



# Vision Voice

Autumn Edition 2020

## MBS rebates for eye injections: What's the latest?

**Our position:** Any cuts to the MBS for intravitreal injections will inherently be passed to patients. MDFA has asked for assurance that any cuts to the MBS be quarantined until alternative models can be developed so that Australians can be assured of accessing affordable sight saving treatment, irrespective of where they live.

Our last edition of 'Vision Voice' outlined the proposed changes to the Medicare rebate for intravitreal injections in the draft Medicare Benefits Scheme (MBS) Taskforce report. As part of a review, the Taskforce suggested a 69 per cent cut to the rebate for eye injections.

MDFA met with the Minister for Health, the Hon Greg Hunt in December last year to request that any cut to the MBS be quarantined because it would have a very negative impact on many patients.

MDFA also commissioned PwC Australia to undertake economic modelling to determine the impact on patients and the unintended consequences of offsetting MBS savings to government, by cost shifting to other parts of the health system. The results were compelling and showed that there would be \$380m MBS and \$428m PBS cost savings to Government (and taxpayers). However, these savings would be offset by increased health and welfare costs. There would actually be a direct net cost of \$168m over the next four years as people lose their vision and require greater support from the health, aged care and social service systems.

## Australian Government invests in education and awareness

MDFA has been awarded \$2.5 million over four years to develop new educational programs, targeting both consumer groups and general healthcare professionals.

Under the Public Health and Chronic Disease Program, MDFA tendered for two new funding streams to raise consumer awareness of macular disease and extend the understanding of professionals like GPs and pharmacists. These were highlighted as critical areas for support in the National Strategic Action Plan for Macular Disease.

MDFA has long provided macular disease education to eye health professionals. The investment will allow greater opportunity for collaboration across a wider healthcare network.

As part of the initiative, MDFA will work with key healthcare professionals as part of a consortium to widen the opportunity to educate all Australians about the risks of macular disease. Our consortium partners will include Optometry Australia, the Royal Australian and New Zealand College of Ophthalmologists, Diabetes Australia, Royal Australian College of GPs, Oculo, Vision 2020, Australian College of Rural & Remote Medicine and the Pharmaceutical Society of Australia.

# CEO Update

It's important to acknowledge the work and support of the Australian community and volunteer firefighters throughout the bushfire and flood disasters, which dominated the start of 2020. We are now assessing the potential ramifications of the Coronavirus (COVID-19) and will keep our community informed of any changes that might occur with education seminars and events, should the situation escalate in Australia.

With the support of the MDFA Board, we decided not to seek donations from our community, given the outpouring of support in a time of crisis. We understand that many in our community are at capacity, and it was a time for all of us to address the immediate needs of our country. Our fundraising appeal program will resume in May and June as part of the end of financial year tax appeal. If you can, we hope you will support our work.

As you will read, the review of the Medicare Benefits Schedule (MBS) continues to be at the top of our agenda. MDFA submitted its recommendations to the MBS Review Taskforce and we expect to receive an update in the coming months. Thank you to all who shared your concerns and voiced opinions.

On behalf of the Board, the MDFA staff, and the whole of the macular disease community, we wish to extend our sincerest thanks to Ita Buttrose AC OBE, who due to increasing work commitments is stepping down as Patron. Ita has proudly, diligently, and generously supported MDFA for the past 15 years. Ita has championed the macular disease cause, and through this awareness and action has

saved the sight of so many living with a macular condition. We are, and will be, forever humbled and indebted to Ita for her leadership. Thank you.



**Dee Hopkins**  
Chief Executive Officer

## MBS rebates for eye injections: What's the latest?

**cont'd.**

We thank the many people within our community who have shared their stories about the impact a cut in the rebate would have on them. Your de-identified stories have formed the basis of our formal submission, and in our representations to the full Taskforce, key members of federal parliament and to Department of Health officials.

To summarise our key activities in representing the macular disease community on this issue to date:

1. MDFA met with Minister Hunt to present the PwC findings, including the feedback we received from you, the people who will be directly affected by such cuts. Minister Hunt understands the difficulties patients currently face and has committed to work with MDFA to ensure your voices are heard throughout the consultation process.
2. MDFA presented the PwC findings to the full Taskforce in December in addition to key members of federal parliament including the Shadow Minister for Health, the Hon Chris Bowen, the Greens and other Coalition backbenchers.
3. MDFA met with several Department of Health officials including the MBS Branch executives to brief them. The Department has received numerous correspondence from consumers and has referred concerned consumers to the MDFA for assistance.
4. MDFA made representations to several members of the Australian Parliament and briefed them on the impact of a rebate cut on patients and asked that they support our position.
5. MDFA developed a summary briefing paper for several related peak bodies and agencies to inform their own submissions in response to the Taskforce. We also met with the Consumer Health Forum who supported our position in its own submission to the Taskforce.
6. MDFA personally briefed the Health Ministers in Victoria, NSW, ACT and Tasmania who have committed to supporting our position in writing to Minister Hunt. We have also written to each Health Minister in every other state seeking an opportunity to brief them and make representations to the federal Minister.

## Next Steps

This MBS review has highlighted that many vulnerable Australians, particularly pensioners and those in financial stress, need public access to this sight saving treatment. MDFA has been discussing with the respective State and Territory Government Health Ministers why expanded public services are needed. We are committed to work with our community, government and other stakeholders to improve our current system of accessible and affordable treatment.

## Let's keep your vision S.A.F.E. this Macula Month

Macula Month has been about raising awareness of macular disease for early detection. This year's 2020 Macula Month in May is now about enabling Australians over 50 to check their risk, improve health literacy and enable them to take early action.

We are asking all Australians to keep their vision S.A.F.E. by remembering the key risks and early detection measures for age-related macular degeneration (AMD).

**S** – smoking  
**A** – age  
**F** – family history  
**E** – eye examinations

In Australia, one in seven over the age of 50 have some evidence of AMD. While there's not much we can do about turning back the ageing clock, we can make changes to diet and lifestyle; learn about our family eye health history; and have regular eye examinations with an optometrist.

If you are between 50 and 60 years and have an AMD diagnosis and would like to share your story, please contact MDFA on our National Helpline or email [communications@mdfoundation.com.au](mailto:communications@mdfoundation.com.au).


If you already have been diagnosed with age-related macular degeneration, we ask that you talk to your family about checking their risk and take early action. You can get more information by contacting MDFA on **1800 111 709** or visiting [www.mdfoundation.com.au](http://www.mdfoundation.com.au).



**You've got your mum's eyes**

**Do you have her macular disease?**

Early action saves sight.  
Get your macula checked today.



## Healthy Choices

### Interior style tips for living with vision loss

Living with low vision means making some adjustments to your life but a few simple changes you can make a huge impact on your safety and ease of your life at home.

### Be bold with colour and contrast

Using bright colours and contrast isn't just a great way to express your inner stylist, it can also be a helpful way to identify furniture and objects in your home. Your brain can quickly distinguish shapes and colours when they stand out against a different backdrop. If you have a dark sofa or table, giving the arms or surface a brighter throw rug or accessory can make living with reduced vision a lot easier.

### Let there be light

You can give yourself a brighter outlook by adding warm light to your home. This is great for darker rooms. It can be as simple as choosing the right lightbulbs with a soft, warm light or angling your lamps to face areas where you generally handle tasks like cooking or organising items.

### Be a master organiser

A great way people can help loved ones with vision loss is to help them organise the belongings they use most often. How to arrange them depends on what's easiest for the person living with reduced vision in their day-to-day routine.

### Embrace new technology

One of the best things about technology is that smart phones and smart home devices like Google Home can be controlled through voice commands rather than visually. This means you can tell your phone to call a family member, or tell a device in your home to switch connected lights, music and televisions on or off.







Ita and MDFA volunteers

## Farewell and thank you, Ita



After 15 years of passionate advocacy, Ita Buttrose AC OBE is stepping down as Patron of Macular Disease Foundation Australia (MDFA).

A journalist, editor, businesswoman and Australian of the Year (2013), Ita has been the public champion of MDFA since 2005.

“I’m passionate about making sure all Australians know that, to a significant degree, they can eat away their risk of developing age-related macular degeneration.

**Ita Buttrose**

In 2019, the same year she was awarded the nation’s highest distinction – a Companion of the Order of Australia (AC) – Ita was appointed Chair of the Australian Broadcasting Corporation. Assessing the demands of this new role, Ita has advised MDFA that she now needs to reduce her charitable commitments.

Ita’s late father, Charlie Buttrose, had age-related macular degeneration (AMD). Three of his siblings also had it, including the youngest, Ita’s Uncle Gerald.

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Let’s stop Australians going blind. For me, it’s personal.

**Ita Buttrose**

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"One thing I have noticed is how few people know that a family history of the disease brings with it a high risk of macular degeneration. When I tell them that I have a 50 per cent chance of getting it too, most people are usually shocked. I get regular exercise, watch my weight and follow MDFA's recommended diet.

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I get my macula checked annually and when my Ophthalmic Surgeon tells me my macula is in pristine condition, his words are music to my ears!

**Ita Buttrose**”

Since becoming MDFA Patron, Ita has been a prominent voice during our Macula Month campaigns, generously appearing in advertising campaigns and fronting the media.

Out of the public gaze, she worked tirelessly as an advocate, making sure the needs of the macular disease community were presented to policy and decision makers. Ita leaves with warm wishes for the future and our heartfelt thanks for using her unique platform to raise awareness of macular disease, particularly AMD.

Gerald and Ita Buttrose



Ita Buttrose on set of Sunrise Channel 7

Ita's commitment, dedication, passion and leadership will have a long-lasting legacy for the macular disease community.

In her capacity as Patron, she has helped saved the sight of thousands of Australians, and for this we are all truly thankful.

**We wish Ita success in her trailblazing career and life. If you would like to share send a message of thanks to Ita, please acknowledge our amazing Patron by emailing [info@mdfoundation.com.au](mailto:info@mdfoundation.com.au) and we will share your words with Ita.**

## Ita's Uncle Gerald

It is not just Ita who shared her family's experience of macular disease. Ita's uncle, Gerald Buttrose, generously allowed MDFA to share his story about living with wet (neovascular) AMD.

Uncle Gerald's story was one that highlighted the benefits of taking immediate action to save sight.

Gerald always had regular eye check-ups and had one in 2002. However, a short time later, he noticed the road markings on the freeway were moving.

When he noticed changes in the vision of his left eye in 2008, prompt intervention by Ita led to a diagnosis of wet AMD in that eye also. He commenced what was, at that time, relatively new treatment of anti-VEGF injections.

It saved his sight and Gerald has had regular injections ever since.

"People have got the wrong idea about the injections – there's nothing to it. There's a split-second sensation... it's well worth it. Why would you hesitate? Your sight's at stake," Gerald said.

## Meet the researchers

### Professor Alex Brown: macular disease and Indigenous Australians



Professor Alex Brown of the South Australian Health and Medical Research Institute (SAHMRI) aims to uncover the reasons why Indigenous Australians experience much higher rates of macular leaking and swelling than non-Indigenous Australians.

"I thought research was an opportunity to generate ideas... and ultimately to create new evidence that help people in their quality of life and hopefully prevented illness in larger populations," Alex says.

Alex's study will research a variety of aspects of health and diabetes, including the social, clinical, and medical. The project will also follow people with diabetes for four-to-five years in the hopes of finding predicting factors for diabetic macular degeneration.

"What we're trying to identify is really the early markers or predictors of those who will develop macular disease over the ensuing 5–10 years."

Diabetes-related vision loss is particularly frequent in Indigenous Australians, affecting approximately five times more Indigenous Australians than non-Indigenous Australian. It occurs when diabetes damages small blood vessels in the eye, causing leakage of fluid at the macula.

The study will involve a wide breadth of research undertaken with Indigenous Australians, including detailed eye examinations, and assessments of the macula and retina called Optical Coherence Tomography (OCT).

"We'd love to be able to be a part of reducing the burden of preventable blindness of Aboriginal people in this country and hopefully identify markers or methods of preventing blindness in other Indigenous populations around the world."

The study has the potential to help target treatments and prevention strategies. This could have a positive impact on reducing preventable blindness in disadvantaged communities around the country and more broadly.

### The first step towards scar-less wound healing in AMD

Grant-awarded research may be the first step towards scar-less wound healing in AMD.



Dr Audra Shadforth has recently received a grant from MDFA's Research Grants Program for her project investigating the potential for scar-less wound healing in age-related macular degeneration (AMD).

While there are currently effective treatments for wet AMD, they are unfortunately not a cure. These treatments, which are called anti-VEGF injections, work to temporarily stabilise the eye's condition in order to maintain the best possible vision for patients. Unfortunately, nearly half of eyes that receive these therapies can continue to develop blinding scars under the macula within two years of treatment.

"The aim of my project is to investigate the scar formation," Audra tells us. "If we cut the skin on our arm, the wound can heal well with minimal scarring, or it can heal up with a gnarly scar. A wound at the back the eye is the same. It is just happening in a really inconvenient location."



“Our project will investigate the cells and mechanisms responsible for scar tissue formation under the macula, and we will use emergent technologies and important clues from studies on human tissues capable of regenerative healing. This means the cells have special properties that allow them to heal a wound without a scar.”

Audra aims to find out if it may one day be possible to instruct the cells in the eye to heal scarlessly. “Do our eye cells have the potential to do this too? Once we understand that potential, we can move along to control that process – to use those cells in a way that might be a cellular therapy – a new, sustainable treatment for AMD, so that patients can retain their sight.”

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## The Centre for Eye Research Australia is seeking Victorians with AMD for early-detection research



Dr Zhichao Wu from the Centre for Eye Research Australia is investigating techniques to better identify who is at high risk of progressing to late stage wet (neovascular) AMD so those people can be monitored more closely.

While there are effective treatments available for wet AMD, delays and challenges with detecting the development of the disease can lead to vision loss.

The Macular Research Unit at the Centre for Eye Research Australia (CERA) is currently seeking volunteers with dry age-related macular degeneration (AMD) to be involved in research trials that will help find a cure and prevent irreversible vision loss from this condition.

These include either treatment trials of novel interventions to slow or prevent disease progression, or non-treatment trials to aid understanding of AMD to develop new management strategies (including treatments or diagnostics).

Patients who have the early signs of AMD (such as drusen, or yellow deposits at the macula) without any vision loss, or those with the later signs of dry AMD where vision has been affected, who have not

previously or are currently having eye injections for AMD, are being sought in these studies. Your optometrist or ophthalmologist will be able to confirm what stage of AMD you have, if you are unsure.

There are no costs associated with participating in these studies, nor are reimbursements provided.

For further information, please contact CERA on (03) 9929 8113 or [amd-studies@cera.org.au](mailto:amd-studies@cera.org.au).



L-R front row - Robert Kaye SC (MDFA Chairman), Dr Shadforth, His Excellency General the Hon David Hurley, Her Excellency Mrs Hurley, Dee Hopkins (CEO). Back row - Prof Brown, Dr Wu.

### TGA & Beovu® registration

The Therapeutic Goods Administration (TGA) has announced the registration of Beovu® (Brolucizumab) solution for the injection for the treatment of wet (neovascular) age-related macular degeneration (wet AMD). Beovu is the first approved anti-VEGF agent in Australia to offer the ability to maintain eligible wet AMD patients on a three-month dosing interval directly after the monthly loading doses.

Trials have shown that this new therapy may extend the duration between treatments for some patients. From a real-world perspective, we hope that greater time between injections will reduce the burden of treatment for eligible patients.

Beovu® (Brolucizumab) is manufactured by Novartis. MDFA receives partnership funding from Novartis to support our work. MDFA does not endorse any specific treatment or therapy. Please consult your ophthalmologist for further information.

# Education Sessions

## Webinars

Webinars are live education sessions that occur over the internet. They are just like our face-to-face education sessions but viewed on your computer as a live video online from the comfort of your own home. These webinars are interactive – you can type in any questions you may have during the session and have them answered by our presenters.

Date	Topic	Time	Location
06/05/2020	Understanding AMD	2pm – 4pm	Online
17/06/2020	Living safely with low vision	2pm – 4pm	Online
23/07/2020	Diabetes and your eyes	10am – 12pm	Online

To be sent an email link to join a webinar, please call **1800 111 709** or email [education@mdfoundation.com.au](mailto:education@mdfoundation.com.au)

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## Face-to-face sessions

Date	Topic	Venue	Time	Address
19/05/2020	Age-related macular degeneration	Falcon eLibrary and Community Centre	2pm – 4pm	Corner Flavir Street and Cobblers Avenue, Falcon, WA
20/05/2020	Age-related macular degeneration	Victoria Park Community Centre	2pm – 4pm	248 Gloucester Street, East Victoria Park, WA
28/05/2020	Diabetes and eye health; in partnership with Sydney Eye Hospital, presented by Clinical Nurse Consultant, Ophthalmology Community Liaison Tae Park	Idea Space, Darling Square Library	10.30am – 12.30pm	Level 1–2, Darling Exchange Building, 1 Little Pier St, Haymarket, NSW
17/06/2020	Age-related macular degeneration	Mount Martha House Community Centre	10am – 12pm	466 Esplanade, Mount Martha, VIC
15/07/2020	Eating for eye health	Balwyn Room 1, Balwyn Library	10am – 12pm	336 Whitehorse Road, Balwyn, VIC
19/08/2020	Age-related macular degeneration	Rosny Library	2pm – 4pm	46 Bligh Street, Rosny Park, TAS

To register to attend any of our face-to-face education sessions, please call our National Helpline on **1800 111 709** or email us at [education@mdfoundation.com.au](mailto:education@mdfoundation.com.au).



**For an up to date list of all education sessions we have available, please visit [www.mdffoundation.com.au](http://www.mdffoundation.com.au), @MacularDiseaseFoundationAustralia on Facebook or call our National Helpline on 1800 111 709.**

We are always looking for opportunities to educate more people on macular diseases. If you are a part of a community group such as Rotary, Probus, retirement village or seniors group that is interested in learning

more about macular disease and what you can do to minimise risk, please contact the Education Team on 1800 111 709 or email [education@mdffoundation.com.au](mailto:education@mdffoundation.com.au). We can also cater for non-English speaking groups.

MDFA continues to watch the unfolding of the Coronavirus (COVID-19). Should we reach a point where education sessions need to be cancelled, we will contact each registered participant and provide you with appropriate information.

## Q&A

# AREDS2 supplements and AMD



## How do AREDS2 supplements affect AMD progression?

If you've been diagnosed with aged-related macular degeneration (AMD), you may have heard about the benefits of taking certain supplements.

According to two major studies (the Age-Related Eye Disease Studies or AREDS studies), taking specific nutrient combinations can contribute to slowing or reducing the effects of AMD over time in certain groups. It's important to know how these supplements can help slow progression of AMD and at which stages.

## Are AREDS2 supplements effective for your stage of AMD?

While supplements are not a cure for AMD, if you have intermediate stage AMD (in one or both eyes), AREDS2 supplements may help lower your risk of progressing to late AMD.

The studies have also shown that if you have late stage AMD in one eye only, supplements may help lower your risk of developing AMD in your other eye.

Unfortunately, supplements don't help in cases of late stage AMD affecting both eyes, early stage AMD, or if you have no signs of AMD.

## What if you're showing no or early signs of AMD?

The best thing you can do is to have regular eye exams and monitor your vision between exams with an Amsler grid. Also, make sure you have an eye-friendly diet. You can download Macula Menus from our website at [mdffoundation.com.au](http://mdffoundation.com.au).

## Where can I get AREDS2 supplements?

AREDS2 supplements are available via a chemist without a prescription and can also be ordered online.

AREDS2 supplements can differ in dosage so talk to your optometrist or ophthalmologist about which supplement is right for you. Remember to speak with your doctor before starting supplements as higher dosages of vitamins and minerals can adversely affect other medications.

You can get more information from our National Helpline on **1800 111 709**.



# Jeremy Manship will embark on a 200km marathon in honour of his father-in-law



MDFA wants to wish good luck to Jeremy and Paul Manship as they embark on a massive 200km journey to help support people with age-related macular degeneration, in honour of Jeremy's father-in-law, Bill.

On Saturday, 2 May 2020, Jeremy will be fundraising for MDFA by cycling 100km followed immediately by a gruelling non-stop walk of 100km. His son, Paul, has put his hand up to join Jeremy for the 100km walking phase.

"I'm really pleased with that and it'll be nice for someone else to suffer as well," Jeremy jokes.

Jeremy's father-in-law, Bill Gray, who lived in Scotland, experienced age-related macular degeneration.

"I'm doing this in memory of my father-in-law, William (Bill) Gray. Bill sadly passed away just before Christmas and although macular disease was not the reason for his passing, he did suffer with it in the last four years of his life.

"Your kind donations will help fund research which could eventually help people suffering with macular disease worldwide."

You can donate to Jeremy's fundraising efforts on his gofundme page, 'Macular Disease Cycle and Walk for Bill'.

**If you would also be interested in raising money and awareness of macular disease, please call us on 1800 111 709.**



Jeremy and Paul



## Roth Gair Golf Day

This year marks the 13th anniversary of this Charity Golf Day for the Roth Gair Shield. The event honours and remembers the late Roth Gair, who was a retired President of the Lions Club of Forest Hill.

Roth Gair lived with age-related macular degeneration, which impacted his ability to play his beloved 19 holes. The event raises funds for MDFA to help continue our ongoing commitment to reducing the incidence and impact of macular diseases.

The importance and dedication of organisations such as Lions and their outstanding contributions are paramount in assisting MDFA in raising awareness of macular disease, as well as supporting those diagnosed with it.

MDFA is committed to providing support services including our National Helpline, education programs promoting key eye health messages to save sight and to raise awareness of macular disease.

## Our Community

### Carers Australia

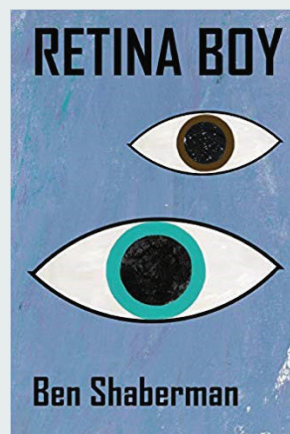
From 6 April 2020, the current national Carer Line will no longer be operated by state/territory Carer Associations.

Carers are advised to contact the new Carer Gateway contact centre on a new number:  
**1800 422 737.**

The Carer Gateway:

- provides practical information and advice
- helps carers to get the services and support they need
- provides free counselling services over the phone
- provides free coaching to help carers in their role
- assist carers to connect with other carers through a community forum.

## Book Club



### Retina Boy By Ben Shaberman

Retina Boy is a quirky 'coming of age' yarn with a sci-fi twist.

Our hero is a boy, born without retinas, and the most hypnotic aquamarine coloured eyes.

Retina Boy grew up as a brilliant but normal American teenager, who had an amazing talent for lead guitar. His girlfriend, Marcy, equally clever, is unable to walk as a result of a childhood spinal injury. Retina Boy is her legs, and she is his eyes, until one day he disappears without trace.

The author, Ben Shaberman, is a writer from the US organisation Foundation Fighting Blindness and was inspired to write the book by his real-life work interviewing people and families impacted by retinal conditions.

The book delivers key facts about retinal disease, research and potential cures in a way that informs, but is never dull.

It is a light, fast-paced fun read that hits all the right notes for young (and even not so young) adult readers.

Intertwined with messages about consumerism and the need to protect the planet, Retina Boy is an intriguing story that reminds us that physical disabilities are no barrier to leading an extraordinary life.

Retina Boy, published by Apprentice House, is available in paperback, on kindle and as an audio book.

*Review by Michelle Hauschild,  
Media and Communications, MDFA*



# How we can support you



## Time for a chat: Peer to Peer

Sometimes you just need a friendly voice on the other end of the phone, and the Macular Disease Foundation Australia's Peer to Peer telephone support pilot program has been such a success, we're extending it.

We know that for people without a support network, vision loss from macular disease can be quite isolating.

The Peer to Peer program will give you the opportunity to speak to and share experiences with one of our volunteers who are either living with or have a close friend or family member with macular disease.

Our Peer to Peer program is not a counselling service. Our volunteers

will not give out any disease information and any questions relating to macular disease will be transferred back to our education team. But they can share their life experiences and are great conversationalists!

89-year-old Maureen, from Queensland, was one of the early participants in the Peer to Peer program. She has wet AMD and while she receives regular injections, her sight is deteriorating. She chatted with Val, an MDFA volunteer, who is also living with wet AMD.

Maureen highly recommends the Peer to Peer program.

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It really helps to talk to someone outside of the family. It does you a lot of good. I enjoyed talking to Val and afterwards, I felt uplifted.

**Maureen, 89**

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MDFA is also setting up a face-to-face peer support group in Melbourne's eastern suburbs.

**Please call the National Helpline on 1800 111 709 for further information or to register for either of these initiatives.**