate your smartphone's camera lens when you call so the volunteer can see and describe an item to you or help you find it.

The Be My Eyes website states:

> **"With over 600,000 blind and low vision users and more than 7 million volunteers, the app is available for free across 170 countries and 180 languages, meaning connection between users and volunteers is in real-time and in their language of choice."**

www.bemyeyes.com/mobile-app

The app is currently available for Android and IOS devices.



Which one is tomatos?

The one on your right.

Has the milk expired?

No, you have two more days.

www.vonage.com.au/resources/customers/be-my-eyes/

Our Community

Cooking up a new stage of life: Shane Somerville tells his story

Sharing stories about people who are going through similar health experiences can help others manage their own condition.

So, when we listened to a very personal and uplifting interview with Shane Somerville from the InSight Systems podcast, we knew we wanted to share it.

Shane started his career as a cook before moving into the audio visual and events industry. Thirteen years ago, however, the now 60-year-old was diagnosed with macular dystrophy, a genetic condition that has led to five percent vision in each eye.

A new way of working

Shane's vision deteriorated quickly, resulting in him having to make changes to how he approached work sooner than he'd anticipated.

"I think that everyone's circumstances are different and unique, but what worked for me was to try and remain positive," Shane reflects during the podcast. "The best advice I could give is, try to utilise the resources that are available and don't shy away from it. I hid from it for too long."

He was well supported by his colleagues and received external specialist support and employment assistance funding from Job Access to help him continue to work, which he highly recommends people in similar situations research.

"The first thing is you as the individual need to embrace your disability. Don't be embarrassed by it because you offer so much.

"Have a think about where your positive attributes are and where you can add value. You can offer a lot with your experience and being able to offer advice in a consultative manner."

"Don't get me wrong, it's frustrating. The last two years of work for me, it physically took me, towards the end, ten times as long to do the tasks I needed to do."

Life after work

Eventually, Shane reached a point where he knew he couldn't continue to work. When speaking about managing the disappointment of needing to finish his career before he'd ever expected to, he says he made the decision not to feel sorry for himself.

"I'm a glass half full guy – I always look on the positive side of things. So I said, "Ok, I've got this condition, there's nothing I can do about it, so how can I live with that? What do I need to do to make myself valuable, and to make my life fulfilled as well?"

And by the sounds of things, Shane has found the answers.

"With my cooking background, I'm going to write a cookbook called blind chef, and make recipes tactile rather than one cup of this, one cup of that – it'll be a handful of that, a pinch of that."

Playing blind golf has also become an important part of Shane's life.

"I'm using my passion rather than my disability to do stuff, and that's I think what you need to do," says Shane. "Just because there's an impediment, that's not the end. There's always ways to navigate around, and other opportunities open up as a result."

Thanks to Daniel Baldwin from InSight Systems for providing the interview with Shane. The full interview is available at www.youtube.com/@insightsystemsgroup

Expanding our community connection

Finding support from others who share similar experiences of living with macular disease can significantly enhance your ability to manage your condition.

This is why MDFA facilitates a series of peer support groups, which we recently expanded to include Adelaide and Hobart.

We are committed to growing our network to reach and support more individuals nationwide.

Update from Adelaide and Hobart

Our inaugural Hobart peer support group kicked-off with robust discussion about living with macular disease. In Adelaide, our volunteer facilitators ran a session focused on building connections for people living with macular disease and their carers. Other sessions focused on low vision technology, as well as nutrition and supplements.

The feedback from our first group was overwhelmingly positive, with one participant saying: "It was great when I could talk about my low vision with people who could understand and also have mutual experience for what I am sharing."

New Peer Support Group planned for NT

Location: Casuarina Library
Start Date: Mid-September

Our meetings last approximately 90 minutes (or as agreed to between the facilitator and participants). Peer groups are limited to 10 participants and usually run once every two months or as the group decides.

If you're interested in joining this group or recommending another location, please contact us at 1800 111 709 or via email at education@mdfoundation.com.au.

Did you know about the 2RPH radio reading service?

MDFA recently had the pleasure of visiting the team at Radio 2RPH, who are providing a great service to people with print disability.

2RPH cater to the needs of blind and low vision communities by broadcasting newspaper, magazine and book readings, and print derived content that covers a wide range of information needs and interests.

In Sydney, people can listen-in on 1224 AM and 100.5 FM as well as on the DAB+ digital platform. If you're in Newcastle, tune in to 100.5 FM or if you're in the Wollongong area, set your dial for 93.3 FM.

Also, anyone anywhere can stream the service from the 2RPH website or listen to their podcasts. Visit www.2rph.org.au for more information.

EYE CONNECT

Eye Connect Journey

Macular Disease Foundation AUSTRALIA

DIAGNOSIS
A diagnosis of age-related macular degeneration (AMD) can be hard to hear and understand.

Feeling overwhelmed, worried or confused is common. That's where a service like EYE CONNECT, run by Macular Disease Foundation Australia (MDFA), can help.

UNDERSTANDING
When you join Eye Connect, our trusted and qualified team will be in touch to learn more about you and your experience with macular degeneration.

PERSONALISED
You'll receive a Welcome Pack to get started, tailored to your situation. Then we will connect with you each month or so to assess your needs and provide more support.

SUPPORT
Accessing resources and information will help you understand your diagnosis and apply advice.

Eye Connect packs will continue to arrive monthly by post or email.

CONNECTION
MDFA will provide ongoing coaching calls, boosting your confidence to manage your AMD.

After receiving Eye Connect support, you will feel positive about life and your future with AMD.

LIVING WELL
You will feel prepared and confident at your future appointments with your eye professional.

We're here for you

Macular Disease Foundation Australia is committed to reducing the impact of macular disease in Australia. Our new Eye Connect community support service enhances our opportunity to be there for you. It's free, and available now.

To learn more, head to **www.mdfoundation.com.au/eyeconnect** or call us on **1800 111 709.**

EYE CONNECT Macular Disease Foundation AUSTRALIA

Dry age-related macular degeneration (AMD)

Dry AMD is a painless but lifelong disease of the macula (that's the part of your eye responsible for detailed central vision).

Dry AMD is classed as late-stage age-related macular degeneration (the other stages are known as early and intermediate AMD). Late AMD is the vision-threatening stage and is divided into dry (atrophic) AMD and wet (neovascular) AMD.

Typically, with dry AMD, central vision changes occur gradually.

What causes dry AMD?

AMD is when the cells of your retina (the light sensitive layer at the back of your eye) degenerate and don't function properly. As the retinal cells gradually die (atrophy) this leads to patches of missing retina and loss of central vision.

Treatment of dry AMD

There is no cure for AMD but there are treatments for dry AMD that have been approved for use in the United States. These treatments are not approved in Australia yet.

It's important to:

- Keep your appointments with your optometrist or ophthalmologist,
- Continue to monitor your vision each day using an Amsler grid, one eye at a time (we have included an Amsler grid with instructions along with this factsheet), and
- Immediately report any sudden changes in your vision to your optometrist or ophthalmologist.

Supporting your macular health

It's possible to have dry AMD in only one eye, or for each eye to be in different stages of AMD.

If you have dry AMD in one eye only, your optometrist or ophthalmologist may suggest you take a nutritional supplement, based on what's called the AREDS2 formula to help support the health of your macula.

The good news is that studies have proven that a healthy diet and lifestyle may slow the rate your disease progresses.

EYE CONNECT Macular Disease Foundation AUSTRALIA

MYTHBUSTERS

Early age-related macular degeneration (AMD) edition

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For early AMD, the best thing you can do is to have regular eye exams and monitor your vision between exams with an Amsler grid.

For later stages of AMD, treatments include tailored nutritional supplements to help protect the macula for intermediate and late-stage dry AMD, and anti-VEGF eye injections for the more aggressive late-stage wet AMD.

EYE CONNECT Macular Disease Foundation AUSTRALIA

AMSLER GRID

The Amsler Grid should be used weekly to check for changes to vision between eye exams. Contact your optometrist or ophthalmologist urgently if you notice any changes.

Instructions:

- Wear glasses or contact lenses normally used for reading
- Hold grid at normal reading distance (~30cm) in a well-lit room
- Fully cover one eye and focus on the centre dot
- While looking at the centre dot, look for:
  - Wavy or bent lines
  - Dark or blurred patches
  - Empty spaces
- Repeat each eye

Contact Us: 1800 111 709

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