



Western Australian Government response

Joint Select Committee on End-of-Life Choices Report *My Life, My Choice*

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1. Foreword

On behalf of the Western Australian Government, I welcome the Joint Select Committee's Report: *My Life, My Choice* (**the Report**) and thank the Committee for its comprehensive review into end-of-life choices in Western Australia.

I would also like to thank the many individuals and organisations that provided submissions to the Committee.

The Western Australian Government is committed to providing patient-centred, high-quality care at end-of-life for people and their family/carers facing life-limiting illness through the prevention and relief of suffering.

The Report reinforces the need for our health system to continue to review, strengthen and adapt the way it delivers end-of-life and palliative care to provide high-quality health care for all Western Australians, including those who are aging, have complex needs and live with chronic disease, while also meeting the increasing demand for these services.

Reflective of the importance of this issue and the need for a clear and defined priorities for end-of-life and palliative care, on the 22 May 2018, the Department of Health released the WA End-of-Life and Palliative Care Strategy 2018-2028 (**the Strategy**), which provides strategic statewide policy direction and outlines the vision, values and priorities for end-of-life and palliative care in WA to 2028.

The Strategy places people and their family/carers at the centre of care and ensures people are cared for within a culture of compassion and quality. It also aligns with National and State strategies, policies and frameworks; and draws from national and international best practice.

Implementation of the recommendations of the Report provides an opportunity to focus improvement efforts and will enhance and build on the work already underway as part of the Strategy.

Care at end-of-life is everyone's business, whether it is provided by specialist palliative care or non-specialist healthcare and community providers. It occurs in all settings, from primary to tertiary health care, as well as community and residential aged care. Policy makers, executives, clinicians, researchers and the wider community all have a role to play to ensure that people of all ages, and their family/carers, have access to high-quality care, systems and services at a time when they feel most vulnerable, during advancing illness and at end-of-life.

On behalf of the Western Australian Government, I am pleased to present the response to the recommendations of the Joint Select Committee's Report: *My Life, My Choice*.



A handwritten signature in blue ink, appearing to read 'Roger Cook', written in a cursive style.

Hon. Roger Cook MLA
Deputy Premier
Minister for Health; Mental Health

2. Introduction

Purpose

To provide the Western Australian Government's response to the Joint Select Committee on End-of-Life Choices Report: *My Life, My Choice*.

Context and background

In 2017 a Joint Select Committee (**the Committee**) on End-of-Life Choices was established by the Parliament of Western Australia. The Committee undertook an Inquiry into the need for laws in Western Australia (WA) to allow citizens to make informed decisions regarding their own end-of-life choices. In particular, the Committee:

- assessed 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;
- reviewed the current framework of legislation, proposed legislation and other relevant reports and materials in other Australian States and Territories and overseas jurisdictions;
- considered what type of legislative change may be required, including an examination of any federal laws that may impact such legislation;
- examined the role of Advance 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.

The Inquiry was conducted over a year and included extensive consultations and research. The Committee received more than 700 submissions and held 81 hearings, during which it heard from 130 witnesses. The Committee visited metropolitan palliative care providers and travelled to the Great Southern region and the Kimberley to visit health providers, hold hearings and meet with local communities.

The Department of Health (**DOH**) and the Department of Justice (**DOJ**) were among more than 700 individuals and organisations that made submissions to the Committee and gave evidence at the Committee's public hearings.

The Committee handed down its report *My Life, My Choice* (**the Report**) to both Houses of Parliament on 23 August 2018. The Report outlined 52 findings and made 24 recommendations in relation to end-of-life choices.

3. Current policy environment

In May 2018 the DOH released the WA End-of-Life and Palliative Care Strategy 2018-2028 (**the Strategy**), which provides strategic, statewide policy direction and outlines the vision, values and priorities for end-of-life and palliative care in WA to 2028. It provides a 10-year vision for improving the lives of all Western Australians through quality end-of-life and palliative care.

End-of-life and palliative care aim to improve the quality of life of people and their family/carers facing life-limiting illness through the prevention and relief of suffering. An increasing demand for services combined with an ageing population with complex needs means that the WA health system needs to continue to strengthen and adapt the way it delivers end-of-life and palliative care. In developing the Strategy, extensive consultation provided healthcare providers, the community and consumers with the opportunity to identify gaps, innovations and improvements, and to contribute to a shared vision for end-of-life and palliative care.

The Strategy identified 6 priority areas to guide and inspire public, private, community and non-government health sectors to partner for the provision of best-practice end-of-life and palliative care for the next 10 years. This includes the delivery of specialist and non-specialist teams providing end-of-life and palliative care. The identified priority areas in the Strategy include:

1. Care is accessible to everyone, everywhere.
2. Care is person-centred.
3. Care is coordinated.
4. Families and carers are supported.
5. All staff are prepared to care.
6. The community is aware and able to care.

The statewide implementation of the Strategy is being led by the Western Australian Cancer and Palliative Care Network (**WACPCN**) in the DOH and performance will be monitored via system wide trends and data collection.

4. Recommendation summary

Responses to the Committee's recommendations have been assisted by consultation undertaken by both the DOH and the DOJ through their subject matter experts in end-of-life, palliative care, financial, legal, legislative and policy matters.

Recommendations have been grouped into 3 distinct areas:

- Advance Care Planning, including Advance Health Directives (Recommendations 1 to 6),
- End-of-Life and Palliative Care (Recommendations 7 to 18)
- Voluntary Assisted Dying (Recommendations 19 to 23).

An overview of the recommendation responses has been provided for each area, outlining the position of the WA Government. Appendix 1 provides a summary of recommendation responses.

In addition, an outline of related programs of work and initiatives that are already underway as part of the Strategy has been included.

Summary of responses

The WA Government supports all of the Committee's recommendations noting in some instances dependencies that require further work.

A summary of the WA Government's response to the recommendations of the Committee is described in table 1 below.

Table 1.

Subject Area	Total Recommendations	Supported	Supported, noting dependencies	Not supported
Advance Care Planning	6	3	3	-
End-of-Life and Palliative Care	12	-	12	-
Voluntary Assisted Dying	6	6	-	-

4.1 Advance Care Planning

Recommendations 1 to 6 are related to Advance Care Planning (ACP) and in particular Advance Health Directives (AHD). These recommendations cover a number of matters including policy and practice, strategy, governance, reporting and education for health professionals and the wider community.

Overview

An overview of the WA Government's response to Recommendations 1 to 6 is described in table 2 below.

Table 2.

	Total Recommendations	Supported	Supported, noting dependencies	Not supported
Advance Care Planning	6	3	3	-

Recommendation response summary

The recommendations related to ACP and AHDs are supported, noting there are a range of dependencies including potential resource and funding implications that must be considered in the context of implementation.

The Attorney General will appoint an Expert Panel in accordance with Recommendation 1. The Panel will be comprised of health and legal experts as well as members of the community and care sector. The Panel will review the relevant law and health policy and practice and provide recommendations in relation to each of the matters outlined in Recommendation 1.

The Panel will also make recommendations on how best to meet outstanding education needs and in doing so work to address recommendations 2 and 3.

The WA Government strongly supports the continued professional development of health professionals and education of the wider community regarding the nature, purpose and effect of AHDs and other planning records, as well as the continued improvement of accessibility and governance of their use. Additional funding would be required in order to broaden the Office of the Public Advocate's community education.

Summary of work in progress

The DOH and the DOJ are committed to improving access and education related to the use of AHDs in WA and maximising the opportunity for the public to make important decisions related to their future healthcare treatment. The work already underway in this area will be reviewed and strengthened to educate health professionals and the public. Current work includes:

- The DOH has developed online eLearning, provided a telephone advisory service and delivered education sessions across the State. In addition, the DOH has updated current resources to enable the completion and to facilitate wording of AHDs and to support Culturally and Linguistically Diverse and Aboriginal communities within WA in relation to ACP.

- The DOH has established a clinical alert for the presence of AHDs within the Patient Admission System used in public hospitals. This alert ensures a patient’s AHD now comprises part of a patient’s medical record and is available to health professionals treating the patient.
- The Office of the Public Advocate currently provides a range of community education activities regarding enduring powers of guardianship, AHDs, enduring powers of attorney, guardianship and administration. In 2017/18 the Office of the Public Advocate delivered 22 community education sessions.

4.2 End-of-Life and Palliative Care

Recommendations 7 to 18 relate to End-of-Life and Palliative Care. These recommendations cover a number of matters:

- Palliative care service provision across WA
- Palliative care service models and funding
- End-of-Life and palliative care policy and governance
- End-of-Life and palliative care education for health professionals and the community.

Overview

An overview of the WA Government’s responses to End-of-Life and Palliative Care Choices recommendations is described in table 3 below.

Table 3.

	Total Recommendations	Supported	Supported, noting dependencies	Not supported
End-of-Life and Palliative Care	12	-	12	-

Recommendation response summary

The DOH will undertake further consultation on how these recommendations may be implemented.

Many of the recommendations build on preceding and current work being undertaken by the DOH and described in the Strategy and The End-of-Life Framework.

The End-of-Life Framework (**the Framework**) guides best practice in care across the end-of-life trajectory, commencing with the diagnosis of a life-limiting illness through to death and bereavement. The Framework was developed by the DOH in 2016 to inform innovative, patient-centred, high quality care at end-of-life and to drive sustainable improvements in care.

Some of the recommendations will entail new work for the DOH and all recommendations will require further work to validate the component parts and determine the feasibility, application, approach and implementation with key stakeholders. This will include prioritisation of relevant policy development and improved governance structures. The recommendations are broad in their scope and will have significant clinical, funding and resource implications.

Summary of work in progress

The work being undertaken by DOH will be better focused and strengthened through the implementation of the Report recommendations. At present the DOH is:

- implementing the Strategy: released in 2018, the Strategy provides statewide policy direction and outlines the vision, values and priorities for end-of-life and palliative care in WA to 2028. The statewide implementation of the Strategy is being led by the WACPCN in the DOH and performance will be monitored via system wide trends and data collection.
- collecting data: The collection and analysis of data is essential to planning, evaluation and ongoing quality improvement in end-of-life and palliative care. At a local level datasets have been implemented across numerous public specialist palliative care services to collect standardised data in relation to Activity Based Funding, clinical management and service activity.
- undertaking the Rural Palliative Care Program: The Rural Palliative Care Model in WA addresses the specific palliative care needs in rural and remote WA and supplements the Palliative Care Model of Care. The Rural Palliative Care Program continues to build workforce capacity and improve access to specialist palliative care.
- providing Evidence Based Clinical Guidelines for clinicians: WA Health has developed comprehensive evidence-based clinical guidelines to support health professionals' decision making regarding care of adults in the terminal phase.
- providing education through the Palliative and Supportive Care Education (**PaSCE**): PaSCE offers a variety of education programs which are aimed at increasing knowledge and understanding of palliative care in all settings. The education programs are facilitated by project officers in collaboration with expert palliative care clinical providers and health professionals.
- providing a palliative care consultancy service: Metropolitan Palliative Care Consultancy Service (**MPaCCS**) is a specialist palliative care team (funded by the DOH), focusing on capacity building of the palliative care sector workforce through training, education, assistance and mentoring where there are currently no specialist palliative care consultation services available. The service operates in an ambulatory manner and services the metropolitan area. The MPaCCS team seeks to work collaboratively with GPs and other healthcare team professionals. The service is available for residents or patients at the following locations:
 - Mental health and psycho-geriatric facilities
 - Residential aged care facilities
 - Residential disability facilities
 - Correctional facilities
 - Aboriginal and Torres Strait Islander medical service facilities
 - General practices, or consultants working in the above facilities
 - Hospitals – for staff engaged in discharge planning for patients who will transfer to a facility or institution.

4.3 Voluntary Assisted Dying

Recommendations 19 to 23 relate to the approach, content and consultation required regarding the development and introduction of legislation for voluntary assisted dying in WA. Recommendation 24 recommends the development and introduction of legislation for voluntary assisted dying.

Overview

An overview of the responses to Voluntary Assisted Dying recommendations is described in table 4 below.

Table 4.

	Total Recommendations	Supported	Supported, noting dependencies	Not supported
Voluntary Assisted Dying	6	6	-	-

Recommendation response summary

The WA Government supports recommendations 19, 21 and 24. A Ministerial Expert Panel (**MEP**) will be appointed to assist in the consultation and development of legislation for a safe and compassionate voluntary assisted dying framework for Western Australia. A Government bill will be introduced into Parliament for voluntary assisted dying.

Recommendations that include specific detail on the development of the legislation (Recommendations 20, 22, 23) are supported, noting that the MEP will provide advice on these matters. The MEP will undertake the required consultation in order to provide expert advice and direction on the development of the legislation.

5. Next steps

Implementation of the Committee's recommendations will require a system wide approach, with consultation and engagement across public, private, community, aged care services, representative bodies and non-government organisations, including primary healthcare teams.

The DOH and the DOJ will initiate a process of detailed planning to mobilise the governance and resources required to support the implementation of the recommendations. A more detailed implementation plan and progress report will be made available in early 2019.

The two Expert Panels will both commence their work in December 2018.

Where possible, the implementation of recommendations will be progressed within current resourcing. Recommendations that require additional funds will require lead agencies to make coordinated submissions for consideration by the Expenditure Review Committee as part of the 2019-20 Budget and/or subsequent budget processes.

6. Appendices

6.1 Appendix 1: Summary of Recommendation responses

Rec #	Recommendation	Assigned Responsibility ¹	Response Commentary
1	<p>The Attorney General, in consultation with the Minister for Health, appoint an expert panel to review the relevant law and health policy and practice – and provide recommendations in relation to the following matters:</p> <ol style="list-style-type: none"> The establishment of a purpose-built central electronic register for advance health directives that is accessible by health professionals 24 hours per day and a mechanism for reporting to Parliament annually the number of advance health directives in Western Australia. A requirement that health professionals must search the register for a patient’s advance health directives, except in cases of emergency where it is not practicable to do so. Amendments to the current Western Australian template for advance health directives in order to match, as a minimum, the leading example across Australia, taking into account Finding 7 (see page 48). Consider how the increasing numbers of people diagnosed with dementia can have their health care wishes, end-of-life planning decisions and advance health directives acknowledged and implemented once they have lost capacity. 	Attorney General	Supported
2	<p>The Attorney General, in consultation with WA Health, and relevant health professional bodies, undertake an immediate and extensive program to educate health professionals about:</p> <ul style="list-style-type: none"> The nature, purpose and effect of advance health directives and enduring powers of guardianship; How to identify a valid advance health directive; and How to identify the lawful substitute treatment decision-maker. 	Attorney General	Supported, noting dependencies

¹ Assigned Responsibility: Responsibility assigned within the Joint Select Committee’s report *My Life, My Choice*.

Rec #	Recommendation	Assigned Responsibility ¹	Response Commentary
3	<p>The Attorney General, in consultation with WA Health, provide greater education for the wider community about:</p> <ul style="list-style-type: none"> • Advance health directives; • Enduring guardians; and • The hierarchy of medical treatment decision-makers. 	Attorney General	Supported, noting dependencies
4	WA Health immediately develop a strategy to ensure that when an AHD is provided by a patient to a hospital, it is easily accessible and stored prominently on the medical record - until there is a central database.	WA Health	Supported
5	The Minister for Health recommends to the Council of Australian Governments an amendment to the Medicare rebate schedule to include preparation of advance health directives with general practitioners.	Minister for Health	Supported
6	The Minister for Health report to Parliament annually on the number of advance health directives held on hospital medical records in Western Australia.	Minister for Health	Supported, noting dependencies
7	The Minister for Health should facilitate the establishment of an inpatient specialist palliative care hospice providing publicly funded beds in the northern suburbs of Perth.	Minister for Health	Supported, noting dependencies
8	The Minister for Health should ensure that community palliative care providers, such as Silver Chain, are adequately funded to provide for growing demand.	Minister for Health	Supported, noting dependencies
9	WA Health should conduct an independent review, from a patient's perspective, of the three models of palliative care in Western Australia: inpatient, consultative and community. The review should examine the benefits and risks of each model and the accessibility of each across the state as well as the admission criteria for hospice care (see Finding 18).	WA Health	Supported, noting dependencies
10	WA Health should implement a process to determine the unmet demand for palliative care and establish an ongoing process to measure the delivery of palliative care services with the aim of making those services available to more Western Australians.	WA Health	Supported, noting dependencies

Rec #	Recommendation	Assigned Responsibility ¹	Response Commentary
11	<p>To improve understanding of palliative care in Western Australia, WA Health should:</p> <ul style="list-style-type: none"> Establish a consistent definition of palliative care to be adopted by all health professionals; Provide comprehensive, accessible and practical information and education services about palliative care to health professionals and the community; Encourage knowledge sharing by palliative care specialists with their generalist colleagues; and Establish a palliative care information and community hotline. 	WA Health	Supported, noting dependencies
12	The Minister for Health should prioritise policy development and improved governance structures for the delivery of palliative care by WA Country Health Services.	Minister for Health	Supported, noting dependencies
13	The Minister for Health should ensure regional palliative care be adequately funded to meet demand.	Minister for Health	Supported, noting dependencies
14	<p>Once a consistent definition of palliative care has been established by WA Health in accordance with Recommendation 11, the Minister for Health should appoint an independent reviewer to audit:</p> <ul style="list-style-type: none"> The level of palliative care activity actually provided in Western Australia's hospitals and compare it against the level of recorded palliative care activity. The actual spend by WA Health on palliative care on a year-by-year and like-for-like basis, across all aspects of palliative care provision, including community service providers, area health services (including WA Country Health Services) and delineating between inpatient, consultancy and community care. 	Minister for Health	Supported, noting dependencies
15	WA Health should provide ongoing professional development for all health professionals – beyond undergraduate training – about the right of a patient to refuse medical treatment. WA Health should also specifically amend the Consent to Treatment Policy to provide comprehensive information in relation to a competent patient's absolute right to refuse medical treatment.	WA Health	Supported, noting dependencies

Rec #	Recommendation	Assigned Responsibility ¹	Response Commentary
16	WA Health should provide ongoing professional development – beyond undergraduate training – for all health professionals regarding the absolute right of a competent patient to refuse food and water. Training should also include those working in aged care.	WA Health	Supported, noting dependencies
17	WA Health should provide ongoing professional development – beyond undergraduate training – for health professionals about the transition from curative to non-curative end-of-life care and effective discussions with patients and families about futile treatments WA Health should consider how it might effectively educate the community about end-of-life decision-making, and implement appropriate health promotion in this area.	WA Health	Supported, noting dependencies
18	<p>WA Health should provide specific guidelines on the use of terminal sedation by health professionals for patients at the end-of-life. These guidelines should include an agreed name and definition of the treatment.</p> <p>As per any other medical treatment, the requirement for informed consent must be clear.</p> <p>The treatment must be specifically noted in the medical record as ‘terminal sedation’.</p>	WA Health	Supported, noting dependencies
19	The Minister for Health should ensure that any bill to introduce a legislative framework for voluntary assisted dying is introduced by the government.	Minister for Health	Supported
20	The Minister for Health should ensure that health professionals are not compelled to participate if any voluntary assisted dying framework is developed for Western Australia.	Minister for Health	Supported
21	The Minister for Health establish an expert panel including health and legal practitioners and health consumers to undertake consultation and develop legislation for voluntary assisted dying in Western Australia, and that this report, together with the Framework contained at the end of Chapter 7, be considered by that Panel.	Minister for Health	Supported
22	The Minister for Health should ensure that legislation require that death be reasonably foreseeable as a consequence of the condition.	Minister for Health	Supported, noting that the MEP will provide advice on this matter

Rec #	Recommendation	Assigned Responsibility ¹	Response Commentary
23	That the Minister for Health ensure the eligibility requirement in the legislation include that the person is experiencing grievous and irremediable suffering related to an advanced and progressive terminal, chronic or neurodegenerative condition that cannot be alleviated in a manner acceptable to the person.	Minister for Health	Supported, noting that the MEP will provide advice on this matter
24	The Western Australian Government develop and introduce legislation for voluntary assisted dying having regard to the recommended framework and following consultation with the Panel established under Recommendation 21.	Western Australian Government	Supported

6.2 Appendix 2: Definitions of Recommendation responses

Response	Response definition
Supported	Recommendation is fully supported. Implementation will be led within current resourcing and operational structures.
Supported, noting dependencies	The general principles of the recommendation are supported. Further work is required to confirm dependencies and implementation (e.g. resources). May be subject to submissions as part of the 2019-20 Budget and/or subsequent budget processes.
Not supported	Recommendation is not supported.

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