

Inquiry into access to and affordability of medical specialists

October 2026

What needs to change?

- People living with dementia need timely and affordable access to specialist care.
- People can wait months to see a specialist. High costs can also stop people from getting the care they need. Specialist care can be harder to access outside major cities.
- The system can be difficult to navigate. Access can depend on a GP knowing which specialist or service to refer someone to.
- These barriers can delay diagnosis and access to care and support.
- Specialists are sometimes required when a GP could provide appropriate care. This puts more pressure on already limited specialist services.

What is Dementia Australia recommending?

- Investment in hybrid virtual memory clinics and specialist in-reach and outreach programs. These models can bring specialist care closer to people and better connect specialist, primary and post-diagnostic care.
- Better system support for GPs to diagnose and care for people living with dementia. This includes increasing Medicare rebates for longer GP appointments and allowing GPs to order subsidised tests and medications.
- Make it easier for health professionals to work together by changing Medicare rules for case conferences between GPs and specialists.
- Improve dementia training for medical, nursing and allied health professionals so there are more specialists with dementia skills, and more people can receive appropriate dementia care earlier.

If actioned, what impact could these recommendations have?

- People could get a dementia diagnosis and supports sooner.
- People could receive better connected care from their GP, specialists and other health professionals.
- Limited specialist services could be used for the people who need them most.

How has Dementia Australia advocated for this position?

- Made a submission to the parliamentary inquiry into access to and affordability of medical specialists.
- Used feedback from a national survey of more than 600 Dementia Australia clients, Dementia Advocates, GPs, specialists and other peak bodies to inform the submission.

What's next?

- The Committee hearings are yet to start.
- Dementia Australia will continue to drive these recommendations through other advocacy avenues.

House of Representatives Standing Committee on Health Aged Care and Disability Inquiry into access to and affordability of medical specialists

Dementia Australia submission 15 October 2026

Executive summary

Access to timely, affordable specialist care is critical for people living with dementia, their families and carers. Medical specialists play a key role in dementia diagnosis, management of symptoms and complex health needs, referral to supports and planning for future care. However, current access remains inequitable and insufficient to meet increasing demand as dementia prevalence is expected to double to more than 1 million people by 2065 [1].

To inform this submission Dementia Australia consulted with people living with dementia and carers in the **Dementia Advocates** program, General Practitioners (GPs), specialists and more than 600 Dementia Australia clients. Consultation identified significant barriers to specialist care, with many reporting that dementia-related specialists were more difficult to access than specialists for other health conditions. Key issues highlighted through this process include:

- **Long wait times:** People typically wait three to six months to see a specialist, with some reporting longer wait times, despite national targets for specialist assessment within three months of referral, which contributes to delayed diagnosis and access to care.
- **Inequitable workforce distribution:** The National Dementia Action Plan states Australia only has specialist capacity to diagnose 35 – 40% of dementia cases [2]. Specialists with dementia capabilities are concentrated in metropolitan areas, requiring many people to travel long distances, experience additional costs and increased inequities for priority populations.
- **Fragmented and inconsistent referral pathways:** Access to specialist care is often determined by the confidence, experience and networks of individual GPs or crisis responses in acute care settings rather than consistent, person-centred referral pathways.
- **Inefficient use of available specialist expertise:** Specialist reports are often required to access aged care, disability and other supports, even where a GP diagnosis would be clinically appropriate, placing additional pressure on already constrained specialist services.

- **Pharmaceutical Benefits Scheme (PBS) and clinical trial requirements:** Specialist assessment is often necessary to access medicines and emerging treatments, creating further inequities for people who face barriers to specialist care.
- **High out-of-pocket costs:** Survey respondents reported specialist consultation costs ranging from \$200 to \$900 per appointment, with many turning to the private system because of public wait times or foregoing specialist care altogether.
- **Complexity of multiple conditions:** More than 86% of people living with dementia are also living with two or more additional chronic health conditions, resulting in people needing more specialist care from multiple practitioners, adding costs and complexity to access [3].

Survey responses and published evidence highlights the impacts for patients, as delays in specialist care further delay access to critical supports which play a key role in maintaining independence, function and quality of life.

Dementia Australia recommends improvements to specialist access and affordability through workforce development and scope clarity, referral pathways, changes to Medicare and PBS settings, and improved service design. This includes strengthening dementia capability across the health workforce, recognising and supporting the role of primary care, and investing in innovative models of care that improve coordination and continuity of care. Innovative approaches such as hybrid virtual memory clinics and multidisciplinary outreach services have been successful in local delivery but need sustained funding to reduce inequities and improve access.

Recommendations

1. **Strengthen the dementia care workforce** by:
 - a. Adopting the recommendations of the **Specialist Training Program (STP) Evaluation Report 2024** to increase specialist workforce and improve distribution, with a focus on meeting unmet needs of priority populations.
 - b. Requiring all medical undergraduates to have specific training and clinical experience in the assessment and management of dementia to improve timely diagnosis, management and care for people living with dementia, reduce hospitalisations and unnecessary referrals to specialists. At minimum, dementia training must be included in specialist training programs for all geriatrics, neurology, emergency medicine, regional health and general practice specialties.
 - c. Requiring all nursing and allied health professionals to have undergraduate dementia training to better support identification of potential dementia, facilitate appropriate care pathways, to reduce hospitalisations and unnecessary referrals to specialists.
2. **Invest in innovative models of care** to support continuity of care with clear referral pathways for diagnosis and clinical and non-clinical post-diagnostic supports, by supporting increased use and availability of:
 - a. Hybrid virtual memory clinics
 - b. Multidisciplinary outreach/in reach programs

3. **Recognise the role of GPs** to facilitate timely diagnosis, reduce barriers to care, and enable most effective use of existing specialist and primary care capabilities. This would be enabled by:
 - a. Investing in an increase to all Medicare rebates for Level C and Level D GP consultations to provide GPs with time to support risk reduction, assessment, diagnosis and ongoing complex case management for people living with dementia or Mild Cognitive Impairment (MCI).
 - b. Reviewing the criteria for Medicare funded MRIs of the brain to allow GPs to order for suspected mild cognitive impairment and/or dementia.
 - c. Reviewing Pharmaceutical Benefits Scheme (PBS) restrictions that require initial prescribing of certain medicines, including cholinesterase inhibitors by specialists.
4. **Consider how Medicare can better support multidisciplinary care** (in community and residential aged care) by:
 - a. Amending case conferencing Medicare Benefits Schedule (MBS) items to allow them to be billable where only two clinicians are present (either two non-GP specialists or a non-GP specialist and a GP).

Implementing these recommendations aligns with Action 4: Improve dementia diagnosis and post-diagnostic care and support in the National Dementia Action Plan 2024-2034 [2].

Introduction

Dementia Australia welcomes the opportunity to provide a submission to the Standing Committee on Health Aged Care and Disability's inquiry into access to and affordability of medical specialists in Australia.

Dementia Australia is the peak body representing the estimated 446,500 people living with dementia and their carers across Australia. This figure includes the 29,000 people living with young onset dementia (aged less than 65 years) and the 1 in every 2,900 babies born with a condition that causes childhood dementia [1]. As the trusted source of information, education, and support services, Dementia Australia advocates for positive change for people living with dementia, their families, and carers, and supports vital dementia research.

Dementia prevalence in Australia is set to increase to more than a million people by 2065 [1]. Dementia is the leading cause of death for all Australians, as well as the second leading contributor to years of healthy life lost [4].

Dementia Australia recognises that dementia does not affect all people equally and that barriers may be compounded for Aboriginal and Torres Strait Islander peoples, people from culturally and linguistically diverse (CALD) backgrounds, people living in rural, regional and remote areas, people with disability, children and other priority populations.

Dementia describes a collection of symptoms caused by disorders affecting the brain. It is not one specific disease. There are many types of dementia, including Alzheimer's disease, vascular dementia, frontotemporal dementia and Lewy body disease. Dementia is a

progressive cognitive disability which affects people of all ages, causing difficulties with thinking, memory, perception, mood and behaviour. Dementia is not just memory loss.

For many people living with dementia access to medical specialists within the current system plays an important part in receiving a diagnosis, maintaining function and quality of life as dementia progresses, but current access remains inequitable and insufficient to consistently meet the needs of people living with dementia. It is estimated that 50% of all people living with dementia do not have any formal diagnosis [5]. The National Dementia Action Plan (2024-2034) recognises this unmet need under Action 4 and highlights specific goals related to specialist care including:

- Improved national consistency in services offered across memory clinics for assessment and post-diagnostic care and support.
- Increased number of people being assessed for dementia in memory clinics.
- Increased number of First Nations people seen and supported through memory clinics, including through clinics embedded in Aboriginal Community Controlled Health Organisations (ACCHOs) and Aboriginal Community-Controlled Organisations (ACCOs).
- Increased number of people with signs and symptoms of dementia who are seen by a specialist within three months of receiving a referral [2].

A range of specialists, most commonly geriatricians, neurologists, psychiatrists and neuropsychiatrists, play an important role in dementia diagnosis, progression monitoring, medication access and management. Specialists are currently the only medical practitioner who can order some subsidised diagnostic tests, such as MBS funded magnetic resonance imaging (MRIs) and fluorodeoxyglucose positron emission tomography (FDG-PET) scans and privately available amyloid PET scans. Specialist consultation or confirmation is required to access subsidised medications and clinical trials. Geriatricians were reported as the main professionals diagnosing dementia for both men and women, followed by GPs for women and neurologists for men [6].

More than 86% of people living with dementia are also living with two or more chronic health conditions in addition to dementia [3]. Other health conditions (e.g. cardiovascular disease, vision loss or diabetes) can increase dementia risk, and the impact of other conditions or treatments can impact cognitive function. Dementia can also impact the management of other conditions, for example medication interactions or difficulties following wound care instructions. This complexity of care increases the need for affordable access to medical specialists across disciplines using a person-centred approach.

To inform our submission, Dementia Australia engaged with people living with dementia, carers, GPs and medical specialists, and synthesised feedback from a national survey of more than 600 Dementia Australia clients. This feedback also reflects specific experiences of people from Aboriginal and Torres Strait Islander and CALD communities.

These responses highlighted barriers to accessing specialist care common across many health conditions. However, people with living experience of dementia told us it was harder to access specialists for quality dementia care than other health conditions.

This submission outlines issues as they relate to each term of reference, noting that each of these issues intersect and can amplify other access and affordability issues. Recommendations similarly offer solutions to address multiple access and affordability issues.

Access to medical specialists

Wait times

The most common barrier identified by Dementia Australia's survey was wait times, with 37% of respondents experiencing long wait times to get a dementia specialist appointment. This was reinforced by the Living with Dementia Survey, which identified that nearly a quarter of participants experienced delays in getting appointments [6]. Average wait times are three to six months following a referral from a GP to get a specialist appointment for dementia care, even in metropolitan areas [7]. Multiple surveys consistently report wait times being generally longer in the public system, but data to measure the scope of the disparity is not available [6]. This is despite the National Dementia Action Plan recommending specialist appointments within three months of referral [2]. Many survey respondents noted their needs and symptoms had progressed before a specialist was available, with some people believing this contributed to otherwise avoidable hospital admissions or emergency department presentations. Additional cognitive or neuropsychological assessments, diagnostic tests and imaging may be required for specialist appointments and any delays in accessing imaging, can then further delay specialist appointments. This is particularly relevant for people living in rural, regional and remote areas who may have to travel to multiple, potentially different locations, for these tests and appointments.

If people also experience long wait times for diagnostic tests or imaging needed for specialist appointments, this can further delay care or require multiple appointments.

Workforce distribution

The smaller the population and the more remote the community, the greater the inequity in availability of and access to specialists [7]. Memory and cognition clinics are considered best practice in dementia diagnosis offering multidisciplinary care with specialists and diagnostic imaging in one place. As of 2024, the Australian Dementia Network (ADNet) registry noted just 20 of 74 participating clinics in regional centres and none in remote or very remote areas [8]. Memory clinics typically focus on assessment and diagnosis but generally do not include ongoing care or consistently clear referral pathways to post-diagnostic support.

Multiple survey respondents highlighted travel requirements to see specialists, with some travelling more than 500km to access specialist care. Particularly in rural and remote areas, specialists were not available locally, with difficulties retaining permanent, locum and travelling services. If there were locally available specialists, it was reported they were locums or, travelling specialists, limiting continuity of care. Visiting specialists were also difficult to access with high demand across large catchment areas and infrequent visits. People also reported having to travel multiple times for allied health, scans and specialist care at different times, adding out-of-pocket travel and accommodation costs. For Aboriginal and Torres Strait Islander people, these regional access issues require people to leave Country or Island Home for care, making it difficult to uphold cultural beliefs and practices, particularly at end-of-life [9].

"There are just not enough specialists available to see in regional NSW. It means little choice and sometimes the necessity to travel hours to Newcastle or Sydney to get a diagnosis, opinion or a course of treatment." ~ person living with dementia

Non-local specialist services had less knowledge of the person living with dementia, limited local knowledge, and reduced ability to connect people to local health and support services. This further impacts Aboriginal and Torres Strait Islander and culturally linguistically diverse communities, where relationships within these communities are fundamental to trust, people feeling comfortable discussing sensitive issues like dementia and delivery of trauma-informed, culturally safe care [9].

Some carers also identified that the lack of choice of specialists in their local area was particularly difficult for people living with dementia who displayed behavioural and psychological symptoms of dementia, where specialists available said they could not care for people with specific symptoms.

"We also live in a rural environment so if my husband upsets one neurologist or they upset him as they do not seem to be able to cope with his erratic and unpredictable behaviour, strange as that is what they have supposedly studied, then there is no one to treat him." ~ carer

People living with dementia and their carers reported that telehealth delivered by centralised health teams is a useful approach to get advice and support on dementia when services are not available locally. However, it is important to recognise that telehealth is not always appropriate for people living with dementia, due to barriers using video and phone technologies. Use is also hampered by poor phone and internet connectivity in some areas. For people living with dementia with more advanced cognitive impairment, telehealth may be inappropriate resulting in increased confusion and disorientation. In some circumstances, telehealth can also limit care where other context cues are not available to give accurate clinical assessment. Access to support people and/or advocates who can assist people to get the most out of technology is essential.

Workforce capacity and capability

The National Dementia Action Plan highlights that currently there is only specialist capacity to diagnose 35-40% of dementia cases, however data on the capacity is limited, with variation across clinic hours, regions, specialities and care settings [2]. The specialist workforce is expected to remain in undersupply, while Australia's population continues to live longer with more years of illness and disability [10, 11]. Demand for specialists, particularly geriatricians, far outpaces current training programs. Specialist medical colleges have identified that workforce development in neurology and geriatrics requires greater emphasis, not only in expanding numbers but also upskilling existing staff in dementia care, delirium recognition, and management of dementia geriatric syndromes [12]. Whilst obstetrics or paediatrics are required parts of the medical curriculum, little focus is given to geriatrics [12]. This can result in an over reliance on geriatricians, neurologists and neuropsychiatrists, when GP and non-GP specialists or allied health or nurses will inevitably care for people living with dementia and could do so effectively in many situations with appropriate training and supports.

Recommendation: Require all medical undergraduates to have specific training and clinical experience in the assessment and management of dementia to improve timely diagnosis, management and care for people living with dementia, reduce hospitalisations and

unnecessary referrals to specialists. At minimum, dementia training must be included in specialist training programs for all geriatrics, neurology, emergency medicine, regional health and general practice specialities.

Recommendation: Require all nursing and allied health professionals to have undergraduate dementia training to better support identification of potential dementia, facilitate appropriate care pathways, to reduce hospitalisations and unnecessary referrals to specialists.

There is also a limited supply of specialists with expertise in young onset and childhood dementias, with many people under 65 noting they found it difficult to access specialists with understanding of their condition. Several survey respondents living with young onset dementia were referred to neurologists or psychiatrists without dementia expertise. Geriatricians skilled in dementia care can often be the only available specialist for some people with young onset dementia but are difficult for people under 65 to access. It is at the discretion of the specific geriatrician to accept under 65 referrals, with several public memory clinics having age thresholds. This poses challenges for people who have limited providers in their local catchment area. A similar challenge is faced by families of children living with dementia, who typically see multiple medical specialists, to receive a diagnosis and ongoing care. This can add delays and costs to see a specialist without the expertise to address needs and requiring further appointments with multiple specialists.

While there are no national estimates of dementia prevalence among First Nations peoples, research consistently shows rates are around three to five times higher than those of the broader Australian population [4]. Despite recent progress in developing culturally adapted dementia diagnostic tools and interventions, the specialist workforce is not sufficiently meeting the unique needs of Aboriginal and Torres Strait Islander people living with dementia or those at risk of dementia. First Nations ways of being and conceptions of dementia can be different to Western models and this, combined with systemic barriers, mean Aboriginal and Torres Strait Islander people are more likely to be diagnosed later, despite earlier age of onset [9]. When people do seek care, symptoms may be overlooked due to stigma, misunderstanding of dementia symptoms and other conditions, and dementia being perceived as lower priority alongside other health conditions [9]. Limited sustained funding and resources for First Nations-led programs limit the expansion of effective, culturally safe dementia care. There is also a shortage of trained First Nations dementia care workers who can deliver these programmes effectively. Specific efforts focusing on expanding First Nations-led dementia care initiatives and increasing cultural competency training for healthcare providers is required, alongside initiatives that support non-Indigenous trainees in community-controlled settings to strengthen trust in the health system and reduce inequities [9].

Recommendation: Adopt the recommendations of the **Specialist Training Program (STP) Evaluation Report 2024** to increase specialist workforce and improve distribution, with a focus on meeting unmet needs of priority populations.

Neurodegenerative nature of dementia

Only a third of survey respondents (34%) felt they could access quality care to manage their dementia, compared to almost half respondents (46%) agreeing they could access quality specialist care to manage other health conditions.

Each person living with dementia has unique needs, but what is common is that capacity will fluctuate and symptoms will advance. Symptoms will differ depending on the type of dementia and can change with internal and external factors, influenced by fatigue, noise, sensory disruptions, medication, delirium, illness, and time of day. These symptoms add challenges to accessing specialist care, which is typically provided in metropolitan hospitals or clinic environments that rarely cater to the needs of a person living with dementia. These environments can be overwhelming or difficult to physically access for someone living with dementia, particularly those who can't drive, have limited mobility or require a carer to support with wayfinding. 14% of survey respondents highlighted travelling to access a specialist is costly and difficult to arrange, and an additional 14% cited the need to have someone take them to an appointment as a barrier [13].

Fluctuating capacity means that behaviours and symptoms may differ from appointment to appointment. The speed of symptoms advancing will also differ from person to person. Many people living with dementia and carers valued seeing the same specialist to accurately assess cognitive changes over time and provide continuity of care but noted this was difficult in the public system. Similarly, many survey respondents noted poor information sharing between allied health, GPs and other care providers, resulting in poor continuity of care.

“In the public system there was no continuity of geriatricians. We saw a different one at each appointment, which meant the level of interaction and care was compromised by both a lack of shared background, and the vastly different competencies of the clinicians. We were also moved from a close clinic to one much further away, for reasons unknown. All of these changes are difficult for a person with dementia.” ~ carer

Changes in thinking and memory also make navigating a complex health system more challenging. Many survey respondents highlighted their access to specialist care was dependent on a well-informed carer or support person to advocate with them and support managing appointments, referrals, transport and other administration. People living in regional and remote locations or in residential aged care particularly highlighted this barrier, where transport, accommodation, and alignment with other health services or care providers were required. Similarly for people from CALD backgrounds, where family members were required for translation and to support cultural needs. This not only negatively impacts the person living with dementia but also places undue pressure on carers.

Referral pathways

Primary care referral pathways

Some people living with dementia and carers noted that their access to specialists was delayed due to limited access to GPs for reasons including high costs of GP visits, fewer GPs offering home visits, or GPs being unavailable within residential aged care facilities.

A common theme from survey respondents was that access to a specialist relied on the individual GP practice rather than consistent referral pathways. Research from The Grattan Institute reinforces these results, highlighting that GPs are reliant on their own professional network, local knowledge of service capacity or must independently find the right specialist [10]. People who had a strong, ongoing relationship with a dementia capable GP with local knowledge reported better care. People who accessed multiple GPs generally experienced

fragmented care and some questioned the quality of care they were recommended. There were also concerns raised that if a GP was aware of long wait times for specialist services, they may not refer.

Dementia Australia's clients identified the confidence and dementia expertise of the GP was critical to access to specialist care. Several survey respondents reported that their GP dismissed initial concerns about changes in memory and thinking, delaying referral to a specialist and consequently a diagnosis. 24% of women and 13% of men had their dementia symptoms attributed to causes other than dementia, and nearly half of people initially received a different diagnosis [6]. Some respondents noted that GPs were reluctant to refer on to specialists for dementia care, with approximately 10% of people not referred by their GP for further assessment or experiencing conflicting advice from health professionals [6]. Others said their GP identified the need for specialist referral because they lacked confidence in dementia care themselves. In the 2016 dementia clinical guidelines, specialist diagnosis is considered best practice [14]. Yet the guidelines position this as low-certainty evidence, and it is acknowledged that specialist diagnosis is not always feasible or necessary. This was confirmed by an independent survey, with 90% of geriatricians supporting efforts to improve accurate diagnoses by GPs [15]. However, less than 20% of people were diagnosed by a GP [6]. People living with dementia, carers and GPs identified limited consultation time, limited dementia training and a lack of multidisciplinary support as constraints that affect the capacity of primary care to diagnose dementia and provide ongoing care, despite many aspects of this being within their scope of practice.

"GP was dismissive about initial concerns to do with mum's memory. I had to insist on geriatric specialist referral." ~ carer

"Absolutely need funding to support case coordination, to make calls/contact specialists, to call family members (this is all unfunded work)." ~ GP

Recommendation: Invest in an increase to all Medicare rebates for Level C and Level D GP consultations to provide GPs with time to support risk reduction, assessment, diagnosis and ongoing complex case management for people living with dementia or Mild Cognitive Impairment.

There is no single test to diagnose dementia. It is common for people to have both cognitive assessments, and brain scans to rule out other possible explanations for their symptoms. GPs routinely do cognitive assessments but cannot refer patients for a Medicare funded MRI for suspected dementia/cognitive decline. This creates an additional step and delay through specialist referral pathways. Whilst a specialist may be needed to interpret results and provide follow up care, the requirement for a specialist appointment to order a subsidised MRI adds costs and contributes to inequities for people living in regional, rural and remote areas who many have to travel for both diagnostic and follow up appointments.

Recommendation: Review the criteria for Medicare funded MRIs of the brain to allow GPs to order for suspected mild cognitive impairment and/or dementia.

Insufficient dementia education alongside increasing comorbidities means that GPs are more likely to need advice from specialists to manage dementia. The lack of payment for time spent planning or discussing complex care with other clinicians means that GPs may refer to a

specialist instead. This adds costs for the patient to access potentially unnecessary specialist care and contributes to wait times, when a GP can provide quality care with advice direct from a specialist.

The majority of people living with dementia and carers also highlighted the fragmented care system, with difficulties entering, navigating and accessing the services they need. A key feature of this was the lack of communication and documentation between medical specialists and their GP, leaving many feeling unsupported or reliant on a carer to facilitate connection between GPs and specialists.

Recommendation: Amend case conferencing Medicare Benefits Schedule (MBS) items to allow them to be billable where only two clinicians are present (either two non-GP specialists or a non-GP specialist and a GP).

Specialist diagnosis requirements for PBS listed medications and clinical trial access

Although there is currently no cure for dementia, there are four Pharmaceutical Benefit Scheme (PBS) listed medications available for symptom management of Alzheimer's disease. A specialist diagnosis and prescription are required to first access PBS subsidised Alzheimer's disease medications. Whilst GPs can prescribe the same medications privately or manage ongoing prescriptions after initiation by a specialist, the requirement for a specialist diagnosis for PBS access adds to wait times and exacerbates inequities in access. The PBS indications require "mild-to-moderate" Alzheimer's disease, meaning that delayed access to a specialist could see people ineligible for subsidised medication if their condition has progressed while waiting.

The Therapeutic Goods Administration (TGA) has also approved two disease modifying therapies for early-stage Alzheimer's disease including donanemab and lecanemab. These currently require specialist prescription and ongoing monitoring and are not yet widely used in Australia. However, as disease modifying therapies become more common, this will place greater demand on specialists. Similarly, as new blood-based biomarker diagnostic tests evolve, and are likely to be more widely used by primary care, demand for specialists will also increase to do more detailed diagnostic work up and ongoing monitoring of people with a confirmed diagnosis [16]. In the absence of a cure, access to clinical trials can play a key role in dementia prevention, risk reduction and care. People who are currently participating in a clinical trial report significantly more specialist care and the benefits this has on their quality of life [13]. Current inequities in specialist access limit the opportunities to participate in clinical trials and receive any potential benefits for many people living with dementia. Importantly, this also entrenches existing inequities as it means future scientific breakthroughs may not be representative of Australia's diverse community and limit future implementation [17].

Recommendation: Review Pharmaceutical Benefits Scheme (PBS) restrictions that require initial prescribing of certain medicines, including cholinesterase inhibitors, by specialists.

Inefficient use of available specialist expertise

It is estimated that 50% of all people living with dementia do not have any formal diagnosis [5]. A specialist diagnosis is a required as part of eligibility assessment to some supports including

National Disability Insurance Scheme (NDIS) supports. Although such assessment and documentation are appropriate in some scenarios, this can place unnecessary burden on specialists.

People living with young onset dementia and their carers report needing reports from specialists within a certain period of their NDIS review to meet requirements for ongoing access to supports. Others have described similar challenges to get appropriate evidence for tribunal hearings to assess capacity and appoint substitute decision-makers. This resulted in people needing to urgently access appointments and documentation, despite not having any new clinical need.

“The main issue we have with cost is the need to get multiple reports from our specialist, paying for each report, to access different services for the same problem (dementia impact). e.g., Carer Allowance (Centrelink) has a different form to Companion Card and NDIA.” ~ carer

Hospitalisation

Some survey respondents noted that as they were unable to access specialists, they were reliant on presenting to emergency departments. Some survey respondents also highlighted that even once in hospital there were barriers to accessing specialists to get the diagnosis and this exacerbated poor outcomes.

“My Mum fell through the cracks and landed up spending many weeks in hospitals, which are not designed to care for dementia patients - and she still was managing to escape all the time...Terrifying also because she was in unfamiliar surroundings and her dementia worsened considerably. Even when she was in the hospital waiting, and the memory unit was downstairs - it still took them 6 weeks to come up in the elevator and officially diagnose her.” ~ carer

Palliative care referral pathways

Current access to specialist palliative care is limited, despite dementia being a terminal condition. Only 22% of people who followed the dementia and frailty trajectory received specialist palliative care, compared to 60% of people who died with cancer. Whilst not specific to dementia, of people over 65 in their last year of life, only 9.3% attended outpatient clinic for palliative care medical consultations and 7.5% received Medicare-subsidised services provided by palliative medicine physicians/specialists. People living in residential aged care were also less likely to access this care [18].

Palliative care, including pain relief, symptom management and the prevention and relief of physical and psychological suffering is important for people living with dementia and their families. Medical specialists do not always but can play an important role in palliative care. Differences in understanding of and beliefs about dementia, decision-making and palliative care across ethnically, culturally and socially diverse communities may shape the role people see specialists playing, but access should not.

Currently there is a lack of awareness by other medical subspecialties regarding the use of palliative care at all stages of dementia, meaning that referrals to specialist services are inconsistent and dependent on the dementia expertise of individual clinicians. There is also a

lack of palliative care resources including beds, outreach services, palliative care trainees and physicians. This is complicated further by a lack of training, expertise and confidence among palliative care physicians in the management of dementia [19].

Affordability

20% of Dementia Australia's surveyed clients noted the cost of specialist appointments as being unaffordable and a barrier to care. This is consistent with high cost of seeing health professionals as a key barrier to diagnosis identified by the Living with Dementia survey [6]. Long wait times in the public system meant many people chose to access specialists through the private system, or in some cases chose not to access specialist care due to cost.

Dementia Australia clients identified out-of-pocket costs for initial consultations ranging from \$200 to \$900 and similar fees for follow up appointments. Several carers noted that after telling their individual specialist they would not proceed with the appointment due to cost, their specialist then offered to bulk bill, highlighting an issue in equity and inconsistency in billing practices. Such processes also contribute to wait times, as once someone determines one specialist is unaffordable, they then face wait times to get a new appointment with a different, more affordable specialist. Greater transparency of fees would avoid this additional wait time.

Similarly public data on bulk-billing by speciality is extremely limited, making it difficult to accurately assess availability of affordable services. Grattan Institute analysis suggests that whilst out-of-pocket fees for geriatric medicine have remained relatively stable, neurology and psychiatry have seen median out-of-pocket costs increase by almost \$100 within a five year period, a significant increase compared to other specialties [10]. More than 20% of psychiatry and 40% of neurology initial consultations are charged at two to three times the MBS schedule fee, compared to 10% of geriatric initial consultations [10].

Dementia symptoms can also be misunderstood or assumed to be other conditions, for example mental health conditions or changes associated with menopause. For people with young onset dementia in particular this can result in people being referred to specialists to investigate conditions they don't have or to neurologists without dementia capability, adding delays in accessing appropriate post-diagnostic support and care.

Carers noted the complexity of getting a person living with dementia to an appointment and having to speak about their concerns in front of the person living with dementia added stress. Carers also noted that the person living with dementia was not always required to attend, for example, when requiring specialist reports for legal processes. However, there is no MBS funded item that facilitates a consultation with either a specialist or GP without the person living with dementia present. This makes it difficult for practitioners to coordinate care with carers and may lead to carer wellbeing issues being overlooked. Autonomy, preferences and supported decision making must always be respected, with strong safeguards to prevent and address potential elder abuse. However, there are some circumstances with appropriate consent, where both the person living with dementia and carer could benefit from one-to-one carer appointments.

Expectations about what costs are and are not covered when referred to a consultant specialist is another concern. When people do access the consultant specialist system, they may be simultaneously navigating both the public and private systems for diagnostic tests and

specialist consultations. They will use public hospital specialist services (e.g. Memory Clinics) if available in their local area but may also access privately funded imaging and consultations if it means more timely access or treatments that may not be available publicly. This dual system navigation is complex, poorly understood and often available too late, removing genuine choice in care.

The impact of high specialist fees is also compounded by the financial circumstances many people experience as a direct consequence of their dementia diagnosis and progression. Whilst data on people living with dementia who are also Pensioner Concession Card, Health Care Card or Commonwealth Seniors Health Card holders is limited, we know many older people living with dementia are on fixed incomes or a pension. For people living with young onset dementia, many may have had to retire early, be on reduced incomes including a disability pension, or have family members who have reduced incomes to maintain caring roles. Additionally, for people with young onset dementia, some found the only specialist with appropriate dementia expertise was a geriatrician, but due to age related barriers to access a public geriatrician, the only option was out-of-pocket private geriatricians. As 86% of all people living with dementia also live with other health conditions, these costs add up quickly when seeking medical care for multiple conditions [3]. Some found the costs of accessing care too much and looked for alternatives that do not reflect safe or quality care as demonstrated in the quote below.

“They will only refer me to a private neurologist too. Expensive, so I and my family use AI and reddit” ~ person living with dementia

Impacts on patient outcomes and broader system

Access and affordability issues contribute to distress, uncertainty and anxiety for people living with dementia and their carers. In Australia, it takes 1.9 years on average between a person experiencing symptoms of dementia to then raise this with a health professional [20]. It is not uncommon for people to delay help seeking after first noticing symptoms due to misconceptions and stigma about dementia, cultural beliefs, underreporting of and normalisation of early symptoms, and stress and emotion around a potential dementia diagnosis.

Most people with Alzheimer’s disease receive a diagnosis an average of three years after first reporting symptoms, while for some other types of dementia, it can take an average of four years [21]. It is recognised that an early diagnosis of dementia benefits the person with a diagnosis and carers. In the early stage, the person has the capacity to understand the nature of their diagnosis, can be supported to come to terms with their diagnosis and plan ahead through post-diagnostic supports and counselling. Further to this, access to pharmacological treatment and non-pharmacological strategies can slow decline and avoid unwanted or premature admission to hospital and/or residential care. With limited access to specialists, people living with dementia miss out on this early intervention and can experience progression in their condition that may otherwise be delayed.

For people living with young onset dementia, or potentially other health conditions, this lack of specialist access can also result in harm, due to treatments for conditions that have been misdiagnosed. Several survey respondents described unnecessary treatment for psychiatric conditions, menopause or other conditions because symptoms were not recognised as

dementia. Similarly, people already living with dementia face a real risk of serious delay in the recognition of new symptoms or worsening of existing symptoms without specialist medical care. This is particularly significant for people living with dementia when both unpaid carers and care staff may face difficulty understanding communications or assessing pain.

Finally, the high prevalence of multimorbidity and polypharmacy in people living with dementia increases the likelihood of adverse drug reactions, poor health and unplanned hospital admissions [3, 22]. People living with dementia experience poorer outcomes from hospitalisation and are often at greater risk of infection, delirium, falls and significant physical, cognitive, functional and behavioural decline. Unfamiliar environments, disruption to routines and communication difficulties can increase confusion and distress and reduce a person's ability to regain function [23].

“My Mum had an extremely delayed diagnosis, and kept getting tested for memory, ignoring the cognitive impairments and fluctuating capacity she had. We were ignored, laughed at and fobbed at by staff (a number of times), and genuinely felt uncared for in the public system. This lack of support resulted in a very delayed diagnosis (4 years after referral to the memory clinic), delayed support in the home, and ultimately led to her significant deterioration which required hospitalisation for psychosis for over 3 months. This accelerated her deterioration and prompted her to go into a nursing home much earlier than she would have had to if we had been taken seriously.” ~ carer

“Every appointment took weeks or months to get to so the process of getting a diagnosis took about 18 months. So getting into the medication was delayed and the process was stressful because it was so drawn out. Access to the geriatrician in an ongoing capacity probably won't happen because it was a clinic.” ~ person living with dementia

Innovative and emerging models of care

Hybrid virtual memory clinics

Hybrid virtual dementia services have the potential to offer timely, effective and efficient dementia diagnosis and care addressing regional inequities, delays in assessment, limited specialist availability, and gaps in post-diagnostic support.

A pilot hybrid virtual model includes an in-person location for telehealth via video where the person with concerns about their cognition has a local allied health professional to support the appointment, with specialist and in some cases allied health care provided virtually [24]. This model includes a local intake officer (nurse or allied health) and a team of clinicians offering services locally as well as allied health as needed. Such clinics would ideally be integrated with existing local services, with shared intake and similar post-diagnostic referral to primary care and post-diagnostic supports. The model includes face-to-face visits and training for regional GPs, practice nurses, occupational therapists, psychologists and exercise physiologists in dementia and mild cognitive impairment assessment, post-diagnostic care, and delivery of interventions. Online post-diagnostic occupational therapy and cognitive intervention programs would also be offered wherever possible, alongside connection to supports like those offered by Dementia Australia.

Hybrid virtual memory clinics reduce risks of technology and communication barriers, support accuracy of virtual cognitive assessments, increase the capabilities of local workforce and reduce several access barriers for specialists. Importantly this model also includes several post-diagnostic supports which can delay decline and reduce the need for urgent and complex specialist management. Whilst such a model will not be appropriate for all regional, rural and remote people experiencing cognitive changes, it offers a feasible alternative for many. It has proven successful in one clinic in regional Victoria, with Medical Research Future Fund grant funding supporting an expansion to three new regional sites across three states [25].

Recommendation: Invest in innovative models of care such as hybrid virtual memory clinics to support diagnosis and continuity of care with clear referral pathways to clinical and non-clinical post-diagnostic supports.

Specialist in reach and outreach services

Across states and territories, several different geriatric outreach programs serve both people living with dementia in the community and in residential aged care facilities. The majority are acute crisis response services that provide expert geriatric care for people with significant behavioural and psychological symptoms of dementia. Such services are important to facilitating specialist care and preventing or reducing the length of hospital stays but to date are primarily for acute care and do not support ongoing care and management.

There are also several models of care offering geriatric specialist care in community and primary care settings for chronic disease management, including dementia. Such hospital in the home or outreach programs typically facilitate geriatrician consultations for cognitive assessments, medication optimisation, falls prevention, driving reviews, chronic disease and co-morbidity management, gait assessments and carer support and education. However, these are less common and are often funded on a short-term, pilot basis.

Such programs typically involve GP identification of people at higher risk of worse outcomes, who then facilitate collaboration between primary care and geriatricians. This ensures specialist resources are directed to those with greatest clinical need. This includes a comprehensive geriatrician assessment and report sent to the patient's GP with recommendations to support onward management and continuity of care. Some programs offer virtual or home consultations while others offer clinic days in a primary care setting allowing multidisciplinary care within a more accessible environment. In addition, some services see specialists undertake assertive follow-up of people who have been discharged from hospital into residential care or community. There is evidence that this reduces emergency presentations and hospital readmissions.

Survey respondents who had participated in such programs noted it was helpful to avoid having to travel for multiple appointments and improved coordination between GP and the specialist. GPs also valued such services, noting that it built strong relationships with local services, offered the opportunity for quick specialist advice and strengthened the primary care team's capacity to manage similar cases in future. However, several GPs reported that such programs were funded as pilots, with no long-term sustainability plans. Such services, offer better ways of using existing healthcare resources to maximum benefit for people living with dementia. Models such as the Multispecialty Interprofessional Team (MINT) Memory Clinic model is one example with demonstrated success in other jurisdictions [26].

Recommendation: Invest in innovative models of care like geriatric in-reach and out-reach programs to upskill multidisciplinary teams, support continuity of care and prevent avoidable hospitalisations.

Issues specific to families impacted by childhood dementia

Childhood dementia results from progressive brain damage caused by more than 100 rare, genetic, neurodegenerative conditions. Most children and young people affected by childhood dementia die before turning 18. Families often feel as though they do not fit in any system [27]. Additionally, the paediatric specialist system operates differently to the adult experience highlighted earlier in this submission.

Children who are eventually diagnosed with dementia, typically experience minor developmental issues around the age of 2 or 3 which results in a diagnostic odyssey that can continue for many years. Assessments are then usually required by multiple health professionals and specialists before a diagnosis is received. As childhood dementias are rare, difficult to diagnose and diverse, many families seek several appointments with multiple specialists, adding costs and delays, often resulting in misdiagnoses. Once families do have a diagnosis, the majority do not have any support or a defined care pathway. As such, they find themselves navigating between multiple health professionals and support services whilst caring for a child with deteriorating symptoms. Care is primarily managed by a single medical specialist, yet without a clear care pathway, many families find themselves trying to access different specialists to advocate for their children and get appropriate care for their child's complex, multisystemic condition. There is a shortage of healthcare professionals, including specialists, trained and equipped to care for children with dementia. Once families are connected to specialist care, it is often expensive due to direct and indirect out-of-pocket healthcare expenses for their child's medications, specialised treatments, and non-covered supportive care, as well as the potential for parents to leave employment to provide full-time care [27].

Paediatric palliative care can provide comprehensive care and support and is often one of the most highly valued services by families. Yet families are not routinely referred to a paediatric palliative care service, and the timing of the referral and the extent of support that families received from paediatric palliative care also varies. If a child then needs to move across to adult palliative care services, the care is often greatly reduced, compared to care provided through paediatric services leaving families vulnerable when they need care most.

Conclusion

Improving specialist access and affordability will play a key role in improving the quality of life of people living with dementia, their families and carers, and help reduce pressures on the aged care, disability and health systems at a state and federal level. In parallel primary care also plays a key and increasingly important role and must be well supported to diagnose and care for people living with dementia, particularly as prevalence increases.

We encourage the committee to consider our recommendations to strengthen the dementia care workforce, invest in innovative models of care, recognise the role of GPs in dementia care and introduce Medicare supports to support multidisciplinary care that best meets the needs of people living with dementia.

We thank the committee for their consideration of these issues. We would be pleased to discuss any of the issues raised in this submission in more detail and provide evidence to the Inquiry.

For more information, please contact the Dementia Australia Policy and Advocacy team on policy@dementia.org.au.

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