



Joint Select Committee End of Life Choices  
Inquiry – Carers WA Submission

October 2017

**AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS**

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## ABOUT CARERS WA

Carers WA is the peak body representing the needs and interests of carers in Western Australia and is part of a national network of Carers Associations. Carers provide unpaid care and support to family members and friends who have disability, mental illness, a chronic condition, terminal illness, an alcohol or other drug issue or who are frail aged. The person they care for may be a parent, partner, sibling, child, relative, friend or neighbour. Illness and disability are non-discriminatory and the caring role can be borne by any individual at any given time, regardless of socioeconomic status, age or location. Caring is a significant form of unpaid work in the community and is integral to the maintenance of our aged, disability, health, mental health, and palliative care systems. A report undertaken by Deloitte, Access Economics, 'The economic value of unpaid care in Australia in 2015', determined the replacement value of the care undertaken by carers in Australia to cost \$60.3 billion per annum.

Some important facts about carers include:

- There are 2.7 million unpaid carers in Australia. More than 856,000 carers are primary carers.
- There are more than 320,000 family and friends in a caring role in Western Australia or approximately 1 in 8 in the community.

## ENQUIRIES

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## Terms of reference

Carers WA will address two of the four committee terms of reference. Carers WA wishes to confine its comments to the impact of end of life choices and palliative care on carers and ensuring adequate support to lessen the burden on carers.

Inquire into and report on the need for laws in Western Australia to allow citizens to make informed decisions regarding their own end of life choices, and in particular

a) assess the practices currently being utilised within the medical community to assist a person to exercise their preferences for the way they want to manage their end of life when experiencing chronic and/or terminal illnesses, including the role of palliative care.

Managing end of life choices and care has a significant impact on families and carers along with the individual receiving the care. Studies show that the impact of end of life caring is substantial with the physical, emotional, financial and social burden resulting in negative impacts on the carers' health. End of life carers have an increased risk of depression, immune system disorders, heart disease and metabolic syndromes.<sup>1</sup>

Any review of end of life choices should recognise that the support and care of families and carers as well as patients, is a crucial part of the process. Carers should be identified as early as possible and referred to carer specific supports and services such as carer counselling, bereavement counselling and social support.

A whole of family assessment approach by service providers will assist to ensure that the support needs of the carer and other family members are identified<sup>2</sup>. Planning for transitions, unexpected events and respite, can be developed within the assessment process.

End of life choices often include a preference to remain at home rather than in hospital. It is important to ensure that formal services are able to step in if the carer feels unable to continue to provide care or needs to reduce the amount of care they are providing at any time through the process.

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<sup>1</sup> Wilkinson, A. M., The carer experience in End of Life Cancer Caregiving: A discussion of the literature, Cancer Forum, Volume 34, Number 2, July 2010.

<sup>2</sup> <https://www.caresearch.com.au/caresearch/tabid/738/Default.aspx>

Inquire into and report on the need for laws in Western Australia to allow citizens to make informed decisions regarding their own end of life choices, and in particular

d) examine the role of Advanced Health Directives, Enduring Power of Attorney and Enduring Power of Guardianship laws and the implications for individuals covered by these instruments in any proposed legislation

Advance care planning has been identified as a way to ensure the patients' own wishes can be taken into account at the end of life. However, there are systemic and individual barriers to the use of this approach and its usefulness is debated.

Carers WA supports increased training for carers to support them to understand advanced care planning and its various components. Increased knowledge around advanced care planning would reduce the burden on carers and assist them in supporting the care recipient in making end of life choices.