



AUSTRALIAN MEDICAL  
ASSOCIATION  
ABN 37 008 426 793

T | 61 2 6270 5400  
F | 61 2 6270 5499  
E | [ama@ama.com.au](mailto:ama@ama.com.au)  
W | [www.ama.com.au](http://www.ama.com.au)

39 Brisbane Ave Barton ACT 2600  
PO Box 6090 Kingston ACT 2604

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## National Dementia Action Plan 2023-2033

### AMA submission to the Department of Health and Aged Care consultation

[dementioplan@health.gov.au](mailto:dementioplan@health.gov.au)

The AMA supports Australia having a 10-year dementia plan that ensures people with dementia receive the care and support they need. The proposed draft National Dementia Action Plan 2023-2033 (Action Plan) is important because it purports to be a shared project between the Australian Government and state and territory governments. Many of the issues faced by people living with dementia happen at the intersections of Federal and State programs, such as for example aged care (federally funded and managed) and hospital system (state managed).

However, the key issue that the Action Plan does not adequately address is the fragmentation of care for older people. Lack of coordination among the multiple professionals working with people with dementia, including medical, health and aged care, is a major impediment to improving care and outcomes. The crucial role of general practitioners (GPs) is not adequately considered or incorporated into strategies by the Action Plan.

The Action Plan is based on the presumption that education and training, as well as additional guidelines, are needed to enable GPs to diagnose dementia adequately and deliver dementia care, without adequate consideration for structural changes needed to ensure that diagnostics happen and that GP practices are sustainable into the future. Unfortunately, the current reality is that the MBS system actually penalises those GPs who provide care to patients living with dementia. Adequate dementia care and chronic disease management care can not be provided in short 15-minute consults. Similarly, for GPs who visit aged care homes and care for people with dementia, MBS items fail to cover the basic cost of the visit.<sup>1</sup> AMA members contend that without fixing these structural problems, there will be no change in the quality of care provided.

The Action Plan does not reflect the true capabilities of primary care in Australia and the GP workforce. There is too much emphasis in the Plan on educating GPs about dementia diagnostics or dementia prevention, largely based on anecdotal evidence presented in the form of consumer/patient feedback. Yet focus and evidence from the aged care sector, particularly residential aged care, is minimal or lacking. This is despite the fact that over 50 per cent of

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<sup>1</sup> <https://www.ama.com.au/submission/ama-submission-royal-commission-aged-care-quality-and-safety>

residents in aged care homes live with dementia, and we have recently had a Royal Commission into Aged Care Quality and Safety that examined in detail issues in the aged care sector.

Dementia is core business for the majority of GPs. AMA members contend that what is needed is support for GPs, more time to be spent with the patient during consultations, better sharing of information between different care providers (including disability and aged care) and better care coordination for people living with dementia.

In dementia care, continuity of health care is crucial for improved health outcomes for older people, especially after they move into residential aged care, yet this is not even referenced in the Plan. A recent UK study found that patients with dementia regularly seen by their own GP have lower rates of delirium, incontinence and emergency hospital admissions, leading to better overall health and quality of life.<sup>2</sup> Another study in the US found that lower continuity of care is associated with higher health care spending.<sup>3</sup> Similar studies in Australia have come to the same conclusions.<sup>4</sup> Yet somehow, a 10-year Dementia Action Plan does not even consider this and fails to elevate the important role of GPs in health care of older people.

The AMA believes that prevention should be a central platform of any dementia strategy, particularly considering our ageing population and the known and recognised risk factors for development of dementia. However, actions proposed to tackle prevention are not reflective of the best practice. The actions included in the Plan talk about “Improving understanding of dementia risk factors/preventive actions for all primary care practitioners”, and “increasing focus on brain health alongside physical health in regular health checks”. These actions will not bring change unless GPs are given more time with their patients through longer consultations that are adequately remunerated. GPs must be central to any dementia strategy and dementia prevention activities.

In addition to the above broader commentary, the AMA submission will address several of the proposed objectives and actions, that are relevant from the medical professional perspective. They include:

- Objective 3. Improving dementia diagnosis and post-diagnostic care and support
- Objective 4. Improving treatment, coordination and support along the dementia journey
- Objective 6. Building dementia capability in the workforce

### **Objective 3. Improving dementia diagnosis and post-diagnostic care and support**

While the National Dementia Action Plan consultation paper acknowledges the challenges associated with early diagnosis of dementia from the GP perspective, the actions proposed to improve the situation do not adequately capture the complexity. For example, the paper accepts that MBS arrangements for Chronic Disease Management may not be sufficient for optimal multidisciplinary care for dementia where there are complex care needs. Yet, the Action Plan

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<sup>2</sup> <https://bjgp.org/content/bjgp/72/715/e91.full.pdf>

<sup>3</sup> <https://jamanetwork.com/journals/jamainternalmedicine/fullarticle/2536188>

<sup>4</sup> <https://onlinelibrary.wiley.com/doi/full/10.5694/mja2.51153>

does not include actions to tackle this issue, other than reviewing the MBS to better support dementia diagnosis.

People living with dementia need coordinated care and that care is best provided by their usual GP. To be able to do that, changes to the MBS arrangements for Chronic Disease Management will be needed to ensure optimal care.

Furthermore, while referral to memory clinics is seen as a useful pathway, AMA members note that memory clinics are not uniform in structure and function across Australia, and there are not necessarily working clinical pathways for GPs and other non-GP specialists to refer for specialist advice. The challenges are particularly amplified in rural and regional areas.

In the AMA view, any workable solution needs to provide direct support and linkage for GPs with geriatricians and specialised psychiatrist services, as well as direct linkages to Aged Care Assessment Teams (ACATs) as the gateway to supports. Currently it is challenging for GPs to follow their patient's journey once they refer them for aged care assessment services, both after they have been diagnosed with dementia, or if the dementia diagnosis happens during an ACAT assessment. While GPs can refer their patients for assessments, they are kept completely out of the loop as to what happens to their patients once they are approved for aged care services. There is no sharing of information from the My Aged Care side, in particular no sharing of health information. If the system is expected to change and ensure coordinated care, then GPs must have access to all information about their patients' health care/aged care journey.

Further challenges and care fragmentation happened with the outsourcing old Dementia Behavioural Management Advisory Service (DBMAS) to private providers in the recent years. AMA members advise that its privatisation has not resulted in increased localised medical expertise and advice, but quite the opposite. For example, the Australian Capital Territory currently has no dedicated medical advice staffing for DBMAS, and appears largely run from New South Wales. The service does not interface with local GPs, geriatric medicine and old age psychiatry specialist services, as it should.

The AMA members argue that the Action Plan repeats the blind assumption that seems to be axiomatic within the dementia advocacy groups, that a very early diagnosis somehow changes everything. On the dementia journey, everyone's path is subtly different. Unfortunately, the reality is that an early diagnosis often does not add to management or prevention of progression unless adequate needed supports are put in place in an equally early manner. AMA members report cases where early diagnosis increases stress and distress of patients rather than helping them manage their journey.

Dementia patients need a system of supports that is coordinated and joined up. GPs are capable of managing dementia in various settings, both community and residential aged care, but they need the appropriate back up and resources, both medical specialist, allied health and especially community support services. There is minimal benefit if dementia is managed medically (remembering that people living with dementia also often have multiple other medical conditions) when the patient is not supported at their home, is not eating properly, or not coping

mentally. The Action Plan should emphasise the importance of support at time of diagnosis, very early on in the dementia journey, in the form of personal and social support at home.

AMA members report that, under the current My Aged Care system, accessing the home support services early on is difficult due to delays with assessments and delays with access to Home Care Packages. The lack of home and social supports is really the key determining factor in the current environment, and unfortunately the actions in the Action Plan do not sufficiently reflect this reality.

The AMA recommends pursuing the following actions to improve dementia diagnosis and post-diagnostic care and support:

- Rather than 'education', GPs need clinical support, both within the aged care service provision in the community and for GPs visiting residential aged care homes. GPs need support for managing their patients physical and mental health issues (for example, falls clinics are not dementia specific but are still vital support for patients and GPs).
- A clear focus on the benefits of preventative health measures, and repairing the MBS system to enable GPs to spend more time with their patients and educate them about prevention and management of chronic diseases.
- An MBS structure that values longer more complex consultations, instead of dementia specific MBS items.
- Adequate and timely social supports for people living with dementia at home.
- Maintain the central role of the GP as a generalist who provides dementia diagnosis and care, along with other essential health care, including care coordination.
- Better funding for GPs visiting residential aged care homes, including for telehealth consults. A specific aged care home telehealth item is required, that would enable GPs to consult with the patient's family and staff caring for them; this is because with many dementia patients residing in aged care homes, GPs are engaging more with the staff and relatives than the patients themselves.
- Funding for care conference/appointments with dementia patients' carers/relatives.
- More optimal funding for the patient's regular GP conducting home visits (this could be linked to voluntary patient enrolment).
- Better support for hospital outreach services that visit residential aged care homes and improved coordination with GPs who care for patients in those homes.

#### **Objective 4. Improving treatment, coordination and support along the dementia journey**

The Action Plan discussion paper rightly recognises that a proportion of hospital admissions for people living with dementia are avoidable and outlines the challenges that include the difficulty managing multiple chronic conditions, and limited access to GPs and specialist consultations. The AMA 2020 research paper found that if governments invested sufficiently in health and aged care, over four years (2021–22 to 2024–25), \$21.2 billion could be saved in public and private health care from avoidable hospital admissions, presentations and stays from older people in the

community or in nursing homes.<sup>5</sup> However, actions proposed under the Action Plan fail to tackle these issues.

For example, actions under *4.2: Care and support during and after hospital care* aim to improve the interface and transfers between aged care and hospital settings without even referencing the role GPs play in that system.

Many transfers from aged care to hospitals happen because there are no nurses on staff in the aged care homes, or because staff fail to engage and contact the GP before the patient is transferred. While nurse to resident ratios to be implemented from this year will help rectify the situation to some extent, the opportunity to elevate the role of GPs in the aged care setting is missed by the Action Plan.

The real-world context is that patients with extreme Behavioural and Psychological Symptoms of Dementia (BPSD) can often be relegated to public mental health services that lack sufficient expert staff and facilities to provide care, due to severe mental illnesses being prioritised with general psychiatry (as distinct from old age psychiatry expertise). This results in patients languishing in old age psychiatry beds or in the general hospital wards. At the same time, aged-care facilities are poorly staffed and equipped to provide longer-term extreme BPSD care, or, as the Action Plan acknowledges, refuse to do so. The inability to discharge patients with extreme BPSD, and patients with dementia in general, contributes to public hospital bed access block.

AMA members who are old age psychiatrists report that the care for people with extreme BPSD is extremely fragmented due to diffusion of responsibility between specialist medical and residential aged care services. Patients with BPSD require intensive care from providers with high levels of expertise to provide effective interventions. In their view, the counsel of perfection would be a vertically aligned system from the GP through to the designated specialist service.

In addition, and as explained previously, since being privatised, the capacity of DBMAS to assist aged care homes to care for patients with BPSD has diminished.

With regards to proposed actions under *4.3: End of life and palliative care*, the AMA is supportive of increasing community based palliative care for people living with dementia, enabling them to die in their homes. The AMA is also supportive of advance care planning and increased uptake of advance care directives for people living with dementia.

However, the AMA does not support dementia specific palliative care services. Palliative care and end of life care should be provided in all aged care settings, regardless of whether the patient has dementia or not. According to an AIHW study, dementia was the leading cause of death for people who used residential aged care services.<sup>6</sup> It should therefore be reasonable to expect that staff in the aged care sector are sufficiently trained to provide palliative care. Rather than developing 'dementia specific' palliative care, the Action Plan should focus on ensuring adequate levels of training for staff working in residential aged care, as well as in aged care in the home.

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<sup>5</sup> <https://www.ama.com.au/articles/report-putting-health-care-back-aged-care-0#:~:text=The%20AMA%20is%20championing%20for,of%20the%20problem%20is%20growing.>

<sup>6</sup> <https://www.aihw.gov.au/reports/aged-care/cause-of-death-patterns-peoples-use-of-aged-care/summary>

Full details of the AMA position are outlined in the AMA Position Statements on Palliative Care in the Aged Care Settings.<sup>7</sup>

While the AMA is generally supportive of the call for hospital environments to be more supportive and inclusive for people living with dementia, we believe that same should also be applied to residential aged care. The AMA would like to see more specialised dementia services in residential aged care facilities and respite centres. We believe it would be more prudent to invest there to reduce the hospitalisations, rather than focusing solely on hospitals.

### **Objective 6. Building dementia capability in the workforce**

The AMA absolutely rejects the introduction of “semi-specialist” GPs in dementia, as proposed by the Action Plan discussion paper. Not only is it disrespectful to GPs who currently diagnose and care for their patients with dementia, but it will also fragment and undermine patient care. Dementia care should be and IS the core business for vast majority of GPs. GPs who care for patients in aged care will be exposed to it more, but the AMA is against formalising the requirements to access MBS remuneration.

Establishing “semi-specialist GPs” would essentially create a two-tiered system where continuity of care would be broken, to the detriment of the older person. Furthermore, would this mean that patients who have a long-term relationship with their GP, that the moment they are diagnosed with dementia, their GP, if not accredited as ‘semi-specialist’ would no longer be able to care for them? The AMA sees this as further fragmentation of care and is strongly opposed to it. However, there is value in providing affordable and accessible training to GPs who would like further professional developments.

The AMA is broadly supportive of other actions proposed under focus area 6.1. We see the need for improved dementia training in the aged care sector, including embedding mandatory core competencies for aged care workers and strengthening the dementia training requirements under the current revision/update of the Aged Care Quality Standards.

AMA members, GPs and non-GP specialists who visit aged care homes, report that the biggest issue they face when visiting aged care is the lack of adequately trained or experienced aged care staff, including nursing staff. GP practices of some of our members used to provide education sessions to upskill aged care staff and educate them about behavioural management of dementia. AMA members contend that, rather than targeting the highest trained practitioners in the system (the GPs), the strategy should focus on improving the basics of poorly trained, poorly paid staff, with rapid turnover, variable English language skills and cultural awareness.

Dementia capability development in the workforce should focus on the following:

- Ensure staff/carers are adequately trained, while minimising turnover.
- Ensure adequate levels of English language proficiency among the carers.

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<sup>7</sup> <https://www.ama.com.au/articles/palliative-care-aged-care-setting-position-statement-2020>

- Support for staff from same language and CALD backgrounds in the form of training they recognise as needed.
- Understanding socialisation, physical activity, good nutrition and activities such as music and arts/crafts contribute to improved wellbeing of residents.
- Improved access to allied health services for patients living dementia (poor food intake/swallowing/dentition issues, poor mobility/falls, behavioural problems).

Staff providing palliative care for patients with dementia should be trained in the following (in addition to the clinical skills required to provide palliative care):

- Recognising signs of deterioration in older people and increasing palliative care needs that require further specialist assessment, including by Specialist Palliative Care services.
- How to talk to the patient and their family members about the diagnosis and the need for palliative care.
- Managing conflicts and stressful situations with people who are receiving palliative care, their family members and carers.
- Bereavement care.
- Resilience mechanisms for coping with death and dying of patients.
- Providing social and spiritual support for dying older people.
- Cultural, religious and spiritual aspects of palliative care.

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### **Contact**

Aleksandra Zivkovic  
Senior Policy Advisor  
Medical Practice Section  
azivkovic@ama.com.au