

Committee Secretary
Senate Legal and Constitutional Affairs Committee
PO Box 6100
Parliament House
Canberra ACT 2600

To Whom It May Concern,

Alzheimer's Australia welcomes the opportunity to provide a **submission to the inquiry into the exposure draft of the Medical Services (Dying with Dignity) Bill 2014**.

Alzheimer's Australia is the peak advocacy body that represents people with dementia, their family and carers. There are more than 330,000 Australians living with dementia and this number is expected to increase to nearly 900,000 by 2050.

The term dementia describes a collection of symptoms which are caused by disorders which affect the brain. These symptoms include progressive change and deterioration in memory, rational thinking, decision-making, language and behavioural and emotional regulation. Dementia is a terminal disease but is different from other terminal conditions; in part because of the long, unpredictable course of the disease, difficult issues around capacity for decision making, difficulties in communication and lack of community understanding of the disease.

As a consumer organisation Alzheimer's Australia is committed to informing consumer choice across all aspects of social and medical care. To that end, Alzheimer's Australia has published a two part publication on Planning for End of Life, the second part of which sets out to inform discussion about euthanasia and assisted suicide (Ref & AA website might be useful here). We consider that there are unique complexities associated with a diagnosis of dementia in relation to the provision of medical services to assist people to die with dignity.

Capacity

The draft Medical Services (Dying with Dignity) Bill outlines that people must be mentally competent and of 'sound mind' to access the dying with dignity medical service. Whilst there is no definition of 'sound mind' in the draft Bill, the legislation with regards to capacity in Australia is based on the United Nations principle of "presumption of capacity". This means that a person does not have to prove that they have capacity; it is assumed that they have capacity unless it can be proven that they do not. Someone with mild or moderate dementia may still have sufficient capacity to make their own decisions. However, there is no one tool that can accurately determine an individual's capacity in relation to dementia and therefore there would be an uncertainty about how best to determine the capacity of the person with dementia at the time of decision-making.

Societal attitudes

Societal attitudes and stigma towards people with dementia and the inadequacy of social support to enable people with dementia and their families and carers to be properly informed and supported in the decisions they make for example about end of life care and especially in relation to pain management. There is a pervasive assumption in most of the community that life loses its value and becomes intolerable for those with dementia and that enjoyment and participation in life end.

Given that many people currently avoid seeking help for symptoms of dementia because they are worried about the discrimination they will face if they receive a diagnosis of

dementia, there is great cause for concern about the discrimination the person with dementia and their family may face in relation to discussing medical assistance to die with dignity.

There is also a lack of information and understanding about how people with dementia feel about their quality of life or how their views on dementia and death may change as the condition progresses.

End of life care

There are currently concerns about the capacity of the health and aged care system to provide quality care for people with dementia at the end of life. Being able to access appropriate care at the end of life should be the first step to a more dignified death. There is also a lack of understanding among many community members and health professionals around what can currently be included in an advance care directive. In addition, often the wishes of a person with dementia are not respected at the end of life because of an uncertainty by care providers on the validity of an advance care directive or the legal authority of substitute decision makers. Alzheimer's Australia submits that before legislation allowing assistance to die is enacted, improving the quality of end-of-life care that people with terminal illnesses receive should be the first priority.

We also have concerns around the following points in the legislation that need further consideration by the Committee:

- There are no requirements relating to the time at which a request for medical assistance to die has to be made. If a person with dementia makes such a decision at a point in time when they still have cognitive capacity but their capacity subsequently changes, how would this be handled?
- There is no reference to how a request for medical assistance to die would be considered if included in an advance care directive.

Given these ambiguities and a lack of knowledge about attitudes related to dementia and medically assisted dying, our priority remains to ensure that quality end-of-life care for people with dementia is available to everyone who needs it, regardless of socio-economic status or geographic location.

Kind regards,



Glenn Rees AM
CEO
Alzheimer's Australia
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