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**CONSULTATION TO INFORM
DEVELOPMENT OF THE AGED CARE
DIVERSITY FRAMEWORK**

RESPONSE FROM ALZHEIMERS AUSTRALIA

JUNE 2017

Survey questions and answers:

Structure of the Framework

Survey question:

- Are there other diverse characteristics and life experiences that should be considered in the Framework?

Alzheimer's Australia is pleased to note that people living with cognitive impairment, including dementia, will be included under the remit of the new Diversity Framework.

Dementia is a complex chronic condition caused by one or more of a large number of illnesses affecting the brain. It is a terminal and devastating condition that robs people of their abilities and memories.¹ It is cloaked in stigma and misunderstanding,² isolates people with dementia and their carers from social networks,³ and carries significant social and economic consequences.⁴

People with dementia experience stigma and social isolation⁵, and family carers often find it difficult to balance work, life and caring responsibilities⁶. The stigma and isolation is often further exasperated for people with Dementia from special needs groups, who often find it difficult to find services that meet their unique needs. Anecdotal evidence from our consumer networks indicates that there is still significant unmet demand for appropriate, high quality services for older people with dementia, particularly those living in rural and remote areas, those with significant behavioural and psychological symptoms of dementia, and those with a need for culturally specific services, such as older people with dementia from Culturally and Linguistically Diverse (CALD) backgrounds or from Aboriginal and Torres Strait Islander communities.

Another vulnerable cohort of consumers that should be considered under the Diversity Framework are people with Dementia who are living alone. Research suggests that up to one third of people with dementia who live in the community reside alone^{7,8,9} There are more than 410,000 Australians living with dementia, so this implies that there could be over a 100,000 people who are living alone with dementia.

The number of people living with dementia at home alone is increasing rapidly¹⁰. This is because people are living longer, more people are ending their relationships in youth and middle age and people are having fewer or no children, such that there are fewer close relatives to take the role of cohabiting carer. However, there is a paucity of research of

¹ Mitchell, S. et al. (2009). The clinical course of advanced dementia. *The New England Journal of Medicine*, 361, 1529-38.

² George, D. (2010). Overcoming the 'Social Death' of dementia through language. *The Lancet*, 376, 586-7

³ Blay, S., & Peluso, E. (2010). Public stigma: The community's tolerance of Alzheimer's disease. *American Journal of Geriatric Psychiatry*, 18(2), 163-71.

⁴ Access Economics (2003). *The Dementia Epidemic: Economic Impact and Positive Solutions for Australia*. Report for Alzheimer's Australia. Available: www.fightdementia.org.au/research-publications/access-economics-reports.aspx

⁵ Alzheimer's Australia (2014) *Living with Dementia in the Community: Challenges and Opportunities*

⁶ Brooks D, Ross C, Beattie E, *Caring for Someone with Dementia: the economic, social and health impacts of caring and evidence-based support for carers*. (2015) Report for Alzheimer's Australia.

⁷ Tuokko H, MacCourt P, Heath Y. Home alone with dementia. *Aging and Mental Health*. 1999;3(1):21-27

⁸ Soniat B. Dementia patients who live alone: Research and clinical challenges. *JAGS*. 2004;52(9):1576-1577

⁹ Alzheimer's Australia NSW. *Living alone with Dementia*: Alzheimer's Australia NSW;2013.

¹⁰ Ibid.

people with dementia who live alone, in part because of the difficulties associated with contacting them and obtaining their consent¹¹

Physicians rated people with dementia who live alone as more at risk for management problems with nutrition, money, hygiene, medication, wandering, delusions, depression, falls and other factors than those living with others¹². Consistent with this are the many anecdotal accounts from home care service providers of the difficulties that people with dementia face when living alone and their vulnerability to exploitation. Home care providers experience difficulty contacting and obtaining permission to provide care, and sometimes feel that they are not able to provide adequate care because of limited hours to service the care recipients who often have complex needs and no other carer.

People with dementia who do not have a co-resident carer are often not diagnosed with dementia before a major incident such as an accident, fall or health crisis occurs¹³. As major incidents often precipitate nursing home admissions or death, these people are more likely than those with a co-resident carer to be diagnosed with dementia later and have missed the opportunity to receive home care services. This is supported by studies that indicate that those still living in the community alone with dementia have lower dementia severity, functional impairment and cognitive impairment than those who live with others.¹⁴

Information is needed to establish whether people with dementia who live alone have different pathways to care to those who have co-resident carers and what type of barriers there are for people with dementia and their informal carers to access services. However it is clear that this is a vulnerable cohort of consumers with special needs that should be considered under the Diversity Framework.

Action Plans

Survey questions:

- Is this an effective structure for the Framework?
- Is there anything missing?

Alzheimer's Australia recommends the addition of a targeted action plan for people living with dementia. Although the Government created a National Framework for Action on Dementia 2015-2019, Alzheimer's Australia has advocated for the addition of a linked, funded national strategy with measurable outcomes. The Framework identifies key areas for action, but without a more detailed action plan underpinning it, the momentum to stimulate quality and choice in dementia services will be minimised.

The importance of a measurable action plan for dementia cannot be underestimated. Dementia is one of the largest health and social challenges facing Australia and is a National Health Priority area. It is estimated that there are now more than 410,000 Australians living with dementia and nearly 300,000 people involved in their care; by 2056 there will be over a

11 Op. Cit. Soniat B.

12 Op. Cit. Tuokko et. al.

13 Lehmann SW, Black BS, Shore A, Kasper J, Rabins PV. Living alone with Dementia: Lack of awareness adds to functional and cognitive vulnerabilities. *Int Psychogeriatr.* 2010;22(5):778-784.

14 Prescop KL, Dodge HH, Morycz RK, Schulz RM, Ganguli M. Elders with dementia living in the community with and without caregivers: an epidemiological study. *Int Psychogeriatr.* 1999;11(3):235-250.

million people living with dementia.¹⁵ Dementia is the second leading cause of death in Australia,¹⁶ and there is no cure.

The estimated cost of dementia to the health and aged care system is at least \$4.9 billion per annum. Dementia will become the third greatest source of health and residential aged care spending within two decades, with the costs to these sectors alone reaching 1% of GDP.

People living with dementia continue to struggle to get access to the services and supports they require to achieve a high quality of life. People with dementia experience delays in diagnosis, stigma and social isolation¹⁷, unpredictable quality of care within residential care and difficulty accessing services and supports to stay connected with their communities. Family carers find it difficult to balance work, life and caring responsibilities, often resulting in reduced workforce participation and adverse physical and mental health outcomes¹⁸. For people from diverse backgrounds (CALD, people from Aboriginal and Torres Strait Islander backgrounds, LGBTI, Homeless, and those living alone) access to quality care and appropriate services can be even more difficult.

Measuring progress

Survey question:

- What monitoring mechanisms would you like to see?

Alzheimer's Australia supports support the broader intent of the Diversity framework and recognise its aim to assist providers, and enhance the sectors capacity, to better meet the diverse characteristics and life experiences of older people thereby ensuring inclusive aged care services.

However, we remain concerned about the current inability of mainstream services to deliver appropriate care and support for people with dementia. Specialist services such as dementia specific advocacy, information and support are critical. People with dementia and their families and carers will experience unique challenges when participating in programs due to the complex symptoms and progressive decline in cognitive functioning that are the hallmarks of dementia. The issues raised by consumers with regard to broader changes to Consumer Directed Care across aged care point to the complexities in balancing the needs of clients, service providers and governments, while ensuring timely access to essential services within a robust framework of consumer protections. This highlights the need for an increased and more robust focus on the quality of care provided to ensure standards of care are maintained and continually improved.

Throughout the consultation process around aged care reforms Alzheimer's Australia has therefore advocated that all changes should address how quality of care is going to be guaranteed and measured. Thus the Framework too should outline a robust process that measures progress and outcomes for consumers. It should also provide for a process to assess whether or not service delivery aligns with the Framework or how successful the

¹⁵ The National Centre for Social and Economic Modelling NATSEM (2016). *Economic Cost of Dementia in Australia 2016-2056*.

¹⁶ Australian Bureau of Statistics (2015) *Causes of Death, Australia, 2013: Cat no. 3303.0*

¹⁷ Alzheimer's Australia (2014) *Living with Dementia in the Community: Challenges and Opportunities*

¹⁸ Brodaty & Green (2002) *Who cares for the carer? The forgotten patient*

implementation of the Framework has been in relation to increasing the quality and appropriateness of care provided.

“Among the monitoring mechanisms that I would like to see implemented for the development of the Framework and Action Plans are separate Delphi forums which may be conducted either on-line or in person, and aimed at both service providers and consumers and consumer representatives and conducted in rural, provincial and metropolitan regions across each state in the commonwealth. This would take into account the different perspectives operating in each of these venues.”

Feedback from Consumer on Diversity Framework

Alzheimer’s Australia again recommends that the Framework be expanded to include information about quality measures.

Elements of the Framework

Vision

Survey questions:

- What do you think of the proposed vision?
- Is there anything missing?
- What factors need to be considered in making clear the intent of the Framework?
- Should specific, measurable goals be set out as part of the vision?
- If so, what could these goals be?

Alzheimer’s Australia is supportive of the draft Vision statement which states that *“All older people receive equitable access, treatment and outcomes and will experience a respectful and responsive aged care system that embraces their diverse characteristics and life experiences.”*

It is also important to recognise that every consumer’s journey with dementia is unique, even though there are many shared pathways. To serve the needs of people with dementia it is important to engage, listen and provide services in a flexible and adaptive way. Alzheimer’s Australia spends a great deal of time and energy seeking to move beyond stereotypes and labels to achieve genuinely responsive care. A one size fits all is definitely not an option for people with dementia – regardless of their gender or sexuality or culture or age or orientation. Fundamentally, consumers don’t want a system that erases and separates them from the person they once were, their friends and their community.

Emerging themes that should be supported through the Framework could include:

- The importance of treating consumers with dignity, respect and an acceptance of the person that they are rather than for the condition they have;
- The importance of community support for individuals to remain engaged and valued;
- The importance of access to a multi-faceted range of services and supports, such as a timely diagnosis, respite, social support, exercise and cultural activities.

The framework should also include clear guidelines that can engender this vision into practical outcomes. SMART (Specific, Measurable, Assignable, Realistic, Time-related) goals should be built into to support the intent of the vision.

Imperatives

Survey questions:

- Are the suggested imperatives the right ones?
- What other imperatives could be considered?
- Do the imperatives cover all issues for Government?
- Do the imperatives cover all issues for aged care service providers?
- Do the imperatives cover all issues for individuals with diverse characteristics and life experiences?
- Do the imperatives cover all issues for carers?

Ongoing changes to aged care and the move to open market approach with no safety nets, especially in areas such as Residential Aged Care can also put vulnerable consumers such as full or part pensioners at risk of being denied aged care places, in favour of those who are full fee paying or opting for additional services. Equity of access for vulnerable cohorts is thus a crucial imperative and we are pleased to see this included in the framework.

To achieve a quality aged care system it is vital that we have informed and engaged consumers, well supported in decision-making. As such, we recommend that the imperatives of this framework include informed decision making. 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.

Achieving participative and informed decision making also presents its challenges, especially for people from vulnerable cohorts. Choice will bring about positive changes for consumers, but there will remain groups of people who could be disadvantaged by this approach – those with reduced capacity, those living alone and/or without a carer/partner or advocate to assist in decision making, those from CALD backgrounds, Aboriginal and Torres Strait Islander people, and others who have faced institutionalised discrimination (e.g. LGBTI people).

Priorities

Survey questions:

- What other priorities can be included to address issues faced by all older people irrespective of their diverse characteristics and life experiences?
- Are there any gaps?
- Are these the right priorities?
- Do these priorities cover the needs of Government?
- Do these priorities cover all issues for the aged care service providers?
- Do these priorities cover all issues for individuals with diverse characteristics and life experiences?
- Do these priorities cover all issues for carers?

Alzheimer's Australia is supportive of the priorities included within the draft Framework. However there is not enough emphasis on understanding and recognising support for carers.

Most people with dementia and their families prefer that the person with dementia remain living at home for as long as possible, and carer support is a critical factor which currently enables 70% of people with dementia to live in the community. The increasing focus on home care as opposed to residential care, while aligned with consumer preferences, is likely to lead to increased demand for support in the community.

There are increasing threats to the sustainability of this carer support, and we face a looming shortage of carers. The impacts of caring are substantial, and while some carers experience positive impacts, many carers experience negative effects on their emotional, psychological, and physical health, social activities, ability to work and finances.

To enable people with dementia to live at home for as long as possible – which meets their preferences, and is also cost-effective for the health and aged care systems – it is critical that their carers are well supported. We urge the Framework to consider supporting carer needs specifically through the Diversity Framework.

Action Plans

Survey question:

- Are there any additional comments or feedback you would like to provide, or any other issues that are not captured in this paper?

Alzheimer's Australia would also recommend each of the identified action plans include a specific emphasis on the needs of people with dementia within that cohort (ATSI people with Dementia, CALD people with Dementia and LGBTI Elders with Dementia)

Although dementia – as well as a broad range of 'special needs' – is treated as 'core business' in an aged care policy context, the operational reality is such that providers are constantly trying to balance a broad range of specialist care needs with clinical efficiencies and financial sustainability. Further targeted investment – and support for such investment – is required to ensure aged care providers are better prepared to meet the needs of people from special needs background who are impacted by dementia, and this can be supported through the new Diversity Framework.