



A New Program for In-Home Care

**A Dementia Australia Submission to the
Department of Health and Aged Care**

November 25, 2022

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Introduction

Dementia Australia welcomes the opportunity to make a submission on A New Program for In-Home Care. As the peak body representing people living with dementia, their family members and carers, Dementia Australia has a long-standing interest in improving the quality of care delivered in home and community aged care, and in particular, the quality of dementia care provided in the sector. We have made a number of submissions to Federal Government and industry consultations in relation to these issues over the last decade, proposing amongst other solutions, compulsory dementia education for all aged care employees, minimum entry level dementia competency requirements and a national registration scheme for all personal care workers. Our submissions to the Royal Commission into Aged Care Quality and Safety, and Parliamentary Friends of Dementia Roadmap for Quality Dementia Care, set out in detail the conditions under which we believe the quality of dementia care could and must be improved in the sector.

About Dementia Australia

Dementia Australia is the peak dementia advocacy organisation in Australia. We support and empower the estimated half a million Australians living with dementia and 1.6 million people involved in their care. Dementia is the second leading cause of death in Australia, yet it remains one of the most challenging and misunderstood conditions. Founded by carers more than 35 years ago, our organisation engages with people with dementia, their families and carers in our activities, planning, policy and decision-making, ensuring we capture the diversity of the lived experience of dementia across Australia. Our advocacy amplifies the voices of people living with dementia by sharing their stories and helping inform and inspire others. As the trusted source of information, education and support services, we advocate for positive change for people living with dementia, their families and carers, and support vital research across a range of dementia-related fields.

Q 1 What are your views on Managing Services Across Multiple Providers?

Care Partner terminology

We would like to preface our submission by making some remarks about the designation 'Care Partner' in the proposed new model. This term has been in longstanding and widespread use in the aged, disability and health care sectors to describe the role of a formal or informal carer i.e. a person that provides direct care and support for another individual. Dementia Australia believes the use of care partner as an equivalent to Case Manager in the way proposed in the new program will introduce an unnecessary level of complexity and confusion for older people, family members, providers and others. We strongly encourage the reconsideration of this term in the interests of ensuring clarity around the role and the program itself. We have additional, substantive concerns about the role and responsibilities of care partners, and these are addressed in more detail below.

Managing a multi-service provider environment

Dementia Australia is in broad agreement with the principle of consumer choice underpinning the proposed new model of aged care service provision in the home. However, as the discussion paper has highlighted, there are advantages and risks to this proposition, particularly in relation to scenarios involving multiple providers offering different services, and the selection, coordination and ongoing evaluation of the appropriateness and efficacy of these services. A multi-service provider environment involves potential risks for consumers, carers and their families, providers, and workers and will need effective regulation and safeguards. Consumers with multiple or complex health and personal issues, including those living with cognitive impairment and dementia, will arguably be particularly vulnerable in this context. As the peak body representing people living with dementia, their family members and carers, we have specific concerns about how multiple providers and their services will be coordinated and implemented for people living with dementia.

The clinical and other needs of an older person will inevitably vary and progress over time. If the care partner is the service coordinator, will that person also be required to assess the appropriateness and efficacy of these services? How will the care partner

assess changing clinical needs for example, if they do not have the skills and knowledge to make these kinds of assessments? Will they be interacting regularly enough with the older person in order to assess their home environment and changing clinical and other needs?

These questions are particularly significant for people living with dementia. Every person with dementia has unique physical and psychological needs which will change over time. Flexible and responsive support for people with dementia at different stages of the dementia trajectory will be critical to ensuring each person can be supported to live at home for as long as possible. Dementia Australia would like to see compulsory dementia education for care partners to ensure they have the appropriate knowledge and skills to communicate with and accurately assess the changing needs of people living with dementia.

Self-Management of Funds

In supporting consumer choice in the proposed new program more generally, and in relation to self-management of allocated funds specifically, Dementia Australia also has concerns about how consumers would be appropriately supported to self-manage their package. Historically, a relatively small number of aged care services consumers have chosen the self-management option but with the proposed changes to the program, it is possible that increasing numbers will choose to self-manage, including people living with dementia. This will require a corresponding need for appropriate supports and safeguards to ensure that consumers have all the information and skills required to undertake self-management.

Dementia Australia supports some form of assessment to clarify decisions around choice and the ability of consumers to self-manage. The older person might partially or fully manage care planning. If an older person elects to partially or fully self-manage their funds, clear guidelines about the role of service providers and care partners must be provided to ensure decision-making is fully informed.

Dementia Australia believes the older person must be in control of the degree of engagement they have with their care partner. As noted earlier, care needs and services for older people are likely to change over time, and particularly for older people living with dementia. Wherever possible, the older person should be the party

who initiates any changes to the degree of support provided by the care partner, and any associated changes their care plan and funding costs.

For those who choose to self-manage but may need assistance to do so, including people living with cognitive impairment and dementia, coordinated management by a third party, supported decision-making and other forms of assistance must be made available. A range of resources, in various formats and accessible to culturally and linguistically diverse, Aboriginal and Torres Strait Island and other diverse communities, will be important in supporting self-management. A simplified online tool that breaks down the official costs of each assessed need, would be worth considering in this context. Equally, safeguards and protections must be put in place for consumers who are assessed as not suitable to self-manage funds.

The multi-service/provider model, the role and responsibilities of care partners and the issue of self-management of funds are all important components of the proposed new program. Dementia Australia supports a series of measures to explore the most effective approaches to all of these components including drawing on the current model of disability services provision, modelling potential scenarios of multi-service/provider coordination and implementation, (including scenarios involving people with dementia), and testing various options with potential consumers.

Q 2. What are your views on Care Partners for Older Australians?

As noted above, Dementia Australia has concerns not only in relation to the term care partner, but the responsibilities associated with role. The discussion paper describes a care partner as ‘an appropriately trained person’ who can partner with the older person to ‘support them to achieve the best outcomes from aged care services’. Dementia Australia believes a stronger definition is warranted, one that emphasises that the person is a suitably qualified professional with the expertise and knowledge to provide high quality assessment and care planning and the capacity to work effectively as part of a multidisciplinary team.

In this context, suitably qualified *must* involve having undertaken dementia education. 65 per cent of all people diagnosed with dementia in Australia live in the

community. It is critical that the home aged care workforce more broadly, and care partners specifically, have appropriate dementia care skills and knowledge. Given the collaborative nature of the proposed care partnership, it will be particularly important for people working in this role to understand how to effectively communicate, engage with and support people with dementia to live as well as possible at home.

The care partner's responsibilities should include reviewing service agreements and support plans, ensuring care and services are aligned with other supports, liaising with the older person and their representatives, ensuring that care and services are culturally appropriate, and identifying and addressing risks to the consumer's safety.

Given the requirements outlined above, Dementia Australia believes the KPIs associated with the care partner's role could include but are not limited to:

- works closely with/consults with older person/carer/family on all decisions about care service planning and provision
- demonstrates a good understanding, knowledge and skills relating to communicating and supporting a person with dementia
- understands, respects and enacts a supported decision-making approach
- regularly reviews services provided and evaluates efficacy
- designs services/responsive care planning and management as care needs change
- demonstrates an understanding of dignity of risk and reporting requirements in relation to issues of risk and safety

Care partners would appear to be a logical choice to coordinate care management and planning in the new program but as outlined above, this raises a number of issues including questions around the coordinating and reporting requirements. The care partner would need to have end to end visibility of the older person and their care needs, and engage regularly with them in order to monitor any changes in care requirements and implement corresponding adjustments in planning and service provision. Developing a trusted relationship between the older person and care partner will be important in encouraging older people to raise concerns in relation to

any aspect of their support plan and for the care partner to act as an independent advocate on their behalf. Dementia Australia strongly supports the care partner role in this context, given the benefits of providing continuity of care and independent advocacy for people living with dementia.

Dementia Australia does not have a view on how the care partner would coordinate services but would note that if the older person was receiving a number of services from different providers and the care partner had both close oversight of the older person and was receiving reports from multiple aged care workers, this could potentially duplicate and complicate the process of assessment, monitoring and service provision. An IT system that ensures effective communication between all individuals and organisations involved in the older person's care will be crucial in supporting the care partner's coordinating role.

The discussion paper proposes that the care partner would '...have a degree of impartiality, even if employed by a service provider responsible for delivering other services and supports.' Dementia Australia believes it would be desirable for the care partner to be independent of the provider, to ensure objective assessments of both the older person's care needs and the reports from providers and their staff, and to minimise any potential conflicts of interest or other complexities. If the care partner is independent of the provider, this introduces a further challenge in relation to ensuring services meet quality standards. The care partner would be responsible for monitoring service provision, but not necessarily the provider's adherence to quality standards. This raises the question of if not the care partner, who has carriage of provider adherence to quality standards?

Dementia Australia supports the concept of a care partner notwithstanding the concerns and questions raised in relation to specific responsibilities associated with the role. We believe care partners will be fundamental to the success of the new program in delivering timely, appropriate, high quality aged care services in the home and would therefore urge more detailed consultation and service mapping to explore the issues raised above.

Q 3. What are your views on a funding model that supports provider viability and offers value for money?

Dementia Australia would make the following general observations in relation to funding for aged care services in the home: funding for aged care providers should be contingent on providing care that is of high quality, person centred and responsive to the clinical, social and emotional needs of all older people, regardless of their location, background or care needs.

The following features must be central to the proposed funding model for aged care home service provision:

- The model provides a cohesive and sustainable aged care system that is responsive to and meets the needs of consumers and is simultaneously viable for providers
- The model must ensure workforce and service quality
- The model offers older people genuine choice and flexibility in service planning and provision
- The care needs of older people with dementia are central to planning and service provision
- The model considers affordability for taxpayers and consumers
- Funding to providers is tied to evidence of quality care and provider accountability
- Equity and consistency are key considerations in determining consumer contributions
- Transparency around fees and charges payable by consumers, including those living with dementia

We would make some further observations in relation to specific aspects of the proposed funding model.

We are broadly supportive of the concept of consistent client contributions across the program, but this would need to be based on rigorous and regular assessment of the older person's financial status and ability to pay. We endorse the proposed mechanism of grant funding for specialised support services, including services providing dementia support, and believe this will be an important component of the funding model. However, the discussion paper's designation of 'advisory support' is broad and lacks detail. Dementia Advisory Services could incorporate a range of services of variable quality and efficacy. We would like to see a more detailed outline of the kind of specialist dementia support services this would potentially encompass, what type of services that would be expected to provide and the criteria for demonstrating the credentials of services that would qualify for grant funding.

Dementia Australia supports a pricing framework (including supplements or grant programs) for market populations clearly identified as thin including ethnically, culturally and socially diverse communities, people living with disability and those living in regional areas. This would assist in maintaining specific services and the workforce associated with these services and contribute to service access and equity. This will be particularly significant for people living with dementia, their family members and carers, who often struggle to access appropriate services for a range of reasons, including regionality and workforce supply issues.

Additional detail to fully understand the range of what is potentially supported under the proposed grants and whether these are envisaged as specifically meeting the unique needs of the older person or reflect of the higher cost of providing support to a particular cohort (for example, a person living with dementia in the Aboriginal and Torres Strait Islander community) would also be helpful.

To ensure a stable workforce and continuity of support and care, Dementia Australia endorses set pricing so that professionals and workers are encouraged to remain in the aged care system.

Q 4. What are your views on support that meets assessed needs but is responsive to changes over time?

Health and care needs vary across the life course and each individual may therefore have different requirements for care and support at different stages of their life. This is particularly germane for people living with dementia. While there are symptoms common to certain types of dementia, every person diagnosed with dementia will experience the condition, and changes in capacities and abilities, differently. Every person living with dementia will therefore have unique physical and psychological needs which will change over time. Flexible and responsive support for people with dementia at different stages of the dementia trajectory will be critical to ensuring each person can be supported to live at home for as long as possible.

The new program must have substantial capacity to be responsive to changes in the older person's circumstances or increasing complexity of care needs. Older people should be able to easily move in and out of different levels and types of service provision as their needs change and where they might need short-term or intermittent interventions. Prompt and streamlined review of support plans when requested by the older person or care partner *without the need for a full reassessment* will be critical to ensuring responsive service provision. Embedding a flexible and responsive capacity in the program will be particularly important for people living with dementia, who as outlined above, experience significant and often acute changes in their care and support needs. We support the need for clear and specific guidelines in relation to the circumstances that warrant a reassessment, and the need for assessment workforce planning to ensure the capacity to respond to reassessment requests in a timely manner.

Dementia Australia broadly supports provider access to proposed 'top up' funds to facilitate minor changes in care needs and supports without requiring a reassessment but would make the following observations:

- 25 percent might seem reasonable for a flexible funding pool but if the amount doesn't meet the cost of a particular service then that flexibility is rendered meaningless (for example, if 25 per cent of your package is flexible but the amount calculated won't cover the costs of specialist wound care services)

- Given the above and noting the discussion paper stipulation that the amount is 'set at around 25 per cent of the total cost of their clients' budgets each quarter', we would endorse flexibility in relation to the flexible funding pool itself, allowing for this amount to be extended beyond 25 per cent of the older person's quarterly budget depending on their circumstances and needs
- Finally, Dementia Australia acknowledges the intention to conform to the Royal Commission into Quality and Safety in Aged Care's recommendations and incorporate a mix of grants and activity-based funding with elements of individualised budgets and case-mix classifications. There is a risk however that the unintended consequence of this approach is an increase in the time and costs associated with the reassessment process, an amplification of the complexity of the system and unhelpful reduction in the clarity and accessibility of the funding model.

Q 5. What are your views on encouraging innovation and investment?

Dementia Australia would make the broad observation that any grants allocated to encourage innovation in the sector would need to be demonstrably aimed at system change and improvement, rather than establishing a competitive point of difference for a provider or a service. We would support the funding of innovative initiatives that are evidence-based, have involved consultation with people living with dementia and their family members and carers, and make a genuine contribution to improving the quality of life and wellbeing of people with dementia.

Dementia Australia acknowledges the three specific areas identified in the discussion paper for further consideration in relation to innovation and investment in the in-home aged care sector. Nevertheless, we would argue that the investment that would achieve the most tangible benefits and result in genuine and sustainable innovation in the in-home aged care sector would be investment in educating, supporting and appropriately remunerating the in-home aged care workforce. Dementia is the second leading cause of death of Australians and the leading cause of death for women.ⁱ Given the projected increase in cases of dementia in Australia in coming decades, caring for people living with dementia is and will continue to be

'core business' for the sector. There is an urgent imperative to support older people to live as well as possible at home, including older people living with dementia. Improving the quality of dementia care through compulsory dementia education for the in-home care workforce must therefore be at the centre of any broader discussion of innovation and investment to encourage quality of care in the sector.

Conclusion

Dementia Australia is grateful for the opportunity to make a submission in relation to the proposed new Program for In-Home Care. Thank you for considering the issues raised in our submission and we would welcome the opportunity for further consultation and can support the Department of Health and Ageing to consult directly with people living with dementia, their families and carers.

ⁱ Dementia Australia, Dementia Statistics, <https://www.dementia.org.au/statistics>