



# Vision Voice

Autumn Edition 2021

## Aged Care Royal Commission recommendations

The Royal Commission into Aged Care Quality and Safety has recommended making aids and equipment more accessible for older Australians in a major win for our community.

Everyone living with a disability in the aged care system should receive daily living supports – such as assistive technologies, aids and equipment – at a level equivalent to what under-65s would receive in the National Disability Insurance Scheme (NDIS), states the Royal Commission's final report.

This crucial recommendation comes four years after MDFA first identified this issue in the 'Low Vision, quality of life and independence' review. It is unfair that over-65s with vision loss living in the aged care system receive less support than under-65s with the same condition in the NDIS.

Our report highlighted how many Australians – including those in aged care – simply cannot afford these life-changing low vision aids and technologies, and called for a national, publicly funded approach to provide equitable access to them.

Now, the Royal Commission has also recognised the aged care system doesn't adequately meet the disability needs of older Australians. If the Federal Government adopts the key recommendation above, older Australians will soon find it easier to get the assistance they need to live well with vision loss.

(continued page 2)

### MBS injections update

While the Aged Care Royal Commission's recommendation on low vision aids and technologies represents eight years of advocacy work by MDFA, the proposed cuts to Medicare rebates for eye injections is the current big issue we've been tackling on behalf of our community.

The Medicare Benefits Schedule (MBS) Review Taskforce submitted its final report to Federal Health Minister Greg Hunt just before Christmas last year.

While we supported several recommendations in the Taskforce's report, we were concerned about the proposal to cut the patient rebate for eye injections by 69% and the impact this would have on patients' out-of-pocket costs.

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# CEO Update

The year ahead is looking brighter with the roll-out of the coronavirus vaccine. Many vulnerable people within our community, and those living within aged-care facilities, will have already received their vaccines.

Page five shows the Government's phased vaccine roll-out so you can estimate the timeframe when you can access your vaccine jab. As this information changes, we'll maintain up-to-date information on our website. You can also call our National Helpline on 1800 111 709 if you have any specific questions relating to your eye health.

The vaccine roll-out highlights the extraordinary work between government and the scientific community in the fight against COVID and to bring much-needed vaccines to Australians.

This year marks the 20th anniversary of MDFA and 10 years of investment into our Research Grants Program. With your support we have played a crucial role in helping to change the landscape for the macular disease community, including a \$4.1 million commitment to medical research.

In May, as part of our anniversary celebrations, we will publish a report on the impact this research has made over the past decade. We will also announce the grant recipients of \$1.1m in the next round of research funding, including the new Grant Family Fund.

The Grant Family Fund will support blue-sky projects and targets early-career scientists and researchers. This new stream of research funding is only possible because of a generous bequest left to MDFA by the late Faye Grant.

I look forward to sharing news about the next round of researchers who will receive funding from your generous donations.



Dee Hopkins  
Chief Executive Officer

Take care and remember to reach out to the MDFA team if you have any queries about your risks of macular disease or need any information, resources or links to support that might help you better manage your condition.



## Aged care report cont'd.

The Federal Government is yet to respond to all of the Royal Commission's 148 recommendations, but Prime Minister Scott Morrison has already pledged an initial \$452.2 million for aged care reforms ahead of May's Federal Budget.

MDFA supports this vital recommendation by the Royal Commission, and we will advocate for the Federal Government to adopt it so older Australians living with low vision in the aged care system can get the practical support they need to improve their independence and quality of life.

We'll keep you updated on this issue.

## MBS update cont'd.

After briefing Minister Hunt in late 2019, MDFA commissioned PwC to develop alternate models of care for wet AMD. This included proposals to establish more regional low-cost clinics to improve treatment access by reducing travel costs and time, and introducing alternative payment options in private clinics by empowering patients to be better informed on the cost of ongoing treatment.

This fully costed report will be presented to Minister Hunt in May and will be submitted to State and Territory Health Ministers later this year. We'll keep you informed with further updates on how we are making your voice heard.

Scan this QR code to read the final MBS Taskforce report.



# Macula Month to boost Check My Macula

Last October, MDFA unveiled Check My Macula ([www.CheckMyMacula.com.au](http://www.CheckMyMacula.com.au)): a short online quiz that reveals your individual risk factors for macular disease in less than a minute, then enables you to book an eye exam with an optometrist.

With tens of thousands already taking the quiz, Check My Macula has been a hugely successful tool to educate people over 50 about their risks of macular disease as well as the benefits of regular eye exams.

And Check My Macula will be the focus of Macula Month in 2021, as we continue to take this sight-saving initiative to the millions of Aussies at risk. Keep an eye on MDFA's digital channels for updates.



## You can help by sharing Check My Macula

If you have been diagnosed with AMD, your direct relatives – such as siblings and children – have a one-in-two chance of being diagnosed, too.

We encourage you to share the Check My Macula quiz with your family, as well as your friends, so they know if they are at risk of developing macular disease and take early action to potentially prevent vision loss.

Get started at [www.CheckMyMacula.com.au](http://www.CheckMyMacula.com.au), or by scanning this QR code.



## Ita Buttrose Oration

To celebrate Macula Month and a welcome return to socially distanced safe events, we are thrilled to launch the Ita Buttrose Oration series.

Ita Buttrose AC OBE has long been both Patron of MDFA and a passionate advocate of prevention and early detection of macular disease. Ita has also lent her influential voice to other health conditions and is widely recognised as the voice and advocate for older Australians and building an Australia that embraces healthy ageing.

Ita will be the keynote speaker at this inaugural oration. She will be addressing the big issues relating to eye health and vulnerable older Australians who are at risk of blindness. The oration series will be presented annually and will shine a spotlight on how we are tracking as a nation to ensure a healthy ageing Australia.

The event will be held at the National Press Club in Canberra. Tickets, which include the keynote address and a sit-down lunch, are available to purchase for those in our community who live in the ACT or are willing to travel for this event.

Tickets are \$90 per person and can be purchased directly at [www.npc.org.au/speakers](http://www.npc.org.au/speakers), or you can contact MDFA on 1800 111 709 and we can register on your behalf.

For those unable to attend in person, you can watch this on the ABC and MDFA will share this via our website following the event.

### Ita Buttrose Oration

12-2pm AEST, Wednesday, 5 May 2021

National Press Club,  
Canberra

Tickets: \$90 per person

To book: visit [www.npc.org.au/speakers](http://www.npc.org.au/speakers) and select Ita's event, or scan this QR code.





## Pilot peer support group launches in Melbourne

Would you be interested in joining a similar group where you live?

MDFA's pilot peer support group has finally held its first face-to-face meeting in Melbourne's east, after months of planning and an even longer delay due to COVID-19.

With the guidance and support of MDFA staff, the group of nine gathered to discuss their lived experience of age-related macular degeneration (AMD), provide support for each other, and learn from each other. Research shows the power of connecting with others with the same health conditions and sharing experiences.

The meeting was facilitated by two people who live with macular disease themselves, Bill and Kerry.

Bill – who has experience facilitating similar groups thanks to his background in social

work in the mental health space – says he was “delighted that everyone was willing to talk”.

“We just went around the group one by one, and everyone responded really warmly,” Bill explains.

“They were all very ready to talk and share ideas and experiences, which was terrific. It was what we were after.

“There was an eagerness to learn – and that was a terrific launching pad for the group.”

Co-facilitator Kerry – a teacher before she retired, as well as a member of the AMD community – was also inspired by the group's openness.

“I was certainly taken by the heroism, I suppose you'd say, of two or three of the attendees who really lived life on their own and did it very successfully and had also worked out how to get whatever supports were available,” Kerry says.

The group now plans to catch up every two months, choosing a different theme – such as nutrition, eye injections and government support – to discuss at each meeting.

### Join a peer support group

While this pilot in Melbourne's eastern suburbs only has room for a handful of extra members, MDFA would like to start similar groups across Australia. We're already planning to launch groups in Melbourne's inner south east, Brisbane and Townsville in Queensland, and Albany in Western Australia.

If you're interested in peer support where you live, MDFA would love to hear from you. Please call our National Helpline on 1800 111 709 or email [education@mdfoundation.com.au](mailto:education@mdfoundation.com.au).

### At home with MDFA

Would you prefer to receive peer support from the comfort of your own home?

Then you might want to join 'At home with MDFA', an online peer support group that connects Australians living with AMD. To express your interest in 'At home with MDFA', call 1800 111 709 or email [education@mdfoundation.com.au](mailto:education@mdfoundation.com.au).

# Update: COVID-19 vaccine roll-out

The Federal, State and Territory Governments have begun rolling out vaccines for COVID-19.

Australia's COVID-19 vaccines will become available in phases, and vulnerable groups of people have been prioritised.



The table below outlines which groups will receive the first doses of the COVID-19 vaccine.

Phase 1a
Quarantine and border workers
Frontline healthcare workers
Aged care and disability care staff and residents
Phase 1b - current
Adults aged 70 years and over
Other healthcare workers
Aboriginal and Torres Strait Islander people aged over 55 years
Adults under 70 with an underlying medical condition, including those with a disability
Critical and high-risk workers
Phase 2a
Adults aged 50-69 years
Aboriginal and Torres Strait Islander people aged 18-54 years
Other critical and high-risk workers
Phase 2b
The rest of the adult population
Catch up any unvaccinated people from previous phases
Phase 3
Under 16-year-olds, if recommended


MDFA will update you via our website and social media with further details as they are announced.

# Education webinar series

We can't wait to welcome you to our next free online education session. To register, please email [education@mdfoundation.com.au](mailto:education@mdfoundation.com.au) or call us on 1800 111 709.

Topic	Date	Time	Presenter
Geographic atrophy in dry age-related macular degeneration: The new treatment frontier	Wednesday, 14 April	2-3pm AEST	A/Prof Andrew Chang from Sydney University, Sydney Eye Hospital and Sydney Retina Clinic
Age-related macular degeneration	Wednesday, 12 May	2-3pm AEST	Drew Sherwin from MDFA
Eye injection costs and rebates Q&A	Wednesday, 30 June	2-3pm AEST	Dilini Manthilaka from MDFA

For an up-to-date list of webinars, please visit [www.mdfoundation.com.au/education-sessions](http://www.mdfoundation.com.au/education-sessions) or scan this QR code.



We also record most of our online education sessions so you can catch up even if you can't attend live. Visit [www.mdfoundation.com.au/content/listen-past-webinars](http://www.mdfoundation.com.au/content/listen-past-webinars) to watch the recordings of our past webinars.

## How to write a Will webinar

Do you want to learn more about making a Will? MDFA is hosting an estate planning webinar with Nicola Platt, a partner at Griffin Legal, to talk you through the legalities of putting together a Will.



Join us on Tuesday, 18 May at 10-11am AEST.

To register, please email [education@mdfoundation.com.au](mailto:education@mdfoundation.com.au), call 1800 111 709 or scan this QR code.

# Eyes on Research

## Meet the researcher: Prof Alice Pébay



Thanks to an MDFA research grant, the University of Melbourne's Prof Alice Pébay has created a bank of stem cells that researchers across the globe can now access to investigate potential new treatments for dry AMD.

Prof Pébay was awarded an MDFA research grant of \$300,000 over two years in 2017 to explore the genetic pathways leading to dry AMD using patients' own cells.

Prof Pébay's team generated and used induced pluripotent stem cells (iPSCs) – cells that can become any type of cell in the body – from 60 AMD patients and 60 control individuals, then made them become retinal cells.

They then used this large iPSC cell bank to identify the genetic differences between the healthy cells and the disease cells, which can now be used to develop new targets for potential treatments of dry AMD.

Since completing her MDFA research, Prof Pébay has gone on to secure more funding from the National Health and Medical Research Council (NHMRC), the Medical Research Future Fund (MRFF) and the Ophthalmic Research Institute of Australia (ORIA) to further develop the iPSC bank.

This shows how MDFA's initial investment can snowball into significant advancements in the field of macular research.

"Macular Disease Foundation Australia is fundamental to the type of work we are doing around the country," Prof Pébay says.

"Without MDFA, much research on curing blindness would not happen in Australia. So the role of MDFA is essential for us to do our work and to do our work well."

## Meet the researcher: A/Prof Laura Downie



MDFA funding allowed A/Prof Downie and her team at the University of Melbourne to develop a clinical audit tool to improve the quality of care that people with AMD receive from their optometrist.

A clinical audit helps healthcare practitioners discover the strengths and weaknesses of their current practices so they can then improve the care they provide their patients. However, there is a lack of audit tools for Australian optometrists.

This is why MDFA awarded A/Prof Laura Downie a \$100,000 research grant over three years in 2015 to develop an innovative auditing platform called the Macular Degeneration Clinical Care Audit Tool (MaD-CCAT) to assess the eye care received by people with AMD.

This MDFA-funded study showed that the MaD-CCAT improved clinical record documentation and several aspects of care, particularly how often optometrists asked patients about modifiable risk factors like smoking (21% to 58%), diet (11% to 29%) and nutritional supplementation (20% to 51%).

"The MaD-CCAT is, to our knowledge, the world's first primary care clinical audit tool for AMD of its type worldwide," A/Prof Laura Downie says.

"I feel passionate about this area of research because the work that we do can lead to immediate improvements in the quality of clinical care."

MDFA's Research Grants Program would not exist without generous donations from people who share our vision to reduce the incidence and impact of macular disease. If you would like to support more life-changing research in the future, please visit [donations.mdfoundation.com.au](http://donations.mdfoundation.com.au) or call 1800 111 709.

As the national peak body for macular disease, MDFA regularly makes submissions to government representing the interests of the macular disease patient community.

MDFA lodged its Federal Pre-Budget submission 2021-22 to Treasury, focusing on preventing the implementation of the proposed MBS rebate cut for eye injections and establishing various programs to support the patient journey and optimal quality of life. We will keep you informed in the event the Government supports these initiatives.

MDFA also contributed to the development of the Vision 2020 Australia Federal Pre-Budget submission 2021-22.



## New report on macular disease impact

In March this year, MDFA launched its inaugural Macular Disease Social Impact Survey report. More than 2,100 members of the macular disease community responded to this survey – the first in a series of surveys to trend patient-reported outcomes and experiences over time to better understand the impact of macular disease on people's lives.

Supporting objectives outlined in the National Strategic Action Plan for Macular Disease, the survey was commissioned by MDFA and prepared by the Centre for Social Impact and the School of Optometry and Vision Science at the University of New South Wales. It was co-designed with input from some of Australia's leading ophthalmologists and researchers.

The insights from the survey have allowed MDFA to understand the successes, concerns and barriers experienced by the macular disease community. Some major findings from the report include:

- 97% of respondents were able to access information about their disease through multiple sources, however 25% of

respondents only had fair to poor knowledge of their condition. Many of these respondents tended to have the poorest vision and a non-treatable form of AMD.

- 75% of respondents using low vision aids saw these items as critical for their quality of life.
- 14% of respondents reported that their condition highly impacted their physical and emotional functions.
- 85% of respondents with wet AMD were receiving treatment. Of the remaining 15% of respondents who were not receiving treatment, 4.3% indicated costs as the primary barrier.

MDFA wishes to thank the Fitzpatrick Sykes Family Trust for their foresight, generosity and trust in allowing this impact study to be developed.

The second report in this series is expected to be released in 2022. We will be reaching out to our community again and hope we can increase the response rate to this important study. The findings provide solid evidence on the issues that are most important to the macular disease community and inform how we represent those needs and influence health policy and eye health practice to improve patient outcomes.

# Five tips for exercise at home

People with low vision are more likely to suffer a fall. But being physically active and staying fit and healthy will help you get the most out of life.

These tips for exercising safely come to us from the Healthy and Active Ageing Team at the Health Promotion Service, South Eastern Sydney Local Health District.

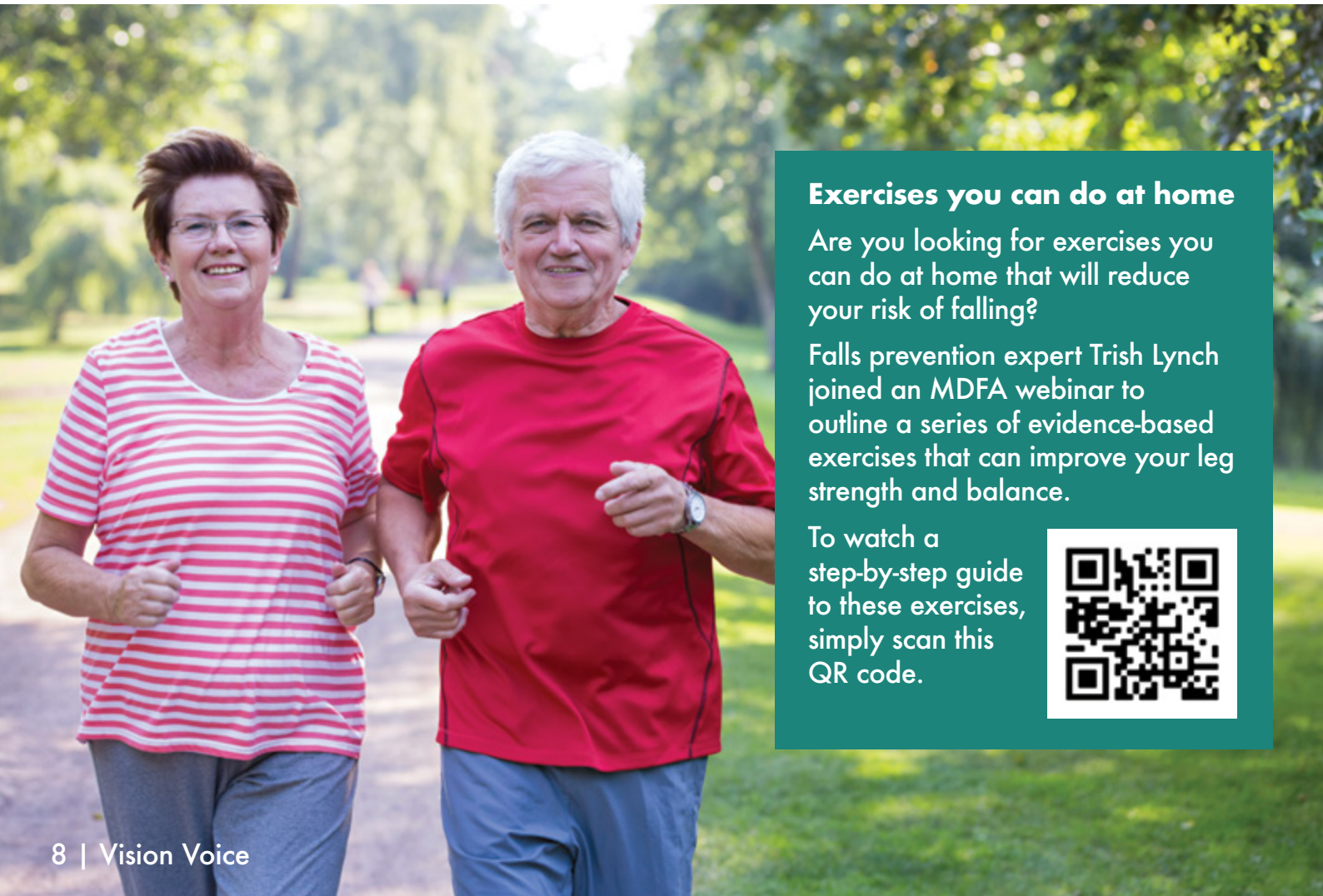
Adults aged 60-plus should be active every day in as many ways as possible, doing a range of physical activities that incorporate fitness, strength, balance, and flexibility.

The Australian Government Department of Health's Physical Activity Recommendations for Older Australians advise at least 30 minutes of moderate intensity physical activity most days or every day if possible, as well as two hours of balance exercises each week. Moderate exercise is described as when you can speak while exercising, but you can't sing!

## Here are five tips to get you moving.

1. The first step: find a safe place to exercise. Remove clutter and trip hazards such as stools, items on the floor, unsecure mats and pets.
2. Find a secure support such as a kitchen bench or a sturdy table to hold on to if it helps perform the exercises.
3. We are all different and exercise doesn't need to be completed at a certain time of the day. Exercises can be sprinkled through the day or completed in the morning or in the afternoon. It depends on what works for you.
4. If you have a new pain when doing exercise, talk to your GP or physio. Some people will need to have their exercises modified.
5. Exercises can be incorporated into your daily activities. For example, do your balance exercises when waiting for the kettle to boil. Stand up from your breakfast table three times rather than once when you are finished as an exercise to help strengthen your legs.

If you are not sure if you should be doing exercises, ask your doctor.



### Exercises you can do at home

Are you looking for exercises you can do at home that will reduce your risk of falling?

Falls prevention expert Trish Lynch joined an MDFA webinar to outline a series of evidence-based exercises that can improve your leg strength and balance.

To watch a step-by-step guide to these exercises, simply scan this QR code.



# Latest low vision aids



## This pen can read your labels

If you have trouble reading labels at home, then the PenFriend 3 audio labeller might be able to help.

This easy-to-use tool allows you to record audio labels using your own voice. Simply stick one of the PenFriend's adhesive labels on the item you want to identify, place the PenFriend on the label, and record your voice identifying the item, including any details like cooking instructions on food or instructions on medicine.

Then the next time you need to identify that item, place the PenFriend on the label and it will play your voice recording back to you.

The PenFriend 3 audio labeller comes with more than 100 labels and can store up to 250 hours of recordings. You can also use the PenFriend as an MP3 audio player and a talking book player.

Contact MDFA for details of where to buy the PenFriend 3 audio labeller.

## Judi Dench benefits from this free app. Would you?

The MD\_evReader is a free app designed to make reading easier for people living with AMD. The app presents whatever you're reading as a single line of large, scrolling text on your tablet or smartphone.

This helps people with AMD read more easily using the eccentric viewing technique, where you utilise your intact peripheral vision rather than your limited central vision to view something.

The developers also offer a similar product called Ev News, for news stories.

The MD\_evReader even boasts one very famous fan. Award-winning actress Dame Judi Dench – who has AMD – described the app as “enormously beneficial”.

To download, search 'MD\_evReader' wherever you download your apps.



## Use your iPhone as a magnifying glass using this shortcut

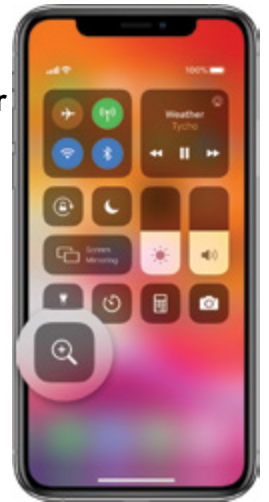
Did you know that you can configure your iPhone so that tapping the back of it brings up a magnifier, or inverts the colours?

If you have an iPhone 8 or later with the latest version of iOS installed, you can set a double tap or a triple tap on the back of the phone to trigger an accessibility shortcut.

Go to Settings > Accessibility > Touch, and select Back Tap. Then choose Double-Tap or Triple-Tap and select the feature you want to activate, such as Magnifier or Invert Colours.

Then the next time you double tap or triple tap the back of your phone, it will automatically open that feature.

Magnifier lets you zoom in on both your screen as well as objects nearby, while Invert Colours can make text on your phone easier to read. You can also access the magnifier on your iPhone or iPad by going to Settings > Accessibility, then selecting Magnifier.



## We want your ideas!

Do you have a tip for living well with low vision, or a handy tool you want to tell others about? Then we'd love to hear from you so we can share it with our community. Please get in touch with MDFA through our National Helpline on 1800 111 709 or email [education@mdfoundation.com.au](mailto:education@mdfoundation.com.au) with your hints and tips.

## Thanks for your service, Des!



Much loved volunteer Des Morton has retired from his role with MDFA, bidding farewell to the many friends he made throughout his time with us.

Des got involved with MDFA through his wife Jean, who was diagnosed with wet AMD in the mid-1990s. Jean was declared legally blind within 18 months of that diagnosis, and Des became her carer.

Jean's ophthalmologist was Dr Paul Beaumont, the founding director of what was originally called the Macular Degeneration Foundation in 2001, so Jean and Des became closely connected to the fledgling foundation.

Jean lived with macular disease for two decades before she sadly passed away in 2015, and Des honoured Jean's memory by volunteering with MDFA.

"Some time later when I was adjusting to a new life without her, I heard about the volunteers who were assisting the Foundation and thought this would be a good way to remember her and to do some good for the community," Des says.

"So I joined the band of Foundation vollies (volunteers). I was made very welcome by them and the MDFA staff."

Des quickly became a cherished member of MDFA's community of volunteers, affectionately known as the A Team (pictured right).

"Tuesdays with the A Team became a very important part of my weekly routine – something positive to do and good company and fellowship to enjoy," Des explains.

"My favourite memory was working around the vollies up and down a loaded table with a full A Team going full steam with our work.

"The work was never mentally taxing, so we made it fun by friendly banter.

"However, I can honestly say that the most rewarding part of my volunteer experience was speaking to patients on the recent Peer to Peer telephone support program. It was so inspiring to hear people's stories about how they were managing to adjust their lives with vision loss."

A television executive before retirement, Des helped MDFA develop community service announcements to raise awareness on our TV screens in the early days of the Foundation.

He then lent his talents to our advocacy efforts, and even modelled for an MDFA photoshoot in recent years!

Turning 94 this year, Des finds catching public transport to the MDFA office a little trickier, so he's reluctantly retiring as a volunteer.

Thank you, Des, for your contribution over many years – the friendships you have formed with the A Team and the broader MDFA family will never be forgotten.



## Porridge with fruit and nuts

This mouth-watering breakfast for two is a filling start to your day that's also good for your eye health.

This recipe for porridge with fruit and nuts is packed full of nutrients that reduce the risk of developing age-related macular degeneration (AMD) and can slow its progression if you've already been diagnosed.

Almonds are rich in Vitamin E, pistachios are full of zinc and selenium, the berries and the banana are brimming with Vitamin C, while the wholegrain oats contain low glycaemic index (GI) carbohydrates, which help keep your macula healthy.

### Ingredients

- 60g almonds
- 40g pistachios
- Four fresh dates, pitted and roughly chopped
- 750ml milk
- 140g wholegrain rolled oats
- Pinch of salt
- 125ml honey
- Extra milk, to serve
- Berries of choice, to serve
- Sliced banana, to serve

### Instructions

Roughly chop the almonds and place them in a small bowl. Add the dates and pistachios and mix them around.

Place the milk, oats and salt in a medium-sized, heavy-based saucepan. Stir over high heat until the mixture comes to the boil.

Reduce the heat to low and leave the mixture to simmer, uncovered, stirring occasionally for about 10 minutes or until the porridge thickens.

Spoon the porridge into serving bowls and sprinkle it with the nut and date mixture. Drizzle with honey and serve with extra milk.

Top the porridge with your favourite berries, the banana slices and extra nuts as desired.

Bon appetit!



**You can find this recipe in our latest Macula Menu, alongside plenty of other recipes that are as good for your eyes as they are for your tastebuds.**

This free online cookbook also contains a five-day meal-planner so you can map out macula-friendly dishes for breakfast, lunch and dinner.

This Macula Menu includes delicious recipes like smoked salmon omelettes, vegetable-and-feta burger patties and a pumpkin, spinach and walnut pasta bake.

Eating a healthy, well-balanced diet – which includes eye-friendly foods – will benefit your overall wellbeing as well as your eye health. But it's important you speak to your doctor before changing your diet or taking any supplements.

Download your copy from our website ([www.mdfoundation.com.au](http://www.mdfoundation.com.au)), or by scanning this QR code.



# How we can help you



## Get your hands on our free resources

MDFA offers a range of free publications – both in print and online – to help you live well with macular disease.

When you visit [www.mdffoundation.com.au/resources](http://www.mdffoundation.com.au/resources), you will find fact sheets and publications on an array of topics, including:

- age-related macular degeneration
- diabetic eye disease
- eye injection costs and rebates
- nutrition and supplements
- living well with vision loss

We also provide info packs for different stages of your journey with macular disease, tailoring information kits

to people living with low vision, or those at risk of, diagnosed or living with either diabetic eye disease or AMD. Don't forget, you can order a free Amsler grid to pop on your fridge to monitor your vision at home.

All MDFA resources are free of charge. To download yours, or to order a printed copy to be mailed to you, simply visit [www.mdffoundation.com.au/resources](http://www.mdffoundation.com.au/resources) or scan this QR code.



### New website launching soon

The next time you visit MDFA's website, you might notice things look a little different.

We're upgrading our website to make it even easier for you to access all the free information, advice and support that MDFA provides Australia's macular disease community.

[www.mdffoundation.com.au](http://www.mdffoundation.com.au)



Contact Us: 1800 111 709

[info@mdffoundation.com.au](mailto:info@mdffoundation.com.au)

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Suite 902, Level 9, 447 Kent Street, Sydney 2000