



LASA
LEADING AGE SERVICES
AUSTRALIA
The voice of aged care

END OF LIFE CARE GAP ANALYSIS

17 July 2018

*A strong voice and a helping hand
for all providers of age services*

Leading Age Services Australia (LASA)

Leading Age Services Australia (LASA) is the national peak body representing and supporting providers of age services across residential care, home care and retirement living. Our vision is to enable a high performing, respected and sustainable age services industry delivering affordable, accessible, quality care and services for older Australians. We represent our Members by advocating their views on issues of importance and we support our Members by providing information, services, training and events that enhance performance and sustainability.

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LASA's membership base is made up of organisations providing care, support and services to older Australians. Our Members include private, not-for-profit, faith-based and government operated organisations providing age services across residential aged care, home care and retirement living. Our diverse membership base provides LASA with the ability to speak with credibility and authority on issues of importance to older Australians and the age services industry.

LASA is pleased to provide comment on the *End-of-Life Care Gap Analysis*. This submission responds to those proposed functions for End of Life Care Victoria, issues and questions presented in the *Consultation Discussion Guide* that LASA identified as relevant to aged care. Should you have any questions regarding this submission, please do not hesitate to contact Marlene Eggert on ph. 02-62301676 or email: marlenee@lasa.asn.au

Introductory comment

LASA would like to make the Victorian Department of Health and Human Services aware that the aged care sector is a key provider of End-of-Life care. Nationally, about 60,000 people die in a residential care facility (RACF) each year¹. Providers of RACFs tend to be involved in facilitating advanced care planning and the delivery of palliative care for many of their residents. People with medical conditions that may make them eligible for voluntary assisted dying (VAD) often live in residential aged care during the last phase of their lives. Thus, a small number of people living in a RACF may access VAD.

LASA encourages the Victorian Department of Health and Human Services to employ lessons from overseas in countries where palliative care and VAD dying practices are considered to be world class, with the highest levels of compassion and consumer choice applied.

¹ Productivity Commission 2018, Reforms to Human Services. End-of-Life care in Australia p.109.

Specific feedback to Consultation Discussion Guide

- Should EOLC be all-inclusive of advanced care planning, palliative care and voluntary assisted dying, or can they be effectively delivered as distinct and separate components of health and community care? On balance, what is the preferred approach and why?

LASA is of the view that End-of-Life care (EOLC) should include advanced care planning, palliative care and VAD. This is because people suffering from medical conditions, such as neurodegenerative diseases, which may make them eligible for VAD under the *Voluntary Assisted Dying Act 2017* are also likely to utilize advanced care planning and palliative care. End of Life Care Victoria may find supporting EOLC easier and more effective to do if it addresses the three key components of end-of-life care listed above.

- How would the functions of End of Life Care Victoria coalesce with the broader policy and strategy functions of the Department of Health and Human Services? How would systems and outcomes in end-of-life care be managed?

LASA is concerned that the articulation between the new national aged care standards (and related guidance material) and the provisions of the *Voluntary Assisted Dying Act 2017* requires clarification. The Commonwealth Government has advised LASA that it is looking at the implications of the Act for Commonwealth legislation, provisions and standards. On a jurisdictional level, LASA raised this issue on 4 June 2018 in a letter to the Minister for Health, Jill Hennessey.

The introduction of VAD may require changes associated with drug licence holders under the *Poisons, Drugs and Therapeutic Goods Act 1966* in aged care facilities. A further concern is any regulation concerning the safe storage of S9 drugs at a RACF.

Further, articulation between the *Voluntary Assisted Dying Act 2017* and the protection of vulnerable people from elder abuse may be required. How should RACF staff react if they perceive that a resident is being bullied into and/or being persuaded to request a VAD service the resident may not really want? This situation could arise if the resident aligns his/her wishes with a powerfully influential family member.

Case studies from overseas should also be looked at to compare the experiences of people residing in countries with VAD feeling pressured with the options faced by patients in countries without VAD.

<https://www.dutchnews.nl/news/2015/07/pressure-on-patients-is-cause-for-concern-euthanasia-expert/>

LASA Members identified that they may need assistance in the form of model policies and practice manuals that provide guidance on VAD and some of the issues raised in this submission. This guidance would also need to provide information in cases where providers or staff wish to opt out of involvement in VAD.

- What are the risks and benefits of segregating EOLC from other components of health and community care?

LASA would like to make the Victorian Department of Health and Human Services aware that, when considering the context of EOLC care delivery in its entirety, the aged care system needs to receive equal attention alongside health and community care.

- Collaborating with existing organisations to support and enhance current work on collecting, analysing and reporting data on end-of-life care practices including palliative care, advance care planning, continuous palliative sedation, and assisted dying; and providing administrative & research support to the Assisted Dying Review Board.

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As the bodies regulating aged care, the Federal Department of Health and Ageing, the Australian Aged Care Quality Agency (AACQA) and the new independent Aged Care Quality and Safety Commission (to be established from 1 January 2019 and replacing the AACQA) require involvement in data collection, analysis and reporting about EOLC practices.

Further, LASA proposes that information about a person's 'preferred place of death' and 'actual place of death' be collected. This data would yield information on how well EOLC policies support a person to die at their preferred place of death.

Proposed functions for End of Life Care Victoria

- Providing education and training programs for health practitioners;
- Provide counselling for health practitioners who participate in assisted dying;
- Maintaining a hotline for health practitioners seeking advice on end-of-life care issues, with a particular focus on assisting health practitioners in rural and regional areas who have limited access to end-of-life care specialists;

Definitions in the *Voluntary Assisted Dying Act 2017* refer to registered health professionals only. However, LASA would like to make the Department of Health and Human Services aware that the aged care workforce includes regulated nurses² who are registered health professionals and a majority of unregulated personal care workers (PCW).

Nurses and PCWs in aged care often develop strong personal relationships with the people they care for. Witnessing a person progressing over time towards their end of life and finally undergoing VAD may be deeply distressing for these nurses and carers morally and/or emotionally. Thus, access to education and training programs, counselling and access to advice about end-of-life issues is required for nurses as well as personal care workers in aged care.

² Regulated nurses are Registered Nurses and Enrolled Nurses.

For nurses and PCWs the education, counselling and advice needs to specifically address their right to conscientious objection to involvement in VAD related care and how to practice this right.

A considerable proportion of regulated nurses and PCWs in residential aged care are recent migrants to Australia. For example, in 2016 in residential aged care, 32.3% of all direct care employees and 40% of recent hires were born overseas³. Many of these nurses and carers arrived from countries with traditional communities that consider VAD a strong moral and cultural wrong. Further, migrant carers in aged care often have limited English language skills which will make the effective delivery of education, counselling and advice more difficult. End of Life Care Victoria needs to consider how to address the educational and counselling needs of this sizeable group of nurses and PCWs in aged care.

Registered nurses in aged care who work in managerial and service coordinating roles have different educational needs to nurses and PCWs in direct-care roles. This too applies to the Approved Provider. The particular education and support needs of this part of the aged care workforce as well as the Approved Provider requires consideration.

How would a single hotline service operate to service the community and health practitioners? What would be the requisite services (e.g. clinical advice, legal advice, referral service)?

LASA believes that the hotline should also provide counselling to health professionals and PCWs or refer them to a free-of-charge counselling service.

Providing information to the public on end-of-life care issues

The Consultation Discussion Guide states: The Panel⁴ noted that:

A key implementation task is to determine how people in the community may be made aware of their option to request voluntary assisted dying, who may be eligible, and how they would access and complete the process;

LASA encourages End of Life Care Victoria to consider how to meet the information needs of members of the public who live in RACFs and retirement villages.

³ 2016 National Aged care Workforce Census and Survey – The Aged Care Workforce, 2016.

⁴ Ministerial Advisory Panel on Voluntary Assisted Dying

While a person’s medical practitioner will be a critical source of information in discussions with the person, there is likely to be value in independent sources of advice and accurate information that is presented in a way that makes it easy for a range of people to understand the voluntary assisted dying process, which might include what the person needs to consider in making a request or coming to a decision about voluntary assisted dying;

LASA considers that Aged Care Nurse Practitioners, Palliative Care Nurse Practitioners and palliative care nurse specialists could act as valuable, independent sources of advice and accurate information. Further, Approved Providers of aged care may identify senior personnel interested in acting as a source of information and advice about VAD.

Further, End of Life Care Victoria should consider the communication needs of members of CALD communities resident in RACFs and retirement villages.

Are there other functions required to support the community? How could these be best accessed?

LASA emphasizes the need for State and Commonwealth Governments to ensure the adequacy of funding and service models for palliative care across specialist palliative care services, outreach palliative care services to residential care and in the home and palliative care in residential care.

LASA welcomes the 2018-19 Budget announcement of \$32.8 million for specialist palliative care support in residential aged care. Palliative care should be core business in aged care, however, this is contingent on matched funding from the states and territories.

Further, even with matching, it is not clear whether this level of funding will be sufficient or to what extent it has been based on modelling of demand. This initiative should be closely reviewed by the sector and Governments with a view to revising it as needed in future Budgets.

LASA draws your attention to this assessment by Palliative Care Australia:

http://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/05/180508-Budget-shows-palliative-care-should-be-core-business-in-aged-care.pdf