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# Access to primary eye care for people living with dementia: a call to action for primary care practitioners to 'think vision'

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### ABSTRACT

Access to allied health services offers significant benefits for people living with dementia, yet access is currently fragmented and inconsistent. The 2023–2024 budget allocated AU\$445 million to further enable general practice-led, multidisciplinary teams, with integrated care located within practices, including employment of allied health professionals. Such team care models are recognised by The Royal Australian College of General Practitioners as vital to delivery of high-quality care for older adults. They are especially relevant for over 250,000 Australians who live with dementia in the community. However, not all allied health professionals are currently based within general practices. Future, sustainable general practice-led models of multidisciplinary care that connect patients with external allied health providers could be considered for a comprehensive and collaborative approach to care. Our focus is on people living with dementia, who are at greater risk of preventable vision impairment. Poor vision and/or ocular health can be detected and managed through regular eye examinations, which are predominantly delivered by community-based optometrists in Australia, in a primary care capacity. However, people living with dementia are also less likely to have regular eye examinations. In this paper, we highlight the value of ensuring access to primary eye care services as part of post-diagnosis dementia care. We illustrate the important role of primary care practitioners in building and sustaining connections with allied health professions, like optometry, through effective referral and interprofessional communication systems. This can help break down access barriers to dementia-friendly eye care, through promoting the importance of regular eye tests for people living with dementia.

**Keywords:** allied health occupations, dementia care, eye health, health services: accessibility, health services: aged, optometry, preventive care, primary health care, post-diagnosis support.

## Introduction

Dementia care in Australia focuses on enabling people with dementia to live at home and maintain their independence for as long as possible (Department of Health and Aged Care 2015, 2023). Post-diagnosis access to allied health services is recognised as integral to achieving this goal, and the benefits of access to community-based allied health services for older adults are manifold (Ho *et al.* 2023). However, current research using longitudinal datasets (Byles *et al.* 2021) and Medicare claims data (Kalisch Ellett *et al.* 2020) suggest low utilisation of allied health services by people living with dementia in Australian communities, despite identified benefits to wellbeing, social participation and maintenance of activities of daily living.

A key aspect of the proposed National Dementia Action Plan is improving quality and coordination of post-diagnostic care and support (Department of Health and Aged Care 2023). The Primary Care 10-Year Plan (Department of Health and Aged Care 2022) also recognises multidisciplinary team-based care as key to person-centred care. A recent systematic review identified that 30% of multidisciplinary care interventions, to help older adults continue living in the community, are delivered by primary care services exclusively,

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with a further 26% delivered collaboratively with secondary care teams (Ho *et al.* 2023). Accordingly, there is increasing emphasis on a holistic, collaborative, and whole-systems approach to post-diagnosis dementia care, and a clear, leading role for primary care.

Supporting this call to action, the 2023-2024 Federal budget allocated AU\$445 million over 5 years to further enable general practice-led, multidisciplinary team care, and integrated care, that is located within practices, including employment of allied health professionals. In Australia, over 400,000 people were living with dementia in 2022. This number is projected to double by 2058 (Australian Institute of Health and Welfare 2022). Two-thirds of people are living with dementia in their communities and will significantly benefit from increased access to allied health services within primary care settings. However, not all allied health professionals are employed within general practices, nor is it necessarily feasible to co-locate within such practices, making their participation in multidisciplinary case conferencing for post-diagnosis dementia care difficult to implement. Optometry services, for example, as part of sensory care, are often overlooked as primary allied health care, and may not be consistently included within other commonly used team care arrangements, such as Chronic Disease Health Plans. A recent systematic review showed that none of the 27 randomised controlled trials of multidisciplinary care for communitydwelling older adults included optometrists or audiologists (Ho et al. 2023), despite many people living with dementia in the community with unmet sensory care needs (Leroi et al. 2022).

# Regular eye examinations are key to vision impairment prevention

Australia led the endorsement of a 2020 World Health Assembly resolution to deliver integrated, people-centred eye care (73rd World Health Assembly 2020), to address the impact of preventable sight loss on societies, economies (Rein 2013) and vision- (McKean-Cowdin et al. 2010) or healthrelated quality of life (Taipale et al. 2019). Integrated, peoplecentred eye care focuses on equitable access to preventive care, through better integration of eye care within primary care and coordination with specialist services. Regular eye examinations, provided by primary care optometrists, are the proven cornerstone of preventive eye care (Taylor et al. 2004; Sloan et al. 2005). Most optometrists are therapeutically endorsed and able to prescribe scheduled medicines to treat eye conditions in primary care, such as glaucoma and dry eye. In 2022, 74% of the 6500+ practising Optometry Australia members had this endorsement (Optometry Australia 2023). Alongside correcting refractive error, optometrists are well equipped to diagnose and manage a range of eye diseases and binocular vision disorders, as well as provide low vision rehabilitation.

In 2022, based on Medicare Benefits Schedule claims, 6500+ optometrists provided close to 11 million consultations to Australians (Optometry Australia 2023). Optometrists predominantly provide care in community-based practices and accessible locations such as shopping centres, through private, independent practices or corporate franchises. This commercial optometry-led primary eye care model has been adopted in many countries. In addition, the need for improved primary eve care access is becoming increasingly urgent as our population ages (73rd World Health Assembly 2020), particularly for people living with dementia, who have greater eye care access inequities (Piano et al. 2023). In the financial year 2022-2023, based on MBS claims, 3.4 million initial optometry consultations were delivered, of which 1.4 million were for people aged >65 years. Although this does not account for privately billed consultations, it is clear that this number of consultations falls far short of the 4.2 million Australians aged  $\geq$ 65 years indicated in the recent census. It is unknown how many of these consultations were received by the estimated 372,000 people aged ≥65 years who were living with dementia in Australia in 2022 (Australian Institute of Health and Welfare 2022).

# People living with dementia experience unique challenges with sight loss

People living with dementia are at greater risk of vision impairment from age-related eye conditions such as cataract, age-related macular degeneration, and glaucoma (Bowen *et al.* 2016; Chriqui *et al.* 2017). This increased risk is because of barriers to accessing routine eye care, rather than a greater risk of developing age-related eye conditions. Moreover, a significant proportion of remediable vision impairment is due to outdated, incorrect or absent spectacles. In a large UK study (n = 708), simple optometric management resolved vision impairment in over 40% of people with dementia (Bowen *et al.* 2016).

Vision impairment increases falls risk (Lord and Dayhew 2001), delirium risk in acute care episodes (Morandi *et al.* 2021), time spent on caring (Lawrence *et al.* 2009; Leroi *et al.* 2022), and significantly affects activities of daily living for people living with dementia (Varadaraj *et al.* 2020). Impaired vision is also a barrier to participation in tailored wellbeing, exercise and social programs to support living well with dementia (Wittich *et al.* 2022), thereby affecting the work of many other professionals involved in dementia care. It is therefore critical that people with dementia access regular eye care.

# What are the barriers to accessing eye care for people living with dementia?

Access to primary care services providing sensory care should be part of routine dementia care, yet people with dementia are less likely to access these services. Based on previous literature and our own unpublished research (semi-structured interviews with 18 optometrists, 14 people living with dementia at home and 15 current or previous carers), eye care access barriers include:

- 1. Fewer optometrists operate in residential aged care. Up to 54% of people with dementia live in residential aged care in Australia (Australian Institute of Health and Welfare 2022). However, domiciliary optometry services are limited, as the additional Medicare Benefits Schedule loadings for care delivered outside an optometry practice are meant to account for transport and equipment costs only (Carter 2021), and do not acknowledge other hidden costs of domiciliary eye care provision, which can be a barrier to optometrists providing aged care services (Carter 2014). Annual domiciliary add-on claims nationally are substantially less than the number of individuals in residential aged care (Piano et al. 2022). One example of a hidden cost, identified in our research (M. Piano, B. Nguyen, J. Conrick, L. Joubert, A. M. McKendrick, unpubl. data), is extended testing times associated with cognitive impairment, reducing overall patient throughput and therefore income from any given domiciliary visit.
- 2. A need to upskill the dementia care workforce about sensory care. Dementia care professionals working in residential aged care have low awareness about how to identify impaired vision and how to refer for assessment (Dawes *et al.* 2021). Some dementia care professionals were unconfident in supporting the use of sensory assistive devices, such as hearing aids and glasses. Residential aged care staff also find it difficult to meet sensory needs; for example, if people refuse to wear their glasses (Bowen *et al.* 2016). There is limited research in home care settings, but it is reasonable to assume that home care staff and family carers experience similar challenges and knowledge gaps.
- 3. A need to upskill the optometry workforce to provide high-quality eye care for people living with dementia. Optometrists feel less confident providing eye care to people living with dementia and have unmet training/ education needs (Bowen *et al.* 2016). Our qualitative work (M. Piano, B. Nguyen, J. Conrick, L. Joubert, A. M. McKendrick, unpubl. data) indicates the eye test experience is more likely to be positive if suitably adapted to accommodate dementia. Negative experiences reduce the likelihood of returning for regular eye examinations.
- 4. Cost of vision aids. Lost or damaged spectacles can be a frequent occurrence for people living with dementia. This can create trust issues, as carers may feel that glasses are expensive and the benefit of reissue uncertain (Bowen *et al.* 2016). Although some Australian states offer spectacle subsidy schemes for people holding concession cards for pension or disability, such as the Victorian Eyecare Service, there are usually limits on both issue and replacement; for example, a 2-year time period. Similar restrictions may also apply to private health insurance claims.

5. Perceived feasibility of the eve examination in people with more advanced dementia. Dementia care professionals and informal carers can be doubtful about how much of the eve examination can be completed for people with more advanced dementia, and therefore question its utility. Contrary to this, a significant proportion of the key elements of eye examinations are still manageable for many people with dementia (Bowen et al. 2016; Chriqui et al. 2017). However, adaptations to testing are required to accommodate cognitive fatigue and other aspects of living with dementia, such as responsive behaviours, communication difficulties and cognitive impairment. This can result in multiple or longer visits being required to complete testing, which are difficult to bill within the current MBS fee schedule for initial or subsequent eye examinations. In our research, some optometrists reported choosing to work unpaid to facilitate provision of primary eye care for people living with dementia, such as scheduling the appointment before a lunch break to work into it, or not billing for additional visits.

# How can primary care practitioners help break down barriers to accessing dementia-friendly eye care?

Access to primary eye care services for people living with dementia can be improved by raising awareness that sensory care is an important aspect of living well with dementia in the community, and in residential aged care. This forum paper is a call to action for all primary care practitioners to break down barriers to accessing dementia-friendly eye care.

To maximise quality of life for people living with dementia and help them maintain their independence, there is a vital role for general practitioners and care coordinators (often primary care nurses) to facilitate ongoing communication and collaboration between external sensory care providers. This could include local optometry and audiology practices, for example, as well as orientation and mobility services for people with concurrent vision impairment. Specifically for improved eye care, our team has developed an online continuing professional development course for optometrists to learn about dementia and upskill in accommodating different aspects of dementia during eye examinations.

It is now possible to search for a local, dementia-friendly optometrist through the website for Optometry Australia, the optometry peak member body in Australia: https:// www.optometry.org.au/find-an-optometrist/. This service can also be used to identify optometrists who visit residential aged care or people's homes, although some residential aged care facilities and home care providers may have their own arrangements with allied health agencies or large domiciliary eye care providers. Living in residential aged care should not be a barrier to receiving regular eye examinations, and increased awareness of domiciliary optometry services could help both primary care and other healthcare professionals working in the aged care sector.

People with dementia, carers and healthcare professionals agree that communication between allied health, nursing and medical disciplines involved in dementia care is a key challenge (Lawrence et al. 2009; Leroi et al. 2022). As well as advocating for regular eve examinations, primary care practitioners can share a person's diagnosis of dementia (with consent) and current care arrangements with sensory care providers, particularly those who lie outside a general practice-led model of multidisciplinary primary care. We have discovered that people living with dementia do not necessarily disclose their diagnosis to the optometrist, which optometrists identified as a major barrier to adapting their examination to be dementia-friendly. Without knowledge of a dementia diagnosis, opportunities for adaptations are missed, such as longer appointments, or rearranging the consulting room to allow a carer to sit close by and provide support.

Two-way communication also facilitates sharing of important information about a person's vision and eye care management that could have implications for other aspects of dementia care. Primary care practitioners leading the provision of multidisciplinary team-based care can cascade this information to others involved in delivering care. Examples include:

- Adding ocular therapeutics and procedures for ocular comfort to the care plan, such as administration of dry eye or glaucoma drops, or lid hygiene.
- Whether optical aids are still being worn, any strategies in place to prevent loss/damage such as spectacle chains or frame engraving, and the nature of any vision impairment without them. Options for replacement can also be shared (e.g. optometrist contact details, private health insurance cover, state spectacle subsidy schemes).
- The presence of visual field defects or visual processing deficits (e.g. depth perception difficulties) that may affect mobility.
- Recommendations for lighting, increased contrast, for daily activities.
- Referrals to tertiary eye care (ophthalmology) for specialist procedures, such as cataract surgery, and setting expectations about post-operative care.

Primary care practitioners can also facilitate onward referrals to tertiary ophthalmology care for procedures such as cataract surgery. Optometrists can provide clinically relevant information about the person's eyes and vision, whereas primary care practitioners can assist with information about dementia and care arrangements to support the case for early cataract extraction. There is a strong advocacy role for all primary care practitioners to help address the known drop-off in likelihood of receiving cataract surgery after dementia diagnosis (Hokkinen *et al.* 2022), despite significant benefits to quality of life after cataract extraction.

These suggested roles for primary care practitioners do not cease following admission to residential aged care, and if anything, become more vital, as people living with dementia are more likely to experience preventable or remediable vision impairment in residential aged care settings (Bowen *et al.* 2016; Chriqui *et al.* 2017). An important take-home message for anyone delivering primary care services in residential aged care or home care settings is that optometrists can visit residential aged care with portable testing equipment.

### Summary

We encourage all primary care practitioners to 'think vision' when consulting with people living with dementia, and advocate for a schedule of regular eye tests (annually if aged  $\geq$ 65 years, every 3 years if aged < 65 years) post-diagnosis. Care partners and dementia care professionals can consult with an optometrist at any time outside normal testing intervals if concerned about changes in visual behaviour, or if glasses are in poor condition and in need of repair. Two-way communication and information sharing between primary care professionals can help break down barriers to accessing eye care for people living with dementia, supporting them to see well and live well, in the community and residential aged care.

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