

Nick Hartland
Acting First Assistant Secretary, Aged Care Policy and Regulation
Department of Health
Emailed to: nacap@health.gov.au

Dear Mr Hartland,

**RE: CONSULTATION ON DRAFT NATIONAL AGED CARE ADVOCACY
FRAMEWORK**

Alzheimer's Australia welcomes the opportunity to provide a submission to the Draft National Aged Care Advocacy Framework (The Framework). Alzheimer's Australia looks forward to commenting on the outcomes of this significant consultation and taking part in any future discussions relating to the Framework. This submission provides general comment on the importance of ensuring independent, specialist advocacy support for consumers in developing the Framework.

Alzheimer's Australia is the peak body providing support and advocacy for people with dementia and their families and carers in Australia. It is estimated that there are already more than 353,800 Australians living with dementia and over a million people involved in their care. By 2050 there will be nearly 900,000 people with dementia. Dementia is the second leading cause of death in Australia overall, and will have an increasing impact on the health system due to population ageing.¹

Dementia poses a unique challenge for Australia due to increasing rates of prevalence, the personal impact and the impact on carers and families not to mention the economic costs and social implications. Approximately 30% of Australians with dementia live in aged care.² People with a diagnosis of dementia make up more than half of the 196,000 aged care residents. The proportion of people with dementia requiring formal support will likely increase over time due to changing family dynamics and increasing numbers of older people living alone.

Overall, Alzheimer's Australia supports the objectives of the Framework to advance the advocacy rights of people throughout aged care, while maximising the choice and control over their lives. This objective should also be afforded to people living with dementia who experience unique challenges when participating in aged care programs

¹ Australian Bureau of Statistics (2015) Causes of Death, Australia, 2013: Cat no. 3303.0

² Australian Institute of Health and Welfare (2012). Dementia in Australia. Cat. no. AGE 70. Canberra: AIHW.

due to complex symptoms and progressive decline in cognitive functioning that are the hallmarks of dementia.

Alzheimer's Australia supports that The Framework includes family and representatives as well as consumers, however we would encourage this definition to be clear and explicit to ensure that carers and family members are able to access the services of the National Aged Care Advocacy Program. This is particularly important for people with dementia who are experiencing cognitive decline.

Consumer Directed Care and Dementia

Alzheimer's Australia supports the broader intent of Consumer Directed Care (CDC), which aims to provide consumers with greater control over their own health and wellbeing by allowing them to make choices about the types of care and services they access and the delivery of those services, including who will deliver the services and when.

However, as the Draft Framework notes, the ongoing changes to the aged care system have a significant impact on how consumers access and receive services, and individual advocacy now plays a very important role in capturing consumer experiences and perspectives. This includes an emphasis on informed and supported decision-making. Moreover, although there are a number of benefits associated with the implementation of CDC, there are also challenges and considerations, especially for people with dementia.

For people with dementia, as for those people without dementia, having a say in their everyday lives is a basic desire and underpins a sense of purpose and well-being. Many people with dementia have expressed a desire to feel that they are participating in decision making regarding their care but also recognise that their ability to do so is, and will be, compromised by the very nature of dementia.

Thus there is a need for focussed and more specific guidance in this area, especially to meet the specialist needs of people with dementia. Genuine consumer directed care for people with dementia can be delivered only when consumers are enabled to be partners in the decision-making process. The advocacy Framework should thus include funded education provision and a focus on the entire interactive communication process for ensuring that a consumer fully understands the proposed healthcare plan and has, where appropriate, supportive information to make an informed decision.

Alzheimer's Australia Inc.

AMA House, Level 1, 42 Macquarie Street, Barton ACT 2600

Postal Address: PO Box 4194, Kingston ACT 2604

T: 02 6278 8900

Alzheimer's Australia ABN 79625582771

Reporting processes and definitions for outcome and output reporting

Alzheimer's Australia notes and commends the Framework's intention to move to make future reporting more outcomes focussed and to ensure that the information gathered is meaningful and usable. However we would encourage the Framework to put a larger emphasis on integrating consumer perspective into the quality assurance and improvement processes as well.

Right now across aged care it is very difficult for consumers to ascertain quality of dementia care. This makes the desired move to a more market-driven system challenging, as informed choice is not possible without accurate information that is readily available. The ongoing development of quality-indicators in aged care is welcome but still limited. We need to move away from a narrow focus on output reporting, to a broader focus on delivering real quality in aged care.

Alzheimer's Australia recommends a consumer-driven emphasis on the development of the reporting process. This would seek to engage consumers and carers to develop and implement consumer and carer based initiatives to monitor and promote the delivery of quality care for people with dementia, and all other aged care consumers. This would include developing checklists and guides for consumers as well as a consumer-audit and feedback program.

Appropriate Language

The words used to talk about dementia can have a significant impact on how people with dementia are viewed and treated in our community.

The words used in speech and in writing can influence others' mood, self-esteem, and feelings of happiness or depression. A casual misuse of words or the use of words with negative connotations when talking about dementia in everyday conversations can have a profound impact on the person with dementia as well as on their family and friends. It can also influence how others think about dementia and increase the likelihood of a person with dementia experiencing stigma or discrimination. We would encourage the Department of health to reconsider the use of the phrase '*older people who are suffering from frailty and disability*', as these words can make consumers feel disempowered and isolated. Instead, we suggest to consider the phrase "*older people with a disability*". For more information on what is appropriate language and why we need it, please review our Dementia Language Guidelines, available [online](#).

Conclusion

A comprehensive aged care advocacy Framework is a critical element that is required to support the implementation of CDC. The scale of reform across aged care is significant, and it is critical to ensure that consumers are supported, empowered and have their rights protected during this period of change and within an evolving aged care system. Genuine consumer directed care for people with dementia can be delivered only when consumers are enabled and supported as partners in the decision-making process, as well as the development process. A robust advocacy Framework is a good starting point in ensuring that consumers have access to advocacy that supports their needs and requirements.

However it is also important to ensure that the Framework supports the unique and specialist needs of people with dementia. We recommend a stronger emphasis on consumer-driven performance reporting, as well as quality and improvement process. We would also encourage the Department to consider the use of more appropriate language to address aged care consumers.

Thank you once again for the opportunity to participate in this consultation. We look forward to continuing to provide input towards this important work.

Yours sincerely



Maree McCabe
A/g CHIEF EXECUTIVE OFFICER
Alzheimer's Australia