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Macular Disease Foundation Australia appreciates the opportunity to provide a submission to the consultation on the funding rules for aged care services.

Macular Disease Foundation is the national peak body fighting for the sight of people living with macular disease, Australia's largest cause of vision loss and blindness.

In general, Macular Disease Foundation supports the new funding rules for the aged care system, however some content is too vague and requires more clarity.

Specific feedback on individual sections are as follows.

Feedback: Quarterly rollover credit (page 7 and page 11)

Macular Disease Foundation **supports** the quarterly rollover of credit, resetting at the start of a new financial year.

The current rules allow for indefinite accumulation of unspent funds, which provides greater flexibility but is dependent on the approval of individual Home Care Package Providers, which can create inequity and inconsistency in meeting the needs of aged care consumers.

The new Support at Home program is intended to provide more comprehensive services to meet the needs of aged care consumers, including the provision of funded goods, equipment and assistive technology for older people with a disability. Limiting the accumulation of unspent funds (credit) until the end of the financial year is better aligned with the new program, as it seeks to ensure that all funding is used in a timely way as per the assessment results.

However, Macular Disease Foundation **recommends** the addition of text providing guidance on the use of unspent funds be added to the Rules, as it is currently unclear how this credit can be used by consumers.

Feedback: Classification type ongoing (page 18)

Macular Disease Foundation **supports** the inclusion of "Assistance dogs" in the Rules. However, further details are required to clarify what types of dogs are defined as assistance dogs.

Macular Disease Foundation **recommends** that the definition of "Assistance dogs" is added to the "Definitions" section (page 2), and should include Guide Dogs, also known as Dog Guides and Seeing Eye Dogs, which assist people with vision loss and blindness.

It is also unclear what the \$2,000 amount attributed to "Assistance dogs" (page 18) refers to. Is this an annual funding amount or a one-off amount for people who require assistance dogs? Does the funding go to the Support at Home client or the Service Provider?

Macular Disease Foundation has consulted with guide dog users and found the average annual cost to maintain a guide dog to be \$2,700. This average cost includes food, grooming and incidentals, veterinary care, and insurance.

Macular Disease Foundation **recommends** that further clarity be provided on assistance dog funding, and that adequate ongoing funding be provided for Support at Home clients and service providers.

Feedback: Rural and remote supplement (page 19)

Macular Disease Foundation supports the inclusion of rural and remote supplement funding, which will better support the sustainability of service providers in low population areas.

Feedback: Working out individual contributions – circumstances and amounts (page 33)

Macular Disease Foundation **recommends** further details be added to the list of funded aged care services below, which involve the sourcing and supply to the individual of products listed in the AT-HM List.

Each category in the current list below needs to define what services, technologies and aids the category will include.

For example, we believe there needs to be clarity about the low vision aids and technologies that will be included in each of the categories listed below, that people with vision loss and blindness will have access to:

- i. Managing body functions
- ii. Self-care products
- iii. Mobility products
- iv. Domestic life products
- v. Communication and information management products

Macular Disease Foundation also looks forward to reviewing the AT-HM List when it becomes available for consultation.

Feedback: Pausing and restarting Support at Home funding and services (currently not in Rules)

Macular Disease Foundation **recommends** clarification regarding the mechanisms for pausing and restarting Support at Home funding and services.

For example, this mechanism would apply to Support at Home clients who need to pause services when they are hospitalised, and restart services after they are discharged and return home. It would be unfair if in this circumstance they are continually charged for services they are unable to use while hospitalised.

This clarification content is currently not included in the Rules.

About macular disease

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

Macular disease is the leading cause of blindness and severe vision loss in Australia.¹ There are over 1.9 million Australians living with some evidence of macular disease.^{1,2}

Age-related macular degeneration (AMD) is the most common type of macular disease, which is the primary cause of irreversible vision loss and blindness among older Australians.^{3,4} There are 1.5 million Australians with some evidence of AMD.⁵

Anti-vascular endothelial growth factor (anti-VEGF) eye injections are the sight-saving treatment available for people with the neovascular form of AMD (also known as wet AMD) and other macular diseases, including diabetic macular oedema and retinal vein occlusion. The injections are typically delivered by an ophthalmologist in an outpatient clinic setting.

People receive eye injection treatment for neovascular AMD every 4 to 12 weeks for an indefinite period to maintain their vision. There is no cure. **Without treatment, people with neovascular AMD will progressively develop severe vision loss and blindness.**⁶

For people living with diabetic macular oedema and retinal vein occlusion, eye injection treatment can prevent further vision loss or even improve vision, and in many cases, treatment may safely be suspended once expected outcomes have been achieved.

In Australia, there are at least **62,000 people with neovascular AMD, 18,000 with diabetic macular oedema and 11,000 with retinal vein occlusion** who receive sight-saving eye injection treatments.^{7,8}

Impact on people living with macular disease

Deteriorating vision significantly impacts a person's quality of life, including loss of the ability to drive, difficulty maintaining employment, and challenges in living independently. This in turn significantly increases the need for costly health, aged care and disability support services.^{9,10,11}

Whilst eye injection treatments for neovascular AMD are available which slow or prevent vision loss, there is limited access to this sight-saving eye injection treatment within the public hospital system across Australia. As a result, the vast majority of people have to pay out-of-pocket costs to receive treatment in the clinics of private ophthalmologists.

Even with the Medicare Benefits Schedule and Pharmaceutical Benefits Scheme safety nets, eye injection treatment is a financial challenge to the most financially vulnerable Australians as it consumes a significant proportion of their income, such as those who rely on the Age Pension for their everyday needs.

The cost of treatment is significant, with out-of-pocket costs estimated at approximately \$1,900 per year based on an average of seven treatments a year, which includes factoring in the additional rebates from reaching the Extended Medicare Safety Net Threshold.^{8,12} Many people will require treatment to both eyes, further increasing out-of-pocket costs.

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

Unfortunately, 20% of people with neovascular AMD will stop treatment in their first year, and 50% of people will stop their eye injections within 5 years,⁸ putting them at risk of severe vision loss or blindness.

This low persistence with treatment is highly concerning for Macular Disease Foundation Australia and should be of equal concern to the Australian Government in wanting to ensure less people experience vision loss and blindness.

There are several factors that result in people with neovascular AMD stopping treatment against the advice of their ophthalmologist, including the financial burden of treatment. A 2020 survey undertaken by Macular Disease Foundation Australia on barriers to accessing treatment found:¹³

- **78% of people paid out-of-pocket costs (after rebates)**, with only 17% of people did not pay any out-of-pocket costs. People who paid out-of-pocket costs, 69% paid up to \$299 per treatment (after rebates), 20% paid between \$300 to \$599, and 6% paid over \$600.
- **69% of people had some difficulty paying their ophthalmologists' fees.** The survey also found that 51% of respondents did not feel comfortable asking their ophthalmologist to reduce their fees; and only 21% asked their ophthalmologist for a fee reduction when it was a challenge to pay for treatment.

- **29% of people considered delaying or stopping treatment due to cost**, and of these 6% actually delayed or stopped treatment.
- **Importantly, 29% of people reported that they had been forced to cut back on other expenses**, including basics such as food and groceries, to be able to afford treatment costs.

People who delay or stop treatment risk irreversible vision loss or blindness.⁶ This should not be happening in a country like Australia, where we expect to have a world-class health system.

Financial impact of macular disease on government

The total annual economic cost of vision loss in Australia is estimated to be \$16.6 billion or \$29,000 per person with vision loss aged over 40.³

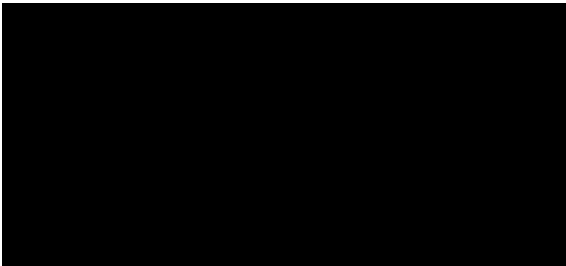
The total annual economic cost of vision loss associated with AMD was estimated at \$5.15 billion, of which the direct cost was \$748.4 million (\$6,982 per person).² In addition, these costs are likely to be an under-estimate, given they are from 2010 and have not been adjusted for inflation.

People with low vision incur significantly higher direct health care costs than fully sighted people. In addition, the loss of wellbeing is the greatest single contributor to the overall cost of vision loss. These costs are associated with the increased morbidity and mortality from vision loss and include a higher risk of depression, falls and hip fractures, and increased admission to nursing homes or health services.¹⁴

Helping Australians to stay on eye injection treatment and maintain their vision is also a win for government in terms of the long-term net savings. Based on a recent economic modelling study, investment that increases eye injection treatment persistence by 25% will result in saving the sight of an additional 22,000 vulnerable Australians, adding up to \$1 billion over 5 years to the government's bottom line.¹⁵

Macular Disease Foundation Australia appreciates the opportunity to input into the consultation on the funding rules for aged care services, and we are happy to provide further information.

Should you have any questions, please do not hesitate to contact my colleague [REDACTED] [REDACTED] or by phone [REDACTED]



About Macular Disease Foundation Australia

Macular Disease Foundation Australia is the national peak body representing people living with macular disease and their carers. Our purpose is to reduce the impact of macular disease through supporting and caring for people living with macular disease; advocating on behalf of the community to government; funding research; and raising community awareness and promoting early detection of the condition.

We currently engage directly with 70,000 members of the community across Australia and are a member of Vision 2020 Australia.

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