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Macular Disease Foundation AUSTRALIA™

Our focus is your vision

Submission to the Productivity Commission

Human Services - Identifying sectors for reform (Phase 2)

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OUR VISION

To reduce the incidence and impact of macular disease in Australia

Ophthalmological services in public hospitals need more resources, not contestability

Recommendation: The Federal Government provide a comprehensive report on existing and future access to public care for macular disease, the major cause of blindness and serious vision loss in Australia.

There is an urgent need to increase the availability of public outpatient clinics for the treatment of macular disease to ensure ongoing sight-saving care for people with limited income.

Macular Disease Foundation Australia's submission to this inquiry focuses on the issues surrounding patient access to public hospital outpatient ophthalmology services for diagnosis, provision of sight-saving treatment and the ongoing provision of care for people with macular disease.

It is the Foundation's position that increasing contestability in the public hospital system is unlikely to increase patient access to outpatient ophthalmology services, given that these services are already in extremely short supply across the country, despite the high need and demand.

Currently, the overwhelming majority of people requiring ongoing treatment (eye injections) for age-related macular degeneration, diabetic macular oedema, retinal vein occlusions and other similar conditions receive these in a private ophthalmologist's rooms.

Most people are elderly, and are commonly pensioners or retirees with limited income. Unfortunately, less than 18% of these injections (Medicare item 42738) are bulk-billed (Medicare, March 2015). For people who are not bulk billed, the average fee charged is $204 above the Medicare rebate per injection (Medicare, March 2015).

Even when a person qualifies for the Extended Medicare Safety Net, the average injection fee charged will entail a $40 out of pocket cost, not including other costs for diagnostic tests and normal consultation fees. As these injections may be required as often as monthly, or twice a month if both eyes are affected, the out of pocket costs for pensioners and retirees on limited fixed incomes can be significant.

It is also a concern that the already low levels of bulk-billing for these injections will be forced even lower with the freeze on Medicare rebates, leading to even greater financial stress for many people.

Patients do struggle with these costs and there is always the risk, as indicated by some Foundation clients, that their choice is either "stopping treatment and going blind, or continuing treatment and going broke".

One option for people who have had difficulty paying for these injections given in private ophthalmologist's rooms is to receive treatment in one of a limited number of public outpatient ophthalmology clinics. However, these are typically found in only two or three of the major teaching hospitals in state capital cities.

These clinics invariably have long waiting lists to receive treatment, highlighting the level of demand from people who cannot afford private care. Treatment for 'wet' age-related macular degeneration and similar conditions cannot wait and a delay longer than a few weeks can result

in significant and permanent irreversible vision loss. Public outpatient ophthalmology clinics providing sight saving injections are underfunded, under-resourced and in very limited supply.

The Foundation is aware that some public outpatient ophthalmology clinics are now in a position of being unable to provide treatment as they have no further capacity, while others are treating people for two or three months and then referring to the private sector for maintenance of treatment. Details on the extent of follow up of these patients, once exiting the public system, is difficult.

Patients may now be forced to choose between extreme financial hardship and stopping treatment, as they are unable to afford ongoing private care, with permanent vision loss or blindness being the consequence.

It is also noteworthy that there are almost no public outpatient ophthalmology clinics providing injections for macular disease away from capital cities.

In some rural and regional communities, patients have little or no choice of treating specialist and are therefore unable to 'shop around' for an ophthalmologist who charges the Medicare rate. Without the option of public care, they have essentially no option available for ongoing sight saving treatment, with cost being the deterring factor.

The acute shortage of public care for many ophthalmology services (including treatment of macular disease) is a complex and long-standing issue, with no easy solutions.

The Foundation strongly disagrees with the statement by Duckett and Breadon (2014) featured in the Preliminary Findings Report which states, “Public hospitals could reduce their annual expenditure by more than $900 million without lowering service quality”. Introducing greater contestability in the public hospital system is unlikely to resolve the lack of patient access to public ophthalmology services nor save the sight of Australians in need who depend upon the public hospital system for health services. In addition, the cost of blindness will always outweigh the cost of treatment, so the lack of service and resources (not addressed by contestability) contributes to increased costs to government.

In order to address the current unmet demand, increased resources and funding are needed to increase the supply of ophthalmology services in the public hospital system. There is also a need for a smarter system to engage more ophthalmologists to work in the public hospital system, given the lack of incentives presently available.

It is unacceptable for people to be losing vision or going blind when there are now extraordinarily effective and safe treatments, which are available via the PBS, but are being underutilised.

Once again it is noted, that the cost of blindness will always greatly exceed the cost of treatment, and hence greater efforts must be made to address the lack of public care and thereby increase choice for the most vulnerable in society.

The Federal Government must provide a comprehensive report on existing and future access to public care for macular disease, the major cause of blindness and serious vision loss in Australia.

This is essential to drive solutions to ensure that Australia continues to provide accessibility and affordability of care for all Australians, regardless of their income.

The concept that increasing contestability between public hospitals could improve the quality of care for those with macular disease, requiring sight saving treatment, is just not viable.

About Macular Disease Foundation Australia

Macular Disease Foundation Australia is a national, independent charity established in 2001. It is the only organisation in Australia that specifically supports the needs of the macular disease community.

- Every day the Foundation is working to save the sight of all Australians and has done so for 15 years.
- The Foundation is recognised nationally and internationally as the Australian peak body for macular disease.
- The Foundation is a robust organisation with a strong governance model:
    - An experienced Board of Directors set the strategic direction of the organisation
    - State Chairs represent the macular disease community in their respective states.
    - Four expert Committees including a Medical Committee, comprising 11 of Australia's leading retinal specialists who provide expertise across all macular diseases, guiding the Foundation on major matters related to prevention, treatment and patient outcomes.
    - The Foundation's National Research Advisor, Professor Paul Mitchell, Professor of Ophthalmology University of Sydney, is a world expert on macular disease and is a key source of information and support.
    - The Foundation has experienced senior staff with backgrounds in science, education, communications, pharmaceutical and medical industries, government policy, media and business. The CEO was a recipient of a Harvard Fellowship in 2013 to study *Strategic Perspectives in Non-Profit Management*.
- The Foundation has a broad national membership of almost 52,000, across all states and territories, comprising: those at risk of developing, or living with macular disease, their family and carers; eye care and allied health professionals including optometrists, ophthalmologists, orthoptists, occupational therapists, dietitians, pharmacists, GPs, diabetes organisations, residential aged care facilities, university faculties and students, low vision rehabilitation providers; CALD communities; industry groups, key interest and advocacy groups.
- The Foundation's work in education, awareness and support services directly correlates to and supports the *National Framework for Action to Promote Eye Health and Prevent Avoidable Blindness in Australia*.
- The Foundation has a highly regarded position in representing the views of the membership to government in a collaborative environment in order to make a positive impact on patient outcomes. This is evident in the marked improvements in access to treatment and rehabilitation, support and subsidies for patients, families and carers. Given government's emphasis on chronic disease and improving health outcomes, the Foundation, as a peak body and in its advisory roles, can continue to play a significant role in reducing the incidence and impact of Australia's leading cause of blindness.
- The Foundation has a powerful voice in the eye health sector for its members, and has developed tools and expertise to ensure it effectively communicates and represents the views of members.
- The Foundation has a proven track record of outcomes for public health in Australia which has been recognised on the world stage, with the publication of its work in leading international, peer-reviewed journals: *Aging and Mental Health*[1], *American Journal of Public Health* (AJPH)[2], *Clinical Ophthalmology*[3], *Eye*[4] and *Value in Health*[5].

- The Foundation has been regularly invited to share its outstanding achievements in local and international fora, including at major international conferences and events in Europe, South America and Asia Pacific. Given the recognition of its best practice approach to public health in relation to macular degeneration, the Foundation organised and co-hosted the first-ever *Global Ageing and Vision Advocacy Summit* in April 2013 in Barcelona, Spain in collaboration with the International Federation on Ageing.

Macular disease in Australia

- It is estimated that there are approximately 8.5 million people **at risk** of macular disease and over 1.19 million Australians with **some evidence** of macular disease.[6]
- Macular disease is the greatest contributor to chronic disease in eye health in Australia.[6]
- Macular disease is a large group of sight-threatening diseases that affect the central retina at the back of the eye, which is responsible for detailed central vision. These diseases include macular degeneration, diabetic retinopathy, retinal vein occlusions and numerous other macular dystrophies.
- Macular degeneration and diabetic retinopathy have been categorised as priority eye diseases for the prevention of blindness and vision impairment by the World Health Organisation.
- Early detection of macular disease is vital. Treatment, along with diet and lifestyle measures, can slow progression of macular disease and, in the case of treatment, save sight.[6]
- The most common macular disease in Australia is macular degeneration:
    - **Macular degeneration is a chronic disease with no cure.**
    - It is the leading cause of blindness and severe vision loss in Australia and is the cause of 50% of blindness in Australia. [6]
    - 1 in 7 (1.19 million) people have some evidence of macular degeneration.[6]
    - **This is estimated to increase 70% to 1.7 million by 2030**, in the absence of adequate treatment and prevention measures.[6]
    - Primarily affects those over the age of 50 and the incidence increases with age. [6]
    - Macular degeneration is a major chronic disease with prevalence 50 times that of multiple sclerosis and 4 times that of dementia.[6]
    - The impact of macular degeneration on quality of life is equivalent to cancer or coronary heart disease.[7]
    - Smoking is a key risk factor as it increases the risk of developing macular degeneration by 3 to 4 times and smokers, on average, develop macular degeneration 5 to 10 years earlier than non-smokers[6].
- Diabetic eye disease is the leading cause of blindness among working age adults in Australia:[8]
    - Almost 1.1 million Australians have diagnosed diabetes. Of these, over 300,000 have some degree of diabetic retinopathy and about 65,000 have progressed to sight-threatening eye disease.
    - The longer you have diabetes the greater the likelihood of sight threatening eye disease.

- One in three people over the age of 50 with diabetes has diabetic retinopathy.
- The expected growth in the number of Australians living with diabetes will lead to a corresponding rise in diabetic eye disease and vision loss – numbers are expected to at least double between 2004 and 2024.
- Almost everyone with type 1 diabetes and more than 60% of those with type 2 diabetes will develop some form of diabetic eye disease within 20 years of diagnosis. Significantly, many people with diabetes are diagnosed late, by which time retinopathy may already be present.
- Almost all cases of vision loss from diabetic retinopathy can be prevented with regular eye tests, careful management of diabetes, the use of certain medications such as fenofibrate, and in some cases, treatment with anti-VEGF agents and/or laser and/or steroids.

Socio-economic costs of vision loss in Australia

- **There is a high cost of vision loss from macular disease to government. Even a modest reduction in the proportion of people who progress to vision loss will generate significant savings.**
- Visual impairment prevents healthy and independent ageing and is associated with[6]:
  - Risk of falls increased by two times.
  - Risk of depression increased by three times.
  - Risk of hip fracture increased by four to eight times.
  - Admission to nursing home three years earlier.
  - Social independence decreased by two times.
- Vision loss from macular degeneration:
  - In 2010, the total cost of vision loss, including direct and indirect costs, associated with macular degeneration was estimated at $5.15 billion, of which the financial cost was $748.4 million ($6,982 per person).[6]
  - The socio-economic impacts of macular degeneration include:
    - Lower employment rates.
    - Higher use of services.
    - Social isolation.
    - Emotional distress.
    - An earlier need for nursing home care.
- Vision loss from diabetic retinopathy:
  - As diabetic retinopathy frequently affects people of working age, the social and economic impact of vision loss can be dramatic and long-lasting. People with vision loss from diabetic retinopathy experience higher rates of unemployment and underemployment, reduced safety in the workplace and home, increased rates of depression and greater dependence on carers due to an inability to drive, mobilise independently and undertake common activities. It is clear that even modest

reductions in the proportion of people who progress to vision loss will generate significant savings to government.[8]

- Vision loss from diabetic retinopathy is nearly always preventable, however thousands of Australians continue to lose vision from the disease. Awareness of the risk of blindness from diabetes is low, and compliance to recommended testing regimens, risk reduction strategies and treatment protocols remains unacceptably poor.[8]

- Vision loss in patients with diabetes also directly interferes with essential tasks to manage diabetes such as insulin administration, glucose monitoring, and exercise, making diabetes progression and other complications more likely.[9]

References

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