Macular Disease Foundation AUSTRALIA

Vision Voice

Autumn Edition 2022

Federal Election 2022

MDFA makes your voice heard on sight-saving treatment

Since the introduction of sight-saving eye injections in 2007, Australia has become one of the best places in the world for patients with macular disease.

Many people have maintained their vision and continue to live full and active lives long after diagnosis with the help of early and regular eye injections.

But for others, the cost and burden of treatment means they often have to find savings by cutting costs in other areas such as groceries, holidays, or other medicines.

Where savings can't be found, many are making the difficult decision to stop or delay treatment and risk irreversible severe vision loss or blindness.

Readers will be familiar with the numerous barriers of adhering to sight-saving treatment and retaining vision.

Treatment cost, distance and travel difficulties for appointments, as well as the burden of regular injections, lead far too many people to stop treatment.

MDFA is committed to advocating to reduce the cost and burden of eye injections.

The forthcoming Federal Election, likely in May, is our chance to make your voices heard.

We invite you to share your stories and tell us why access to affordable eye injections is important to you.

Many people from across Australia have already told us how sight-saving treatment has enabled them to continue spending quality time with loved ones.

They have also discussed the sacrifices they make to continue treatment, and shared stories of vision loss when treatment is no longer viable.

Your stories will be a central part of our campaign against the proposed 69% Medicare rebate cut, our advocacy for greater cost transparency for eye injections, and efforts to increase access to eye doctors for those facing problems with distance and travel.

"We look forward to the day when every patient in Australia has the best chance of benefiting from treatment and retaining vision for the rest of their lives," MDFA CEO Dee Hopkins says.

CEO Update

2022 is already proving to be an interesting year, with the upcoming Federal Election and learning to adjust to the ebbs and flows of a new world as we hopefully continue to emerge from this pandemic.

As you will read in this issue of Vision Voice, we remain committed to working and engaging with the next 47th Parliament to support the macular disease community by preventing the proposed 69% rebate cut to the MBS for eye injection treatment but also to improve access and prevent irreversible vision loss.

Our 47,000 Reasons advocacy program will voice the concerns of our community, and I encourage anyone who has a story to share to go to our website to learn more about how to get involved in the campaign. Please visit www.mdfoundation.com.au/47K

We welcome Mr Graeme Head AO to the position of Chair of the MDFA Board. Graeme brings to this position a wealth of experience within public policy and administration, having led multiple public agencies at the Federal and State levels.

We also extend our thanks and gratitude to Retired Brigadier Mr John Fenwick who has faithfully served on the MDFA Board since 2015.

We also congratulate MDFA Ambassador and friend, Dr James Muecke AM, on being appointed Lieutenant Governor of South Australia.

As you will continue to read in this edition, we are expanding our support in SA through a collaboration with James' foundation Sight For All, as well as a new collaboration with the Brien Holden Vision Institute.

Both programs are assisting with expanding sight-saving support for Aboriginal and Torres Strait Islander communities.

I wish you all the best for the year ahead and we look forward to being of service to you whenever you need it.

Dee Hopkins
CEO

New Chair Appointed

Graeme Head
New MDFA Chair

Meet Mr Graeme Head AO, the new Chairman of the MDFA Board. Graeme is a Partner with EY Port Jackson Partners in Sydney and has had a lengthy and distinguished career in public policy and administration in both the Commonwealth and New South Wales public sectors.

Over the past 26 years, Graeme has held CEO and senior executive positions at Government agencies including Commissioner of the NDIS Quality and Safeguards Commission, Commissioner of the NSW Public Service Commission, Director General of the NSW Department of Commerce, and Chief Executive of the Sydney Catchment Authority.

Graeme has also been a senior executive in the NSW Department of Premier and Cabinet, the Commonwealth Department of Health and Ageing, and the NSW Environment Protection Authority.

Graeme has deep experience in policy development, regulation and program management and has worked predominantly across three areas of the public sector: health and human services, environment and natural resource management, and central government.

Graeme began his professional life as a nurse in the late 1970s and moved from nursing to health education and promotion in the mid-1980s, when he was involved in leading some of the early HIV prevention initiatives.

"I am deeply passionate about improving the health outcomes for Australians, both systemically by working closely and collaboratively with Government, and by assisting MDFA through good governance to be a powerful voice for the macular disease community," Graeme says.

Graeme is a Fellow of the Institute of Public Administration of Australia and was made an Officer in the Order of Australia in the Australia Day honours in 2019.

Macula Month – your month, your voice

Macula Month in May is the time of the year when our community comes together to raise awareness of our cause: to reduce the incidence and impact of macular disease in Australia.

We expect this year's Macula Month will coincide with the Federal Election, making our campaign an even greater opportunity to shine a light on some of the key systemic issues facing our community.

This includes barriers to sight-saving treatment such as the proposed 69% cut to the MBS rebate for anti-VEGF injections, establishing a National Vision Program to provide access to affordable low vision aids and equipment, and highlighting the lack of medical research funding into macular disease compared to other widespread chronic diseases.

Macula Month is our time to raise our collective voice.

As we celebrate 15 years of Australians having access to sight-saving eye treatment, we will also voice your concern over the proposed Medicare cut that would further reduce access for the most vulnerable in our community.

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Your month, your stories

Macula Month will focus on members of our community who have been passionate and brave and shared their stories with us.

Throughout the month, we'll meet people like Alison, who's lost her vision because she was fed up with catching a regional bus to receive eye injections for 11 years.

We'll share the fears of Michael, who's resigned to losing his vision when he retires from work because he will no longer be able to afford sight-saving treatment.

And we'll hear from pensioners like Anne and Kerrie, who'd be forced to make serious sacrifices to continue injections if the Government cuts the Medicare rebate.

Ron's story

Pastor Ron has been a minister for almost half a century.

In 2004, he was awarded the Medal of the Order of Australia (OAM) in the Queen's Birthday Honours list for his ministry and for helping seniors with their computer skills. In 2005, he was nominated for the Senior Australian of the Year Award.

Despite officially retiring in 2015, Pastor Ron maintains a global online ministry with 3,000 subscribers. But he would not be able to continue preaching if he could not afford his sight-saving eye treatment.

That's why Pastor Ron is concerned about a proposal to cut Medicare rebates for eye injections by 69%. If the Government approves this cut, Pastor Ron would no longer be able to afford this crucial treatment, and he would go blind.

"I'd be in big trouble," Ron admits.

"I don't know how I'd manage. My ministry and activity on the internet depend on my sight. It's my life. If I lose that, I may as well give up and move into a residential nursing home."

If you have a story to share this Macula Month, please contact us at:
info@mdfoundation.com.au or
www.mdfoundation.com.au/47K

Education

Free webinars coming up

Don't miss our online education sessions!

Topic	When	Presenter
Occupational therapy and low vision: How to live safely with vision loss	Wed, 27 Apr 2-3pm AEST	Teresa Bayer and Claire Grennall from Guide Dogs
Q&A: Ask a patient and an optometrist Everything you wanted to know about diagnosing macular conditions and what to expect when receiving sight-saving treatment	Tue, 24 May 2-3pm AEST	MDFA volunteer Val Nicholson and optometrist Victoria Heaton
Understanding and living optimally with vision loss – for those living with vision loss, their families and friends	Wed, 1 Jun 2-3pm AEST	Cameron Algie, author and former Vision Australia support group leader
Know what supports are available to you to live an optimal life with vision loss or blindness	Wed, 15 Jun 2-3pm AEST	Jane Britt from Blind Citizens Australia

To register:

P: 1800 111 709

E: education@mdfoundation.com.au

W: www.mdfoundation.com.au/education-sessions or scan this QR code.

Catch up on our past webinars on YouTube

Visit YouTube.com/MDFoundationAus or simply scan this QR code.

Peer support: 'I don't feel so alone anymore'

When Val was first diagnosed with wet AMD, she didn't know what to do next. Val knew very little about her condition, and she didn't know anyone else who had it too.

When Val reached out to MDFA's National Helpline (1800 111 709), one of our Health Promotion Officers explained her diagnosis and helped her live an optimal quality of life.

Val was so grateful to MDFA that she wanted to give back, and decided to become a volunteer.

During a conversation with MDFA CEO Dee Hopkins, Val became interested in providing support over the phone to members of the macular disease community who wanted to talk to someone who was in the same boat.

Now, Val provides regular calls to eight different people – each at different stages of their eye health journey – as part of MDFA's Peer to Peer telephone support program.

"You're supporting people who are in a similar position to yourself – and to me, that's sometimes supporting you as well," Val says. "I would love to have had something like this when I was first diagnosed. It's very rewarding to help people in a similar position to me.

"I can't afford to give MDFA lots of money, but I can give my time. It's my way of giving back to MDFA and the community."

Llevelyse is one of the people Val calls. "I really needed support – because I was floundering. I definitely have found that support… I don't feel so alone anymore," Llevelyse says.

Would you like to sign up for peer support?

Phone: 1800 111 709
Email: education@mdfoundation.com.au

Providing education to GPs, pharmacists and Aboriginal health workers

General practitioners and pharmacists can soon access educational courses on age-related macular degeneration and diabetic eye disease developed by MDFA and Australia's leading retinal specialists.

GPs and pharmacists are often the first people you speak to about the early signs of macular disease, so it's crucial they recognise the symptoms and know how to refer you to eye health professionals for diagnosis and treatment.

These continuing professional development (CPD) courses aim to improve how healthcare professionals communicate with you about macular disease, including how to reduce your risk, manage your diagnosis, and connect with support services.

As well as these new courses for GPs and pharmacists coming soon, MDFA also offers free CPD for optometrists and orthoptists, launched last year.

Plus, MDFA has teamed up with the Brien Holden Foundation (BHF) to increase access to eye care for Indigenous communities and address the inequities in Aboriginal and Torres Strait Islander eye health.

The BHF has delivered hundreds of retinal cameras and slit lamps to clinics across Australia to empower practitioners to screen for diabetic eye disease, which is more prevalent in Indigenous communities.

Aboriginal health workers also receive training and extra resources to help them better care for their patients.

This project was scheduled to end last December but MDFA's partnership allows the BHF to continue rolling out training until the end of this year.

Mythbusters

Ophthalmologist A/Prof Alex Hunyor sets the record straight on some common misconceptions about your eyes.

Will getting stronger glasses help my AMD?

No, it won't help the AMD itself – but for people with reduced vision that is not severe, the right level of magnification (and good lighting) may help with near vision.

AMD affects the macula, which is the centre of the retina at the back of the eye. The retina is the light sensitive layer that works like film in a camera. Glasses work by helping the eye to focus light on to the retina.

It is important to use the correct strength glasses to maximise vision, but stronger glasses won't actually help the macular degeneration.

Are dry eyes the same thing as dry AMD?

No, these are very different conditions. Dry eye occurs when there's a problem with the tears that lubricate the cornea and conjunctiva, the outer structures of the eye.

Dry AMD occurs much deeper inside the eye at the macula. Dry AMD is a painless disease causing gradual loss of central vision.

Once I've been diagnosed with AMD, there's nothing I can do to stop it from getting worse, right?

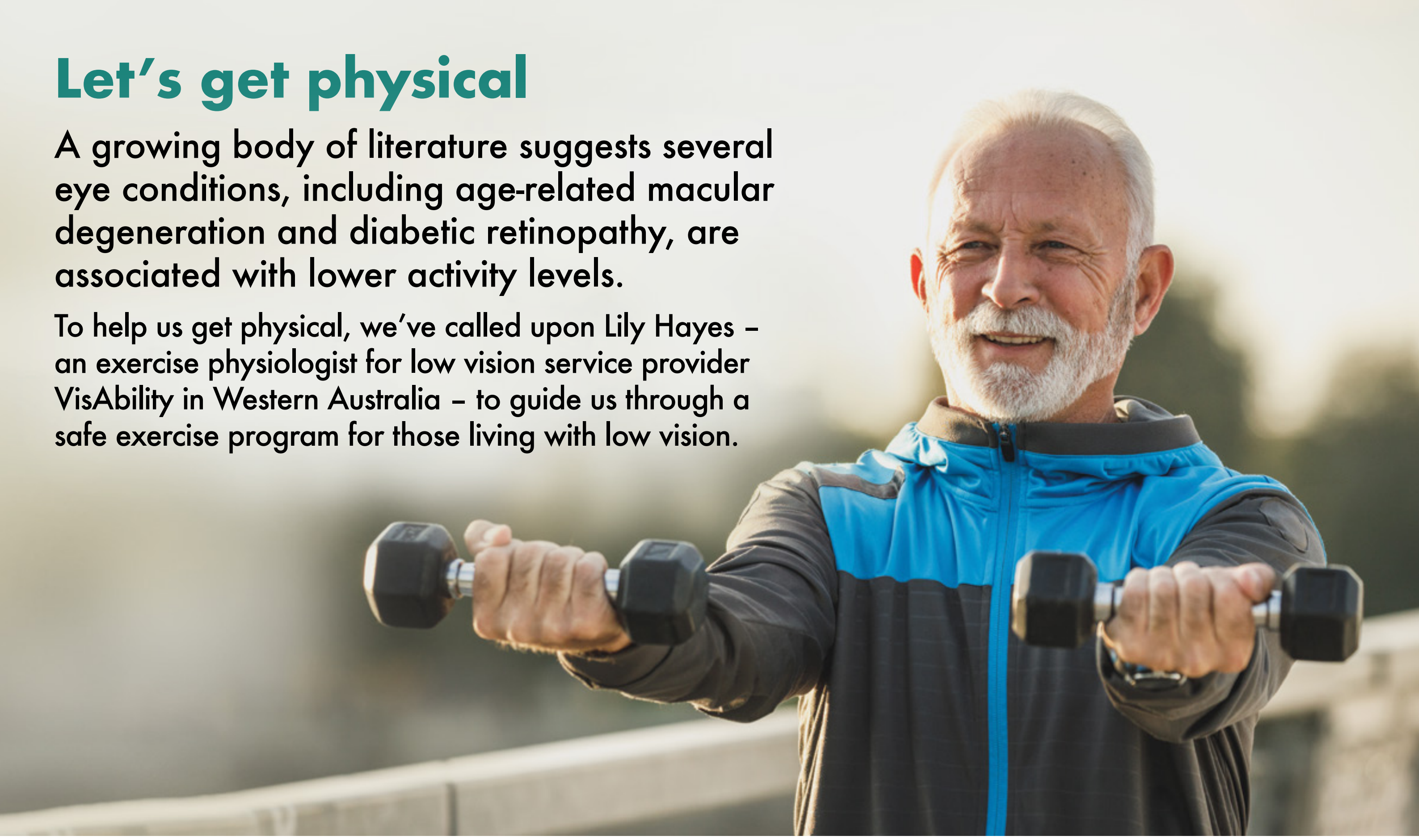
No. In fact, it's important to start treatment as early as possible.

Treatments include tailored nutritional supplements to help protect the macula in dry AMD and anti-VEGF eye injections for the more aggressive wet AMD.

Let's get physical

A growing body of literature suggests several eye conditions, including age-related macular degeneration and diabetic retinopathy, are associated with lower activity levels.

To help us get physical, we've called upon Lily Hayes – an exercise physiologist for low vision service provider VisAbility in Western Australia – to guide us through a safe exercise program for those living with low vision.



The benefits of exercise for older Australians

Exercise has huge benefits for older Australians. Not only does exercise help reduce the risk of lifestyle-related diseases like heart disease and diabetes, but it also makes day-to-day tasks easier, such as carrying groceries, gardening, dressing, and cooking.

Exercise also helps you avoid falls, improves your mental health and increases bone density to reduce the risk of bone breakage.

Exercising with lower vision

There is always a way that exercise can be modified so that you feel safe when exercising. Vision loss should not prevent you from exercising.

Many clients at VisAbility have no vision and exercise is a great way for them to stay in tune with their bodies.

When you live with low vision, it's important to find an exercise professional such as an exercise physiologist you feel comfortable with who can help you get started and learn what your body is capable of.

Tips for exercising at home

- Most importantly, always make sure you consult with an allied health professional or your GP before you begin home exercises to ensure they are safe for you
- Make sure you feel comfortable in the space where you're exercising
- Remove unnecessary objects that may be a trip hazard
- Some everyday objects can be useful for exercise, such as stable dining chairs, which can be used for squat exercises, and tinned foods are great weights

- It is very important to make sure you have someone at home that can supervise your exercise to ensure your safety
- Only complete exercise that you're comfortable and confident with, take exercise slowly, and never push through pain

The Australian guidelines for physical activity and exercise recommend adults over 65 years complete at least 30 minutes of moderate intensity physical activity every day, if possible.

If you're currently doing no physical activity, you should start slowly with potentially only 5-10 minutes daily and build it up to 30 minutes.

Skier with Stargardt speeds to second Paralympics

Patrick Jensen can't drive a car, but he can zoom down a mountain at 120 kilometres an hour.

That's because Patrick – who lives with macular dystrophy and Stargardt disease – is one of the 10 athletes who represented Australia at the Winter Paralympics in Beijing this March.

The 26-year-old from Newcastle is a para-alpine skier, capable of conquering the slopes despite losing vision in both eyes.

"In slalom, you get up to about 60 kilometres an hour. In downhill you're getting up to about 120 Ks and hour," Patrick explained before his maiden Paralympic campaign in 2018.

"At high speed, I can't see much [but] vision-impaired athletes have a guide, and we try to ski as close as we can behind them.

"We work on a Bluetooth system – there's two earpieces inside the helmet where I can hear whatever she's saying, and she can hear what I say. It works on a lot of trust, understanding that they're going to put you where you need to be."

Patrick was diagnosed with inherited retinal conditions macular dystrophy and Stargardt disease at the age of seven. He has 70% vision in his left eye and 30% in his right.

Patrick excelled at athletics and swimming as a kid, and also loved skateboarding and surfing at Nobbys Beach.

But his passion lay elsewhere – music – and Patrick planned to become a musician until his careers advisor convinced him to attend a sports try-out day.

"I didn't want to do it, but I did what she told me and that year (2013) I got sent to Perisher for a Disabled Wintersport Australia camp," said Patrick, who scratches his musical itch by drumming in local band George Booth when he's not on the snow.

"Within the year, I was competing in Austria, and I've never looked back."

After honing his skills in Europe, Patrick made his Paralympic debut at PyeongChang 2018 with sighted guide Lara Falk, finishing 11th in the Men's Giant Slalom Visually Impaired and competing in the Men's Slalom Visually Impaired.

Patrick has a good sense of humour about his diagnosis – his nickname is 'Blinky', and his left arm carries a tattoo of himself as a Lego character riding a skateboard with a cane.

But he's serious about his skiing, wearing the green and gold at a second Paralympics in Beijing this March alongside guide Amelia Hodgson.

"Once you go to try one of these sports, you're going to feel more included than what you possibly have in your whole life," Patrick said.

"It makes you feel just like anyone else."

Research update

Volunteers wanted: AMD and quality of life

Quality of life is an important concept we all understand, yet measuring it is complex and difficult.

Dr Sheela Kumaran, a Sydney-based researcher, is developing better tools to assess patients' perception of their own wellbeing and how they are affected by AMD.

AMD has major impacts on independence, emotional wellbeing, and all-round quality of life of people living with AMD, Australia's leading cause of blindness and severe vision loss.

"This research is focused on developing a smart questionnaire that can precisely and comprehensively measure the quality-of-life impacts posed by AMD," Dr Kumaran says.

The questionnaire covers eight important quality-of-life areas: activity limitations, symptoms, mobility, emotional wellbeing, health concerns, social impact, convenience, and economic impact.

Dr Kumaran explains that the study, supported by MDFA research funding, aims to develop a questionnaire that is reliable but needs less time for patients to complete.

"This has huge potential to help doctors understand how AMD affects their patients over time and to provide the right kind of support when it is needed," Dr Kumaran says.

If you have AMD, you're over 50 and you're interested in taking part in this study, visit redcap.link/AMDQoLproject or scan this QR code.

Alternatively, contact Dr Sheela Kumaran on 02 9065 9964 or sheela.kumaran@unsw.edu.au

Australian regulators review two new macular disease treatments

With injection burden and cost being major problems for patients receiving eye injections for macular disease, two treatments facing regulatory scrutiny in Australia may benefit patients.

Wet AMD is the leading cause of severe vision loss and blindness in Australia. Diabetic macular oedema (DMO) is a common complication of diabetes, which can lead to loss of detailed central vision and even blindness.

Susvimo® is a permanent eye implant refilled every six months with a special formulation of ranibizumab. It will be used to treat wet AMD.

Vabysmo® (faricimab) is an eye injection containing an antibody that binds two different molecules that cause abnormal vessels to develop and leak in the eye. It will be used to treat wet AMD and DMO.

Clinical studies published in the prestigious journal The Lancet indicated that some patients receiving faricimab injections could extend their treatment interval to 12 or even 16 weeks.

Both treatments are approved by the US FDA and will be reviewed by the Australian Pharmaceutical Benefits Advisory Committee in the coming months.

If approved, these products could reduce treatment burden and cost, which in turn could help patients continue taking sight-saving treatment.

Dr Sheela Kumaran

About the Research Grants Program

Dr Kumaran was one of eight researchers who received funding in the MDFA Research Grants Program announced in May 2021.

MDFA is the largest non-government source of research funding for macular disease in Australia, committing $5.1 million to 25 Australian researchers over the past decade.

Delivering diabetes education to rural SA communities and Aboriginal health workers

Macular Disease Foundation Australia has partnered with Sight For All to develop a new education program to raise awareness of diabetic eye disease.

Diabetic eye disease is the leading cause of avoidable vision loss and blindness in working-age Australians.

It's estimated that up to one in three Australians with diabetes have some stage of diabetic retinopathy, which is one of the diabetes-related conditions that affects the retina and can lead to macular damage.

The free education program will focus on delivery to rural and regional communities in South Australia that have higher rates of diabetes.

So far we've visited Port Lincoln, Port Augusta, Peterborough, Port Pirie and Berri.

Future sessions to central and south-east SA are being planned. The program will cover the types of diabetic eye disease, how to reduce the risk of vision loss and the local support team that's available.

The program has also been modified to train Aboriginal health workers working at regional Aboriginal health clinics on patient management and education.

Here's some of the feedback from the last few sessions:

**"Both presenters, Jo and Natasha, were very informative. The presentation was very easy to understand"
– Port Pirie attendee**

**"The information was very well presented – my issue is macular degeneration, but all the info was important"
– Port Augusta attendee**

**"It was great. Easy to listen to and understand"
– Pika Wiya Health Service clinician**

SIGHT
FOR ALL
TEACHING
THE WORLD
TO SEE

To stay up to date with future sessions near you, please follow MDFA's Facebook page, visit our website www.mdfoundation.com.au, or call our National Helpline on 1800 111 709.

Special thanks to Lions Australia and local optometry practices that helped promote the events.

Healthy choices

Creamy spinach and salmon with sweet potato mash

When the weather cools down, this eye-healthy recipe will warm you up. The salmon and spinach gives you a delicious meal that's packed full of macula-friendly nutrients Omega-3, lutein and zeaxanthin.

Ingredients

2 sweet potatoes

1 tbsp olive oil

2 salmon fillets, skin removed

2 garlic cloves, thinly sliced

170g baby spinach

1 lemon (½ zested and juiced, ½ thinly sliced)

75g mascarpone cheese

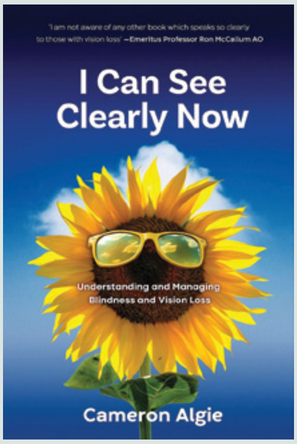
5 tbsp milk

Instructions

1. Heat oven to 200°C. Pierce the sweet potatoes a few times each and microwave on high for five minutes until soft, or bake for 35-40 minutes. Keep warm until ready to serve.
2. Heat half the olive oil in a frying pan and lightly brown the salmon on both sides – don't worry about it being cooked through at this point. Transfer the salmon to a plate, wipe out the pan and heat the remaining oil.
3. Cook the garlic for 30 seconds, without letting it brown, then add the spinach, lemon zest and juice and some seasoning. Stir in the mascarpone and two tablespoons of the milk and cook until the spinach has wilted.
4. Tip the spinach mix into an oven-proof dish and top with the lemon slices and salmon fillets. Bake for five to eight minutes until the salmon is cooked through.
5. Meanwhile, scoop the sweet potato flesh from the skins and mash with the remaining milk and some seasoning. Serve the sweet potato mash alongside the salmon and creamy spinach.

You can find this tasty recipe – and many more eye-friendly meal ideas – in our warming winter Macula Menu.

Download your free e-cookbook by scanning this QR code.



Book review: 'I Can See Clearly Now' by Cameron Algie

'I Can See Clearly Now: Understanding and Managing Blindness and Vision Loss' provides a refreshingly honest perspective of experiencing vision loss – not only for the individual, but also for family and friends. I was so taken by Cameron's authenticity, and his pragmatic approach to living a best possible life with vision loss, that I have asked him to present at one of MDFA's popular webinar series.

To buy the book, visit www.icanseeclearlybooks.com

Dee Hopkins, CEO, MDFA

Our Community

MDFA Ambassador Dr James Muecke appointed SA Lieutenant Governor

MDFA congratulates Dr James Muecke AM on his appointment as South Australia's next Lieutenant Governor.

SA Premier Steven Marshall appointed the 2020 Australian of the Year and MDFA's Diabetic Eye Disease Ambassador to the position in January.

Since beginning his medical career in Kenya three decades ago, Dr Muecke has dedicated his life to saving sight in vulnerable communities.

The Adelaide ophthalmologist is a co-founder of Sight For All, a not-for-profit that delivers eye care to Indigenous people here in Australia as well as marginalised groups across the globe.

Although Dr Muecke has retired from surgery, he continues to tirelessly raise awareness of the impact diabetes can have on our eyes – including in his role as MDFA Ambassador.

As Lieutenant Governor, Dr Muecke effectively serves as deputy to Governor Frances Adamson AC.

Watch the video: What low vision aids could help me?

One of the most difficult things about declining vision is not being able to do some of the things you need and want to do.

Low vision aids can help you maintain independence and quality of life – and there's a huge range that can help you keep doing the things you love.

MDFA has released dozens of short videos to help you on every step of your journey with macular disease, including this one on which low vision aids could help you.

To watch this video, as well as the whole video series, please scan this QR code.

Write your Will for free

As part of a 12-month trial, MDFA is offering our supporters free access to a secure, simple, step-by-step online Will-writing service.

We have partnered with Australia's top-rated digital Will-making platform **Gathered Here** so you can write your Will online for free.

Gathered Here allows you to create and complete your Will in less than 20 minutes via the internet, providing a safe, easy-to-use and legally binding alternative to a paper Will.

We know that making your Will is one of the most important things you will ever do. It protects your loved ones and ensures your estate is divided the way you intended.

We hope that when you are making your Will, you might consider how you can contribute to a future where no one loses their sight to macular disease.

Adding a charitable gift in your Will won't impact your wealth during your lifetime, but it will have a huge impact for future generations.

Whether your gift is large or small, it has the power to effect real change. As little as 1% of your estate can make a significant and lasting impact.

For more information about leaving a gift in your Will, please scan this QR code.

Sign up for peer support

Our Peer to Peer program matches volunteers who have a personal experience of macular disease with people who are struggling with their diagnosis, feel isolated, or just want to speak with someone who can relate to their experience.

Volunteers can speak to you over the phone or meet up face-to-face.

These meetings are not a counselling service, but they do give you the opportunity to share your thoughts, ask questions and raise concerns in a safe, welcoming and inclusive environment that could ultimately help you feel less alone and better understood.

Would you like to sign up for peer support?

Please call our National Helpline on 1800 111 709.

Plus, we're also on the lookout for volunteers to join this program.

If you're looking to give back to the community, and have a personal experience with macular disease, call us on 1800 111 709 or email education@mdfoundation.com.au

Sign up for peer support

Phone: 1800 111 709

Email: education@mdfoundation.com.au

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Follow us on social media

If you like what you're reading in this newsletter, you'll love following MDFA on social media.

Please join our community on Facebook, Instagram and Twitter for even more useful content.

Plus, social media is a great way to share your feedback with us. We want to hear your voice!

facebook.com/MacularDiseaseFoundationAustralia

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twitter.com/MacularDisease