

Thursday 09 July 2020

Joint Select Committee on Palliative Care in Western Australia

Parliament of Western Australia

[palcare@parliament.wa.gov.au](mailto:palcare@parliament.wa.gov.au)

Dear Committee members

Thank you for the opportunity to comment on the inquiry into Palliative Care in Western Australia. Dementia Australia commends the Parliament of Western Australia for prioritising palliative care in the 2019-20 state budget and is supportive of the Committee's terms of reference:

- (1) That a joint select committee of the Legislative Assembly and Legislative Council into palliative care in Western Australia be established.
- (2) That the joint select committee inquire into and report on —
  - (a) the progress in relation to palliative care, in particular implementation of recommendations of the Joint Select Committee into End of Life Choices;
  - (b) the delivery of the services associated with palliative care funding announcements in 2019–2020;
  - (c) the delivery of palliative care into regional and remote areas; and
  - (d) the progress on ensuring greater equity of access to palliative care services between metropolitan and regional areas.
- (3) That the joint select committee consist of six members, of whom —
  - (a) three will be members of the Assembly; and
  - (b) three will be members of the Council.
- (4) That the standing orders of the Legislative Council relating to standing and select committees will be followed as far as they can be applied.
- (5) That the joint select committee report to both houses by 19 November 2020.

While in support of the inquiry, Dementia Australia would also like to flag the importance of including the specific palliative and end of life care needs of people living with dementia, their families and carers as a key consideration of the inquiry and Committee terms of reference.

People with dementia will differ in the rate at which their abilities deteriorate. However, it is inevitable that a dementia diagnosis will lead to progressive cognitive and functional decline. Most people in the later stages of dementia need significant care and support across almost every aspect of their life. In the later stages of dementia, people will often experience more complex personal and clinical care needs, in addition to experiencing psychological pain and distress.

Access to high quality palliative care and end-of-life support is therefore of peak importance to people living with dementia, their families and carers. Dementia Australia believes people

with dementia should be able to exercise choice over how they die, be able to die with dignity and without pain – and for those who may choose to do so – access voluntary assisted dying.

There are more than 459,000 Australians living with dementia and without a significant medical breakthrough, there will be over one million people living with dementia in Australia by 2058. In Western Australia, there is an estimated 42,900 people living with dementia in 2020. Without a medical breakthrough, the number of people living with dementia is expected to increase to an estimated 56,900 people by 2028 and 108,000 people by 2058.

Dementia affects people's abilities and memories and has a profound impact on the individual and their loved ones. It is cloaked in stigma and misunderstanding, isolates people with dementia and their carers from social networks, and carries significant social and economic consequences. People living with dementia constitute one of the most vulnerable groups in our society.

As such throughout this inquiry, Dementia Australia highlights the need for the inquiry to upskill the workforce, particularly those within Western Australia Health, to ensure that all staff, including medical practitioners and decision makers receive specific dementia training.

A lack of dementia-specific knowledge is well documented across a number of professional groups, including aged care workers, community groups and even medical practitioners – who have reported on their lack of confidence in diagnosing dementia.<sup>1</sup> Without a working understanding of dementia, the symptoms associated and the progressive nature of the condition, we cannot expect accurate and informed decisions to be made by medical or care staff with regards to their care. Therefore, mandatory dementia education for all care and medical staff should be seen as a critical priority across all states and territories, including Western Australia.

To appropriately support an individual's end of life decisions, medical professionals are required to have the appropriate skills and training. Dementia Australia supports a collaborative approach, whereby medical professionals in addition to receiving dementia training, utilise the expertise of neuropsychologists, geriatricians, palliative care professionals and dementia experts to ensure the best possible advice is being given to people living with dementia, their families and carers.

We would also like to draw your attention to a recent paper we developed – [\*Dying Well: improving palliative and end of life care for people with dementia\*](#), which outlines specific recommendations for state, territory and federal governments to consider if they are to meet the palliative care needs of people living with dementia, their families and carers. The discussion paper covers the key areas:

- Workforce;
- Advance Care Planning;
- Flexible and responsive funding models;
- Improved access and service coordination; and
- Better community awareness of dementia and palliative care.

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<sup>1</sup> Brodaty, H. H (1994) General practice and dementia: a national survey of Australian GPs. Medical Journal of Australia, 10-14

For the most effective outcome, State and Territory governments will work collaboratively with the Australian government to standardise approaches to palliative and end of life care in order to ensure consistency of care for people with dementia, no matter where they live.

Dementia Australia is calling on the Parliament of Western Australia to work in collaboration with the Australian government and other State and Territory governments to systematise and customise palliative care for people with dementia, acknowledging the contextual complexities of dementia care within the different health care and community settings.

Should the Joint Select Committee on Palliative Care in Western Australia wish to discuss this submission further, Dementia Australia would welcome the opportunity.

Yours sincerely

Kaele Stokes  
Executive Director, Advocacy and Research  
Dementia Australia