

Introduction

On 7 May 2015 the Legislative Council agreed that the Legal and Social Issues Committee should inquire into the need for laws in Victoria to allow citizens to make informed decisions regarding their own end of life choices and, in particular to:

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 care, including the role of palliative care;
2. review the current framework of legislation, proposed legislation and other relevant reports and materials in other Australian states and territories and overseas jurisdictions; and
3. consider what type of legislative change may be required, including an examination of any federal laws that may impact such legislation.

The Victorian Government welcomes the Legislative Council's Standing Committee on Legal and Social Issues (the Committee) Inquiry into End of Life Choices Final Report and would like to thank the Committee for its comprehensive review into end of life choices in Victoria.

Government is pleased to be able to formally respond to the Committee's final report.

The Victorian Government believes all Victorians are entitled to quality end of life care, which relieves pain and suffering, and provides empowering support to family, friends and carers. In May 2015, at the time Legislative Council agreed to refer the Inquiry into end of life choices to the Committee, Government placed on record its intention to consider two reforms that related to the scope of the Inquiry. These were to:

- undertake a program of improvements to palliative care and end of life services to provide responsive, appropriate and innovative home-based palliative care models in Victoria; and
- fulfil its commitment to give statutory recognition to advance care directives so competent Victorians can document treatment preferences for future conditions and articulate their end of life care wishes.

Government's July 2015 submission to the Inquiry identified four issues that it would address in order to improve end of life and palliative care in Victoria. These were to: improve the capacity of, and access to, specialist palliative care; better matching what people want and what is provided; improve integration across service delivery; and increase knowledge about end of life care amongst all clinicians and services. To address these, Government outlined its work to develop a framework to guide quality end of life care.

Government commitment to end of life care has resulted in major policy reform that address a significant number of the recommendations made by the Committee. The table following these introductory pages addresses the individual recommendations of the Committee.

Victoria's end of life and palliative care framework

After extensive consultation with communities, patients, carers and clinical and service stakeholders, Government released *Victoria's end of life and palliative care framework* (the Framework) in June 2016. The Framework sets a clear vision and identifies key priorities and actions to build responsive and sustainable end of life and palliative care. The key priority areas are:

1. Person centred services
2. Engaging communities, embracing diversity
3. People receive services that are coordinated and integrated
4. Quality and end of life care is everyone's responsibility
5. Specialist palliative care is strengthened

In 2016-17 \$7.2 million was committed to support the Framework implementation including funding to community palliative care services and regional palliative care consultancy services to meet growing demand and dedicated funding for reforms to be implemented progressively, with 2016-17 reforms providing the foundations for further improvements over the coming decade. In 2016-17 these reforms include:

Person-centred services

- Introducing legislation that gives statutory recognition of advance care directives for current and future conditions.
- Implementing advance care planning across health services and develop an advance care planning monitoring and evaluation framework.
- Establishing two demonstration sites (one metropolitan and one rural) to test approaches to supporting end of life conversations, education and strategies for positive ageing through local government services and population wellbeing plans.
- Creating a centralised and improved end of life and palliative care information portal.
- Reviewing after-hours support services for home-based palliative care across Victoria.
- Optimising specialist home-based palliative care by identifying expected core components of care.

Engaging communities, embracing diversity

- Establishing a medical scholarship to support Aboriginal palliative medicine trainees and developing culturally response palliative care strategies.
- Working with leaders from culturally and linguistically diverse communities to develop culturally response palliative care strategies for their communities.
- Providing access to training for health interpreters on end of life and palliative care so they can better support those from culturally diverse backgrounds in their interactions with healthcare providers, including advance care planning.

- Ensuring information about end of life and palliative care on the newly formed centralised information portal is translated into the most frequently used languages in Victoria.

People receive services that are coordinated and integrated

- Testing new integrated models of that deliver flexible end of life and palliative care.
- Improving regional coordination and referral pathways to support local health services to provide end of life care.

Quality end of life and palliative care is everyone's responsibility

- Working with palliative care education and training experts to develop an interactive education program for clinicians.
- Working with the Palliative Care Clinical Network to develop resources to assist health services to implement the National Consensus Statement on end of life care.
- Supporting the development of volunteer training, education and mentoring strategies.

Specialist palliative care is strengthened

- Developing a single point of entry for all referrals to community palliative care across metropolitan Melbourne to improve timely access.
- Strengthening the role of the Palliative Care Clinical Network in leading clinical improvement.
- Supporting growth in regional consultancy services to develop responsive interdisciplinary teams and build capacity across rural regions.
- Working with the Palliative Care Clinical Network to establish standardised processes for all patients transitioning from hospital palliative care services to home-based palliative care.
- Developing anticipatory prescribing guidelines to provide people being cared for at home with a 'standardised rescue medication and care package'.
- Improving access to palliative care neonatal services.
- Providing additional support to the Victorian Paediatric Palliative Care Program for Monash Children's Hospital.

Outcome measures

Outcome measures are being developed that support shared responsibility for patient outcomes for end of life care. Measures being developed include: a performance framework for specialist palliative care services; end of life care measures; and patient and carer experience. Measures will be developed and tested with the intention of a phased introduction over 2017 and 2018.

Statutory recognition of advance care directives

The Victorian Government committed to providing Victorians a greater say in their end of life care underpinned by a legislative framework for advance care directives so competent Victorians can document treatment preferences for future conditions and articulate their end of life care wishes.

In July Government released the *Simplifying Medical Treatment Decision Making and Advance Care Planning Position Paper*. On Wednesday 14 September the Medical Treatment Planning and Decisions Bill 2016 was second read in Parliament.

The Medical Treatment Planning and Decisions Bill

The Bill will introduce a new legal framework for medical treatment decision making for a person without capacity and repeal the *Medical Treatment Act 1988*, repeal and amend relevant provisions of the *Guardianship and Administration Act 1986* and the *Powers of Attorney Act 2014*. The Bill will:

- create a consistent definition across the statute book of medical treatment that includes prescribed pharmaceuticals and treatment for mental illness;
- apply to all health practitioners registered under the Health Practitioner Regulation National Law and to paramedics;
- introduce a single test for capacity in relation to medical treatment decision making;
- provide safeguards and protections for people making advance care directives and for health practitioners who comply with an advance care directive in good faith;
- clarify the legal hierarchy for selecting a medical treatment decision maker and remove the confusion about the powers of medical treatment decision makers;
- expand the role of the Public Advocate and ensure clear dispute resolution mechanisms, including provision to apply to the Victorian Administration and Civil Tribunal; and
- allow advance care directives for current and future conditions so adults and children with decision making capacity can:
 - make an instructional directive; and/or
 - make a values directive; and/or
 - in the case of adults, appoint a medical treatment decision maker; and/or
 - appoint a support person.

Developing an integrated community and stakeholder engagement campaign about end of life care, advance care planning and the role of the Bill in supporting medical treatment decision making will be a core component of effective reform and implementation over the next two years.

Government response to recommendations

No	Recommendation	Government response
1	That the Victorian Government develops a holistic, evidence-based funding framework for the palliative care workforce that includes targets to meet the current shortfall and growing demand for palliative care services.	Support
2	That the Victorian Government support an interdisciplinary approach to end of life care that focuses on continuity of care for the patient through the implementation of measures to encourage the efficient organisation and exchange of information with all parties. This includes patients, substitute decision makers, general practitioners, nurse practitioners, community nursing services, Aboriginal health services, home care workers, and managers of community and residential aged care facilities.	Support
3	That the Victorian Government encourage integration of palliative care with other health services by: <ul style="list-style-type: none"> • incorporating palliative care principles into care for patients with chronic conditions • ensuring timely referral of patients to palliative care (see also Recommendation 37) • encouraging timely advance care planning conversations through a 	Support

	<p>dedicated Medicare item number (see also Recommendation 34)</p> <ul style="list-style-type: none"> ensuring staff are trained to communicate and facilitate appropriate advance care planning and end of life care. 	
4	<p>That the Victorian Government prioritise integrating patient data systems and improve information sharing options for communicating with palliative care services, including information technology.</p>	Support
5	<p>That the Victorian Government increase access in rural and regional communities to community palliative care services by:</p> <ul style="list-style-type: none"> identifying health and community organisations that provide best practice community palliative care and enabling them to expand their services and/or guide the development of similar services in other rural and regional areas providing funding for administrative support to community palliative care organisations, so that they can focus on providing frontline palliative care services, such as respite for carers increasing funding to community palliative care services in rural and regional Victoria implementing incentive programs to attract palliative care expertise to rural and regional Victoria providing increased local training opportunities for palliative care staff in rural and regional Victoria 	Support

	<ul style="list-style-type: none"> • increasing focus on telehealth projects connecting palliative care patients with health practitioners so patients may remain in their own home with the support of community palliative care services • fostering community–academic partnerships to promote research and education that contributes to local education and understanding • investigating targeted funding programs to help people in rural and regional Victoria access allied health palliative care services such as social workers and bereavement counsellors. 	
6	That the Victorian Government work to reduce inequities in the provision of palliative care by ensuring consistent palliative care services across residential aged care facilities.	Support
7	That the Victorian Government work to prevent unnecessary emergency department presentations from aged care facilities and reinvest any savings into palliative care.	Support This recommendation is addressed through The End of Life and Palliative Care Framework.
8	That the Victorian Government support programs, such as the workshops provided by Palliative Care Victoria, to increase the visibility and highlight the benefits of palliative care to Aboriginal and culturally and linguistically diverse Victorians, through initiatives specifically targeting these communities.	Support This recommendation is addressed through The End of Life and Palliative Care Framework.
9	That the Victorian Government provide support to carers from groups that are	Support This recommendation is addressed through The End of Life and Palliative Care Framework.

	less likely to have access to palliative care, including Aboriginal and culturally and linguistically diverse groups.	
10	That the Victorian Government work with the Commonwealth Government to incorporate the National Consensus Statement: Essential elements for safe high quality end of life care into the National Safety and Quality Health Service Standards.	Support This recommendation is addressed through The End of Life and Palliative Care Framework.
11	That the Victorian Government establish standards of care to clearly discern criteria for referral to specialist palliative care and the expectations of palliative care knowledge and capability for generalist health care providers. This should include referral of patients who: <ul style="list-style-type: none"> • have chronic or non-terminal illnesses • are currently underrepresented in palliative care • would benefit from palliative care. 	Support This recommendation is addressed through The End of Life and Palliative Care Framework.
12	That the Victorian Government update the regulations regarding the storage of and access to medications at home and in residential aged care facilities for palliative care patients so that unnecessary barriers to treatment and pain relief are removed, while mitigating the risk of potentially dangerous and addictive medications being accessed inappropriately.	Supported in part. Alternative action provided This recommendation will be addressed by the Framework through the following actions: <ul style="list-style-type: none"> • Develop 'Ready for Care' protocols with the goal of improving communication between acute to community services. • Agree and develop a standard pack of 'anticipatory' medications, medical orders authorising administration equipment and guidelines to ensure safe access and management of medications in home settings. • Department of Health and Human Services will consider what, if any, changes to the Drugs, Poisons and Controlled Substances Regulations 2006 (amended in 2011) are required to support better delivery of palliative care.
13	That the Victorian Government provide support to community palliative care services so people who wish to can	Support Growth funding was provided in the 2016/17 Budget to support additional community palliative care services. Growth funding to address unavoidable demand will continue to be provided.

	receive end of life care at home, and choose where to die.	
14	That the Department of Health and Human Services model the potential budget savings of an increase in palliative care patients dying at home, as compared to dying in hospital. Such modelling should include budget outcomes for the current percentage of patients dying at home and incremental increases in the rate of home death for palliative care patients.	Support
15	That the Department of Health and Human Services model the budgetary impact on the hospital system of a stronger community palliative care system, in particular the impact on intensive care and emergency department costs that could be avoided with an increase in capability and availability of community palliative care.	Support This recommendation is addressed through The End of Life and Palliative Care Framework.
16	That the Victorian Government, recognising the value of community palliative care and informed by its investigations as stated in Recommendation 14 and Recommendation 15, increase support and funding to community palliative care services.	Support Growth funding was provided in the 2016/17 Budget to support additional community palliative care services. Growth funding to address unavoidable demand will continue to be provided as part of Government's annual health allocation.
17	That the Department of Health and Human Services provide detail on palliative care service provision and expenditure as part of its annual reporting, including a breakdown of funding sources and the value of the volunteer workforce contribution.	Support with alternative action The department as part of its annual reporting provides information on health expenditure, including palliative care. Alternative action

		The department, as part of the palliative care workforce 'snap shot' surveys, will continue to collect information about the volunteer workforce and its contribution to palliative care service delivery. This information will be reported in the department's annual report for those years when the survey is undertaken.
18	That the Victorian Government, as a priority, work with palliative care services to increase awareness of existing telephone support services, including afterhours support, to the community.	Support This recommendation is addressed through The End of Life and Palliative Care Framework.
19	That the Victorian Government increase availability of reliable respite services for carers, particularly in rural and regional areas.	Support This recommendation is addressed through The End of Life and Palliative Care Framework.
20	That the Victorian Government, in consultation with key stakeholders, design a strategy to ensure an appropriate level of high quality palliative care curriculum content in medical, nursing and allied health degrees, including how to have conversations on end of life care with patients.	Support This recommendation is addressed through The End of Life and Palliative Care Framework.
21	That the Victorian Government investigate expanding programs such as the MedeSims and virtual clinical setting programs offered at Deakin University School of Medicine, to better educate medical students in communication skills, particularly around difficult end of life conversations.	Support A palliative care workforce taskforce will be established to provide advice to the Department of health and Human Services.
22	That the Victorian Government develop an education package for residential aged care workers on end of life care.	Support This recommendation is addressed through The End of Life and Palliative Care Framework.
23	That the Medical Board of Australia include end of life care elements in periodic revalidation for any health practitioner who is likely to manage	Support

	patients with end of life care needs, including continuing professional development.	
24	That the Victorian Government requires that health services adopt palliative care training modules in orientation programs and annual competencies for clinical staff.	Support This recommendation is addressed through The End of Life and Palliative Care Framework.
25	That the Victorian Government introduces a coordinated approach to disseminating information on palliative care and associated health services.	Support This recommendation is addressed through The End of Life and Palliative Care Framework.
26	That the Victorian Government establish a taskforce to create appropriate guidelines for the administration of continuous palliative sedation to address the existing absence of data on continuous palliative sedation which undermines transparency.	Support in part. Additional action proposed Appropriate guidelines The Australia and New Zealand Society of Palliative Medicine (ANZPAM) would be better placed to review guidelines for sedation. Any recommended guidelines produced by ANZPAM will be considered for appropriate implementation support.
27	That the Victorian Government establish a requirement for all cases of continuous palliative sedation to be reported to the Department of Health and Human Services, and for the Department to include this data, de-identified, in its annual report.	Not supported It is not clear on the basis of the evidence provided by clinicians to the Committee, as quoted in the report, what problem collecting data on 'continuous palliative sedation' seeks to address. An unintended consequence of monitoring 'sedation rates' may be that health services become more conservative about the use of medications that are used in symptom management practices that also cause sedation. This may result in a range of patients who would benefit from these medications missing out. Developing appropriate guidelines for symptom management identified as the action in recommendation 26 above will better address the use of sedation medication use by both specialist and non-specialist medical practitioners (such as general practitioners) through appropriate clinical guidelines for symptom management. The Palliative Care Clinical Network should provide advice and direction about best practice standards.
28	That the Victorian Government enacts in legislation the common law doctrine of double effect to strengthen the legal	Under review

	protection for doctors who provide end of life care.	<p>Considerations about the doctrine of double effect will need to balance any legislative reform for the doctrine of double effect with the possibility that by doing so this may make the doctrine of double effect more limited, and its application would still remain case dependent.</p> <p>Legislation alone would not resolve the perceived uncertainty and in any legislative scheme there would continue to be 'grey areas' because the question of what constitutes proportionate pain relief and the intention of a medical practitioner will always depend on the particular circumstances of the case.</p> <p>Supporting an information campaign</p> <p>The report clearly identifies doctors' lack of knowledge about the law in relation to end of life care and the impact with may be having on patient care. This will be addressed through a targeted information campaign for health practitioners.</p>
29	That the Victorian Government legislates to enact the protection doctors currently have under the common law regarding withholding or withdrawing futile treatment. In this regard the Committee recommends Government give consideration to the South Australian Consent to Medical Treatment and Palliative Care Act 1995 section 17.	<p>Under review</p> <p>Currently, a doctor will face neither criminal nor civil liability for withholding or withdrawing futile treatment in accordance with proper medical practice and in good faith. An assessment of futility is a medical assessment that must be made on a case by case basis.</p> <p>Legislation alone would not be able to resolve the perceived uncertainty and in any legislative scheme there would continue to be 'grey areas' which may or may not fall within any provisions as the question of whether treatment is futile will always depend on the particular circumstances of the case.</p> <p>Supporting an information campaign</p> <p>The report clearly identifies doctors' lack of knowledge about the law in relation to end of life care and the impact with may be having on patient care. This will be addressed through a targeted information campaign for health practitioners.</p>
30	That the Victorian Government undertakes a community awareness campaign to improve understanding of end of life choices, particularly advance care planning.	<p>Support</p> <p>This recommendation will be considered as part of the 2017-18 End of Life and Palliative Care Framework work plan.</p>
31	That the Victorian Government through COAG Health Council or the Australian	<p>Support</p>

	Health Ministers' Advisory Council lobby the Commonwealth Government to undertake a national public awareness campaign on advance care planning to reinforce state efforts in this regard.	
32	That the Victorian Government support the recognition of Annual Dying to Know Day on 8 August.	Support
33	That the Victorian Government propose that the Commonwealth Government consider creating a Medicare Benefits Scheme item number for advance care planning to provide incentive for increased uptake.	Support (as part of broader discussions about the best way to promote advance care planning in general practice)
34	That the Victorian Government provide education to health practitioners about the option of using existing Medicare Benefits Scheme item numbers for advance care planning.	Support
35	That the Victorian Government include measures in its end of life care framework to ensure that end of life discussions and planning occurs. This should include nominating trigger points for conversations about end of life preferences between general practitioners and patients, such as: <ul style="list-style-type: none"> • over 75 health assessments • entry to residential aged care • allocation of high needs home care packages • discharge plans for those likely to die within 12 months. 	Support
36	That the Victorian Government establish a voluntary target to measure and	Support

	encourage improvements in the level of advance care planning across Victoria.	
37	That the Victorian Government undertake a health practitioner education campaign to improve understanding of advance care planning and how to facilitate this process with patients.	Support
38	That the Victorian Government implement guidelines and resources for health practitioners to support advance care planning and end of life conversations with patients with communication difficulties.	Support
39	That the Victorian Government lobby the Australian Medical Council to examine the adequacy of compulsory teaching in medical schools about substitute decision making and substitute medical consent.	Support
40	That the Postgraduate Medical Council of Victoria ensure that medical interns are adequately trained on the subject of substitute decision making.	Support
41	That the Victorian Government require doctors and nurses to undertake continuous professional development on advance care planning.	Support
42	As part of its longer term strategy in this policy area, that the Victorian Government implement a long-term systemic approach to integrating the My Health Record (including appropriate Information Technology infrastructure) into standard medical practice for the following purposes: <ul style="list-style-type: none"> • to record advance care plans 	Support

	<ul style="list-style-type: none"> • to use as core documentation for transfer of care • to develop a system of alerts and triggers that indicate a person has an advance care plan and how it can be accessed across health services. 	
43	That the Victorian Government, through End of Life Care Victoria recommended in this Report as part of the assisted dying framework, establish a registry hotline to improve access to advance care plans for emergency medical services.	<p>Not supported</p> <p>Advance care planning should not be conflated with a body established for assisted dying. The Medical Treatment Planning and Decisions Bill 2016 does not require registration of advance care directives or a central registry. Compulsory registration would be a barrier to people making advance care directives and is likely to create difficulties in accessing advance care directives. If registration is voluntary, this is likely to create confusion, as health practitioners are unlikely to look beyond the voluntary register, meaning many people’s advance care directives may be ignored.</p>
44	That health services prioritise the implementation of advance care planning and meet all the Department of Health and Human Services’ data collection and reporting requirements.	Support
45	That the Department of Health and Human Services improve its advance care planning reporting to better understand the level of uptake.	Support
46	That the Department of Health and Human Services, working with experts and stakeholders, develop and distribute an advance care directive form to allow patients to record their values and preferences as detailed in Recommendation 48.	Support
47	That the Victorian Government, as part of legislating to reform advance care planning, standardise the definition of	<p>Support</p> <p>The Medical Treatment Planning and Decision Bill will introduce a standard definition of medical treatment.</p>

	medical treatment across Victorian statutes.	
48	<p>Repeal relevant legislation</p> <p>That the Victorian Government repeal the Medical Treatment Act 1988 and repeal health substitute decision making provisions in the Guardianship and Administration Act 1986 and the Powers of Attorney Act 2014.</p> <p>New legislation — the Future Health Bill 2016</p> <p>That the Victorian Government introduce legislation providing for:</p> <ul style="list-style-type: none"> • instructional health directives, which will replace the refusal of treatment certificate. This should specify: <ul style="list-style-type: none"> — refusal of or consent to a particular medical treatment will be taken to be a binding provision, which can apply in limited circumstances all other provisions of an instructional health directive, such as value statements, are non-binding provisions • the ability to refuse or consent to treatment in relation to future conditions • protection for ambulance officers when they act in good faith in reliance on an instructional health directive • substitute decision makers, with the equivalent of an enduring power of attorney (medical treatment), to be able to refuse medical treatment. 	<p>Support</p> <p>This recommendation is addressed through The Medical Treatment Planning and Decisions Bill, 2016.</p>

49	That the Victorian Government introduce a legal framework providing for assisted dying, by enacting legislation based on the assisted dying framework outlined in this Report in Annex 1, Assisted Dying Framework Summary.	<p>Under review</p> <p>This recommendation and the supporting information in the report about this recommendation lack the legal, clinical and organisational detail about the implementation, practicalities and issues related to introducing an assisted dying framework. Further significant and detailed work would need to be undertaken considering the implementation of this recommendation, including the role and membership of the proposed Implementation Taskforce and the Assisted Dying Review Board.</p> <p>Consistent with the introduction of any new medical intervention or procedure, rigorous review of the assisted dying framework should be undertaken including safety and quality considerations and the impact on wider health care delivery including resource implication for palliative and end of life care.</p>
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