25 October 2024

Aged Care Legislative Reform Team
Via email - AgedCareLegislativeReform@health.gov.au

Dear Aged Care Legislative Reform team,

Macular Disease Foundation Australia appreciates the opportunity to provide a submission on the new Aged Care Service List. 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 Aged Care Service List as it covers the essential services needed by older Australians in the aged care system.

Specific feedback on individual sections are as follows.

Feedback – Home support

For **Division 2 (home support service types)**, Macular Disease Foundation:

- **Recommends** greater clarity be provided for **Section 42 (nutrition) Item 1a** on the meaning of "supplementary dietary products (enteral and oral)", and what supplementary dietary products will be covered under this category. Clarity is required to understand whether this would include dietary supplements used to manage chronic age-related medical conditions, such as AREDS 2 supplements for age-related macular degeneration.[1]

  The rationale for this recommendation is that randomised clinical trials have shown that AREDS 2 supplements, which contain a specific formulation of vitamins, minerals and antioxidants, is protective in slowing the progression to later stages of age-related macular degeneration.[2] However, community members have told Macular Disease Foundation the expense of these supplements can be prohibitive.

- **Recommends** greater clarity for **Section 47 (transport)** by expanding the "Services in the service type transport" table to provide better guidance on the purposes for funded transport services. Examples should include transport for medical treatment and clinical care. For example, people with neovascular AMD require transport to attend regular eye injection appointments every 4 to 12 weeks, usually for the rest of their lives. In addition, "community transport" should be added to the table to ensure that this type of not-for-profit transport service continues to be funded and utilised.

  The rationale for recommendation is that surveys undertaken by Macular Disease Foundation have indicated that the burdens of the cost of treatment and travel to treatment appointments are major contributors to people discontinuing their eye injections.[3]

- **Does not support** the inclusion of **Section 46 (therapeutic services for independent living)** and recommends its removal from the Aged Care Service List**.** It is inappropriate for the taxpayer funded aged care system to subsidise complementary and alternative medicines and therapies, as they are not essential for people to live independently at home. These therapeutic services should not be funded through the new Support at Home program, and people who choose to access them may continue to do so through private health insurance or self-funding.

  Instead, Macular Disease Foundation **supports Section 32 (allied health and therapy)** as it allows funding for therapeutic services for independent living, essential for managing health and age-related conditions, delivered or supervised by

accredited health professionals, such as remedial massages delivered by physiotherapists.

Macular Disease Foundation also **recommends** that the wording for **Section 46 Paragraph 2(a)**, "(that the service) uses evidence-based techniques to manage social, mental and physical wellbeing in support of the individual remaining safe and independent at home" be moved to **Section 32** to strengthen its focus on funding only evidence-based therapies.

Feedback – Goods, equipment and assistive technology

Macular Disease Foundation **commends** the Australian Government for the inclusion of **Division 4 (assistive technology service types)**. This new goods, equipment and assistive technology program within the aged care system **must** also help people with vision loss or blindness who live at home to access affordable low vision aids and technologies to continue living independently. Macular Disease Foundation has long championed for the establishment of this program.

Low vision aids and technologies must be included under **Section 51 (equipment and products) Item 6 (assistive technology prescription and clinical support)** as products that address "an individual's functional ability", that will be appropriately delivered by an allied health professional, and that clinical wraparound services related to the product will also be funded.

It is **recommended** that "non-clinical" wraparound services related to these products are also added to **Section 51 Item 6**, to provide flexibility that allows services not directly related to the clinical aspects of the product to be funded. It is important to note that Items 1 to 5 include "non-clinical" wraparound services, and Item 6 should equally follow suit.

Macular Disease Foundation looks forward to **reviewing the "AT-HM List"** once it becomes available to ensure that the appropriate types of low vision aids and technologies are funded.

Macular Disease Foundation also **recommends** that consideration be given for **Division 4 (Assistive technology service types)** and **Division 5 (Other specified matters for assistive technology service types)** to be extended to residential care in the future. This would allow people with vision loss and blindness living in residential aged care facilities to access affordable low vision aids and technologies and maintain a good quality of life, (e.g. reading books and newspapers).

Feedback – Residential care

For **Residential care service types (Division 8)**, Macular Disease Foundation **commends** the Australian Government for the inclusion of **Section 60 (residential clinical care) Item 6 (general access to medical services)** to require residential aged care facilities to make **(b)** "arrangements for the individual to attend any necessary health professional appointments".

Macular Disease Foundation has long championed for residential aged care facilities to be responsible for funding and arranging residents' transport to medical treatment, as they are no longer eligible for transport funding provided in aged care home support programs once they are no longer living independently, and become fully dependent on their residential aged care facility for transport to treatment appointments if they do not have a family member or friend to assist them.

People with neovascular AMD, diabetic macular oedema, and retinal vein occlusion require regular and ongoing eye injections to maintain their vision. These eye injections are predominantly delivered in private ophthalmology clinics and in some public hospitals, so it is essential that patients living in residential aged care facilities can travel to their eye injection appointments, or they will lose sight and go blind. This is completely avoidable.

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**.[4] There are over 1.9 million Australians living with some evidence of macular disease.[4,5]

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.[6,7] There are 1.5 million Australians with some evidence of AMD.[8]

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.[9]**

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.[10,11]

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.[12,13,14]

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.[11,15] 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,[11] 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:[3]

- **78% of people paid out-of-pockets 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.**Error! Bookmark not defined.**
- **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.[9] 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.[6] 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).[5] 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 heath 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.[16]

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.[17]

Macular Disease Foundation Australia appreciates the opportunity to input into the consultation on the Aged Care Service List, and we are happy to provide further information.

Should you have any questions, please do not hesitate to contact my colleague Mark Choo, Senior Policy Advisor at [redacted] or by phone [redacted]

Yours sincerely,

[redacted]

Dr Kathy Chapman
CEO

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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