

Ms Toni Smith
Director
Palliative Care Section
Department of Health

cc Christina Griffiths/Poppy Wise, Urbis

Dear Ms Smith,

Evaluation of the National Palliative Care Strategy 2010

Alzheimer's Australia welcomes the opportunity to provide input to the evaluation of the National Palliative Care Strategy 2010.

Alzheimer's Australia is the peak body providing support and advocacy for people with dementia and their families and carers in Australia. 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 affects people's abilities and memories. It is surrounded by stigma and misunderstanding, isolates people with dementia and their carers from social networks, and carries significant social and economic consequences. The care and support of people with dementia is one of the largest healthcare challenges facing Australia. It is estimated that there are now more than 353,800 Australians living with dementia and over a million people involved in their care; and that by 2050 there will be nearly 900,000 people with dementia.

Alzheimer's Australia has a strong focus across the continuum of the condition for people with dementia and their carers, including issues relating to end of life care. Being able to access appropriate care at the end of life is a critical factor in a more dignified death. This requires early planning and documentation of wishes, particularly for people who have progressive neurological diseases such as dementia. Appropriate discussions with clinicians and family members are also important in achieving end-of-life care aligned with the consumer's wishes and goals. Coordination of care amongst various care teams such as health, community, residential and interdisciplinary care teams is needed, and care staff should have training in providing end-of-life care.

A number of factors currently contribute to poor access to quality end of life care for people with dementia. Firstly, there is a lack of understanding that dementia is a terminal illness, which leads to delays or inability to access palliative care services. There is also often poor understanding of the legal rights of people living in aged care, by both health professionals and family members. In addition, we still see a relatively low rate of Advance Care Planning by people with dementia and their families which means that there may be uncertainty about the person's wishes for end of life care; and we also hear of care providers not adhering to end of life care wishes due to staffing issues or concerns about legal implications. There is also evidence of a lack of assessment and appropriate treatment of pain for people who have difficulty communicating their discomfort.

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Alzheimer's Australia and Palliative Care Australia have developed a joint position statement on palliative care and dementia. The statement highlights the challenges around access to end-of-life care for people with dementia and makes recommendations to improve access to care. This statement is attached, for the information of the evaluation team.

We note that the purpose of the National Palliative Care Strategy evaluation is to assess the value and effectiveness of the Strategy, and identify new and emerging priorities and opportunities in relation to palliative care for improvement in the future. These objectives are welcomed.

The Strategy acknowledges that chronic life-limiting conditions such as dementia are increasing, and have changed the pattern of death. The Strategy is explicitly inclusive of frailty and dementia and notes that the disease trajectory in these cases is generally characterised by prolonged dwindling prior to death.

The Strategy also points out that most Australians would prefer to die at home, but the majority in fact die in hospital or some other institutional setting. Alzheimer's Australia will be keen to see any evidence of the impact of the Strategy in increasing the proportion of people, including people with dementia, who are able to die at home; noting that for the 30% of people with dementia who live in residential aged care, this is in fact their "home". Unfortunately, input from consumers indicates that it is still very difficult for people with dementia to die at home, whether that be at their own home in a community setting, or in a residential aged care home. Alzheimer's Australia is particularly concerned that the continuing decrease in ratios and absolute numbers of registered nursing staff in residential aged care facilities will only compound the current situation where people with dementia who are nearing end of life are transferred to hospital, as the aged care facility lacks appropriate staffing and confidence to provide end of life care. These transfers to hospital are disruptive and often upsetting to the person with dementia, and in hospital the person may be given invasive medical treatment which is costly, futile, and against their expressed wishes.

We are keen to see a full assessment of these issues in the context of the Strategy evaluation, and in the recommendations for future national strategic approaches to palliative care. There are some good models of palliative care support for people with dementia (for example, the provision of home-based and residential aged care-based palliative care by Clare Holland House, ACT), which could be considered for broader implementation, to enable more people with dementia to die at home.

An important priority area within the Strategy for people with dementia is Action Area 4 under Goals 1 and 2 (Awareness and Understanding): "Support the national roll out of Advance Care Planning across all sectors (primary, acute, aged care) including addressing any barriers to uptake." Again, we will be keen to see any evidence of progress made in this area. Clearly, timely diagnosis of dementia and the opportunity for people to put instruments in place early in the disease process while they still have capacity – including Advance Care Plans, as well as other instruments such as Enduring Power of Attorney, Enduring Guardianship, and Wills – can help to ensure that the wishes of people with dementia are known and respected as their condition progresses. Australian and international research confirms there are still significant delays in diagnosis of dementia; and our experience based on consumer input is that there is still an insufficient focus on Advance Care Planning at all levels of health and aged care. We are also aware that in some cases where

Advance Care Plans are in place, they are not respected and followed by care staff. Further effort in these areas will be required in the next phase of the Strategy, and we note that national action on advance care planning will need to take into account state/territory legislation and regulation, and regional mechanisms.

Alzheimer's Australia supports the development of consumer resources on advance care planning, advance care directives and other end-of-life care matters for people with dementia; and further effort in education and training for health professionals on advance care planning, advance care directives and end-of-life care for people with dementia.

Action Area 5 under Goal 3 (Appropriateness and Effectiveness) refers to the need to "Support the national roll out of an integrated care pathway across all sectors (primary, acute, aged care), including addressing any barriers to uptake." Alzheimer's Australia sees this as a particularly important area for national action. We are aware of some good work that has been done to develop integrated pathways of care for people with dementia, including through partnerships involving Primary Health Networks, but we are not aware of a national roll out of such pathways, nor are we aware of the extent to which palliative care services and approaches are integrated into these pathways. Integrated palliative care pathways need to be reflective of state structures and regional mechanisms. These will be important areas to assess in the evaluation, and to address further in the next iteration of the Strategy.

Alzheimer's Australia is also strongly supportive of the actions listed under Goal 5 (Capacity and Capability), including actions to: identify and recommend improved funding models that explicitly promote flexibility to meet the needs of the patient and their family; explore new and enhanced roles for aged care providers in palliative care; undertake further research and ongoing monitoring of the relative cost of care and cost effectiveness of care models in the last year of life; further improve the skill and confidence of the generalist workforce to work with people with palliative care needs; work to improve end of life and palliative care competencies in all care worker training packages; and incorporate Advance Care Planning in enhanced primary care planning. All of these actions are very relevant to the issue of appropriate end of life care for people with dementia, and we will be very interested to see what the evaluation finds with respect to the implementation of these actions, and any recommendations for the next phase of the strategy. In particular, Alzheimer's Australia calls for the further development of expertise and resources on grief and loss counselling for loved ones of people with dementia, and support for capacity building for service providers, particularly in the aged care sector.

Thank you again for the opportunity to comment, and I hope that these comments are helpful.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Carol Bennett', written in a cursive style.

Carol Bennett
CEO, Alzheimer's Australia
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