Victorian Parliamentary Inquiry

End of Life Choices

Submission from
Advance Care Planning Working Group and Consortium (East Hume and Border)
Central Hume Primary Care Partnership
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Email: [redacted]

The Advance Care Planning Working Group (hereafter referred to as ‘the Working Group’) and Consortium (East Hume and Border) support communities and health care organisations and their workforce to take a regional approach to the implementation of Advance Care Planning. The Working Group has been actively providing advance care planning community education (driven by community members), inter-professional education and resource dissemination since early 2014.

Advance Care Planning (ACP) is the process of planning for future health and personal care whereby a person’s values, beliefs and preferences are made known so they can guide clinical decision making at a future time when that person cannot make or communicate their decisions due to lack of capacity (Department of Health, Advance Care Planning: have the conversation; A strategy for Victorian health services 2014-2018, page 11).

The ACP Working Group and Consortium (East Hume and Border) include professionals and community members experienced in and passionate about ACP.

ACP is a crucial aspect of End-of-Life Choices and as such relevant to the focus of this inquiry into the need for laws in Victoria to allow citizens to make informed decisions regarding their own end of life choices.

We request the committee take into consideration the following issues and responses.

Terms of Reference 1: 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, including the role of palliative care

1.1 Border anomalies are an everyday feature of life in Murray River communities. Border anomalies are of increasing relevance given the mobility of people across borders for work, access to services and recreation e.g. Grey Nomads. Border anomalies are both a complicating factor in life along the river and an opportunity to identify best practice across different state systems.

The government frameworks and legislation shaping medical practices, funding and reporting in Victoria and New South Wales are similar in their commitment to person-centred-care but different in their implementation (e.g. language and documentation).

The common commitment to person centred care means health services on both sides of the border are committed to recognising the end-of-life choices of patients no matter what format the ACP documentation may take.

The unnecessary differences between Australian States negatively impact the people in border communities in ‘making informed decisions about end-of-life choices’.
This issue has been substantiated at recent community ACP forums organised with local volunteers where the Working Group provided information about the legal and practical (ambulance, emergency care, residential aged care) aspects of ACP. This information necessarily included both Victorian and NSW requirements and documentation. Community members and health professionals reported finding different State requirements as confusing and an additional barrier to making informed decisions for end-of-life care.

Different state government IT systems also require different ways of recording the existence of ACP or Power’s of Attorney details.

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<td>Promote ACP policies and procedures that recognise inter-state ACP documents e.g. Northeast Health Wangaratta ACP Guidelines 2013 state ‘NHW will honour Advance Care Planning documentation from other organisations’.</td>
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<td>1.1.2</td>
<td>Nationwide end-of-life care legislation and systems including IT alert systems, recording and data</td>
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1.2 Ambulance Services: The Victorian and NSW Ambulance Services have a cross border agreement that assists them in dealing with the different practices in place on either side of the border. The different ambulance systems are a case in point in relation to comparing systems to shape best practice across borders.

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1.3 Elder Abuse has received increasing attention in recent years and is particularly relevant in relation to end-of-life choices.

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people. For example, access to affordable independent assistance to complete an Advance Care Directive (see ‘multi level program’ below) and ensure Statement of Choices includes identifying who the person does NOT want involved in end-of-life decision making especially where abuse and conflict have been a factor.

1.4 ‘Having the ACP conversation’: The Victorian government ACP strategy emphasises the importance of ‘having the conversation’. The Working Group has been talking with communities and health professionals across the East Hume and Border and has been implementing a number of strategies aimed at ‘having the ACP conversation’.

Based on the experiences of the Working Group there is a need for increased support to assist people to ‘have the ACP conversation’.

**Response**

1.4.1 A multi-level support program is needed to assist Victorians across diverse communities and population groups to have the ACP conversation that will assist in making informed end-of-life choices.

The multi-level ACP support program could include

1. Financially support health professionals to undertake ACPs as a cost effective health measure e.g. dedicated Medicare Item or as per Medicare Insurance in the United States of America (www.thelancet.com, Editorial, Vol 386 July 18, 2015)
2. Establish agreements between health services and GP clinics for Advance Care Planning facilitators (RPC or equivalent trained) to assist people to complete ACPs during appointments booked through GP clinics (main referral pathway GP, Practice Nurse) – as per Barwon Health model
3. Establish a pool or register of ACP Volunteer Champions to assist people in ‘having the ACP conversation’ and beginning to complete documents – along the lines of the Tax Help program i.e. training, support, confidentiality and especially access to support for disadvantaged people and clear referral pathways for complex ACPs e.g. where competency is an issue
4. Support ACP community awareness forums and web based information to encourage the need to discuss and plan for care in advance and to provide documentation.

1.5 Organisational and professional cultural change: Cultural change amongst medical professionals must have support from the most senior decision makers to improve end-of-life care and choices.

Senior clinicians play a crucial role at end-of-life (ACSQHC 2015:8) in reviewing care plans and influencing the likelihood that safe and high-quality end-of-life care is patient and family-centred, and whenever possible, it should be aligned with the values, needs and wishes of the individual, and their family or carers. Such care should consider the patient’s expressed wishes regarding the circumstances, environment and place in which they wish to die. (ACSQHC 2015: 4) A recent article (‘Give death it’s due in a system focused on life’ http://www.theage.com.au/comment/hospitals-must-shift-focus-of-endo-life-care-from-disease-to-people-20150707-gj6joz.html) illustrates an ongoing barrier to the organisational culture change required in health services, that is, the difficulty engaging senior medical decision makers in ACP and end-of-life education.
1.5.1 Encourage senior medical professionals/decision-makers to honour ACP wishes through indemnity insurance requirements and/or VMO and Senior Specialist contracts

1.5.2 Ensure Mortality and Death Reviews include questions related to identification of ACPs and honouring of end-of-life choices.

1.6 **Palliative care resources** The Hume Region requires additional palliative care resources i.e. carer respite and a local palliative care physician.

**Response**

1.6.1 Provide additional palliative care resources in the Hume Region.

**Inquiry Terms of Reference 2:** review the current framework of legislation, proposed legislation and other relevant reports and materials in other Australian states and territories and overseas jurisdictions

As previously mentioned, a crucial issue confronting community members and professionals involved in facilitating end-of-life choices in East Hume and Border communities is the lack of consistency of legislation across Australian State borders.

**2.1 Consistent legislation:** the Respecting Patient Choices summary of Australian legislation relating to ACP (http://advancecareplanning.org.au/advance-care-planning/for-professionals/the-law-of-advance-care-planning/) provides evidence of the differences that create barriers to informed end-of-life care and choices.

Changes in legislation require an education and communication program to support cultural and practice change.

**Response**

2.1 Establish nationwide legislation related to end-of-life care and choices

2.2 Keep end-of-life legal arrangements simple and accessible e.g. continue breadth of people able to witness Powers of Attorney/Guardianship/ACP documents, ensure low cost and multi-level, community support to develop ACP/PO documents

2.3 Improve implementation of ACP legislation by providing online ACP education and information kits for legal and financial advice professionals dealing with Wills and Estates e.g. Solicitor ACP Kits being developed by the Advance Care planning Initiative (East Hume and Border)

2.4 Embed protection against elder abuse in end-of-life legislation

2.5 Adopt a common language approach when discussing end of life and advance care planning to eliminate differing terminologies between states.

**References**

Australian Commission on Safety and Quality in Health Care (2015) national consensus statement – essential elements for safe and high-quality end-of-life care

Department of Health (2014) Advance Care Planning: have the conversation; A strategy for Victorian health services 2014-2018