REPORT

SELECT COMMITTEE ON END OF LIFE CHOICES IN THE ACT

MARCH 2019

THE COMMITTEE

COMMITTEE MEMBERSHIP

Ms Bec Cody MLA	Chair
Mrs Vicki Dunne MLA	Deputy Chair
Ms Tara Cheyne MLA	Member
Mrs Elizabeth Kikkert MLA	Member
Ms Caroline Le Couteur MLA	Member

SECRETARIAT

Mr Andrew Snedden	Secretary
Mr Danton Leary	Senior Research Officer
Ms Josephine Brown	Senior Research Officer
Ms Brianna McGill	Senior Research Officer
Ms Lydia Chung	Administration Officer

CONTACT INFORMATION

Telephone	(02) 6205 0199
Post	GPO Box 1020, CANBERRA ACT 2601
Email	LACommitteeEOLC@parliament.act.gov.au
	committees@parliament.act.gov.au
Website	www.parliament.act.gov.au

ACCESSIBILITY

The Committee has made every effort to ensure that this document is accessible. If you are unable to read this document, please contact the Committee Support Office.

RESOLUTION OF APPOINTMENT AND TERMS OF REFERENCE

The Resolution appointing the Select Committee was passed by the Legislative Assembly on 30 November 2017.[1]

The Committee's Terms of Reference are:

That:

(1) a select committee be established to inquire into end of life choices in the ACT, including:

  (a) current practices utilised in the medical community to assist a person to exercise their preference in managing the end of their life, including palliative care;

  (b) ACT community views on the desirability of voluntary assisted dying being legislated in the ACT;

  (c) risks to individuals and the community associated with voluntary assisted dying and whether and how these can be managed;

  (d) the applicability of voluntary assisted dying schemes operating in other jurisdictions to the ACT, particularly the Victorian scheme;

  (e) the impact of Federal legislation on the ACT determining its own policy on voluntary assisted dying and the process for achieving change; and

  (f) any other relevant matter;

(2) the select committee shall consist of the following number of members, composed of:

  (a) two Members to be nominated by the Government;

  (b) two Members to be nominated by the Opposition; and

  (c) one Member to be nominated by the Crossbench;

(3) the select committee be provided with necessary staff, facilities and resources;

(4) the select committee is to report by the last sitting day in 2018;

(5) if the Assembly is not sitting when the committee has completed its inquiry, the committee may send its report to the Speaker or, in the absence of the Speaker, to the Deputy Speaker, who is authorised to give directions for its printing, publishing and circulation;

(6) the foregoing provisions of this resolution, so far as they are inconsistent with the standing orders, have effect notwithstanding anything contained in the standing orders; and

(7) nominations for membership of the committee be notified in writing to the Speaker within two hours following conclusion of the debate on the matter."—

(8) notwithstanding the provisions of standing order 241, Committee considerations do not preclude Members from publicly discussing Territory rights, including the current

[1] ACT Legislative Assembly, *Minutes of Proceedings, No.43*, 30 November 2017, pp 628-629.

> Federal legislative restriction on voluntary assisted dying, to allow all Members to comply with that contained within (4) of the unanimously passed *Voluntary Assisted Dying* motion of 1 November 2017.

On 2 August 2018, the Legislative Assembly passed a motion amending the terms of reference for the Committee inquiry[2]:

> Legislative Assembly - Voluntary Assisted Dying motion of 1 November 2017
>
> Paragraph 4 – see resolution passed on 2 August 2018 (above).
>
> …….
>
> (4) calls on the ACT Government and each Member of the Legislative Assembly:
>
> (a) to raise with Federal political colleagues and counterparts, as appropriate, the increasingly paternalistic and unreasonable curtailment of ACT Legislative Assembly legislative powers, and how poorly this reflects on the Commonwealth Parliament's understanding of the ACT's capacity to govern itself;
>
> (b) to convey to the Commonwealth Government and Opposition, at every available and appropriate forum, the need to repeal the Euthanasia Laws Act 1997 and restore to the Territories the right to make laws in respect of voluntary euthanasia and voluntary assisted dying; and
>
> (c) to consider as soon as practicable, upon the passage of a scheme in any Australian State to allow voluntary assisted dying, whether and how the ACT community can have input on a possible model for such a scheme in the ACT.
>
> ……

On 27 November 2018, the Legislative Assembly passed a motion amending the resolution appointing the Committee, as follows:

> That the resolution of the Assembly of 30 November 2017, which established the Select Committee on End Of Life Choices in the ACT be amended by omitting the words "last sitting day in 2018" and substituting "last sitting day in March 2019".[3]

[2] ACT Legislative Assembly, *Minutes of Proceedings No, 64*, 2 August 2018, pp. 914-915.

[3] ACT Legislative Assembly, *Minutes of Proceedings No, 80*, 27 November 2018, p. 1140.

ACRONYMS

ANMF	Australian Nursing and Midwifery Federation
ACAT	ACT Civil and Administrative Tribunal
ACD	Advance Care Directive
ACP	Advance Care Plan
ACT HRC	ACT Human Rights Commission
ADACAS	ACT Disability Aged and Carer Advocacy Service
AHMAC	Australian Health Ministers Advisory Committee
AIHW	Australian Institute of Health and Welfare
AMA	Australian Medical Association
ANS	Australian National Strategy (for Palliative Care)
CASP	Community Assistance and Support Program
CHA	Catholic Health Australia
CHH	Clare Holland House
CHHS	Canberra Hospital and Health Services
COAG	Council of Australian Governments
COTA (ACT)	Council of the Ageing ACT
EOL	End of Life
EOLC	End of Life Care
EPA	Enduring Power of Attorney
HCCA	Health Care Consumers' Association
HCP	Home Care Packages
LCMHC	Little Company of Mary Health Care Limited

ANMF	Australian Nursing and Midwifery Federation
MND	Motor Neuron Disease
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
PAS	Physician Assisted Suicide
P C	Productivity Commission
PCA	Palliative Care Australia
PCNA	Palliative Care Nurses' Association
PEPA	Program of Experience in the Palliative Approach
RACF	Residential Aged Care Facility
SDM	Substitute Decision Maker
SSP	Specialist Service Plan
TCH	The Canberra Hospital
VAD	Voluntary Assisted Dying

TABLE OF CONTENTS

THE COMMITTEE I

Resolution of appointment and terms of reference iii

ACRONYMS V

RECOMMENDATIONS IX

1 INTRODUCTION AND CONDUCT OF INQUIRY 1

Inquiry referral and terms of reference 1

Conduct of the inquiry 2

Submissions 2

Hearings 2

Committee Report 3

Structure of the Committee's Report 4

Preparation of Committee Report 4

Acknowledgments 4

2 ADVANCE CARE PLANNING 6

Introduction 6

Importance of Advance Care Planning 7

Loss of Capacity and Care at End of Life 9

Current Provisions in the ACT 11

Advance Care Directive Legislation in other Australian Jurisdictions 17

Issues raised by Witnesses and Submissions 19

3 OTHER OBSERVATIONS AND COMMITTEE COMMENT ON ADVANCE CARE PLANNING 34

Committee Comment 35

4 THE NEED FOR IMPROVED DEATH LITERACY 36

5 THE NEED FOR SAFEGUARDS TO BE PROVIDED TO ADDRESS ELDER ABUSE 40

Committee Comment 40

6 PALLIATIVE CARE 42

Introduction 42

Definitions 43

Palliative Care in Australia 45

Palliative care as a central element in Australia's health-care program 47

Committee Comment and Recommendations **50**

7 PALLIATIVE CARE DELIVERY IN THE ACT 53

Introduction **53**

Current Palliative Care Arrangements in the ACT **53**

Palliative Care Delivery in the ACT - Hospitals **54**

Palliative Care Delivery in the ACT – At Home **55**

Palliative Care in the ACT – Paediatric Care **56**

Palliative Care Delivery in the ACT – Residential Care **58**

Lack of a dedicated palliative care unit in The Canberra hospital **59**

Support for palliative care staff **61**

Access and Referral to Clare Holland House **62**

Palliative Care for People with Disabilities **67**

Palliative care model for the ACT – implementation **70**

Other Observations **71**

Committee comment **72**

8 VOLUNTARY ASSISTED DYING — BACKGROUND 74

Introduction **74**

History of legislative approaches to Voluntary Assisted Dying by the ACT Legislative Assembly **74**

Amendment to the *ACT Self-Government Act 1988* by the Commonwealth parliament **75**

Proposed Repeal of the Prohibition on Euthanasia **81**

Recent History in Other Australian Jurisdictions **83**

9 VOLUNTARY ASSISTED DYING — COMMITTEE FINDINGS AND COMMENT ... 87

Introduction **87**

Views on Voluntary Assisted Dying provided in submissions and evidence **88**

A Future Approach to Voluntary Assisted Dying in the ACT **94**

10 COMMITTEE CONCLUSIONS 97

APPENDIX A – LIST OF WRITTEN SUBMISSIONS 99

APPENDIX B – WITNESSES 109

APPENDIX C – COMMITTEE VISIT PROGRAM 113

APPENDIX D – ROYAL COMMISSION ON AGED CARE QUALITY 115

RECOMMENDATIONS

RECOMMENDATION 1

2.70 The Committee recommends that the ACT Government develop a community education campaign on Advance Care Planning, or update existing community education resources, including:

- **Information about what an Advance Care Plan entails and why it is important.**
- **Information about the benefits of discussing and of like choices and developing a plan early.**
- **Information about the importance of ensuring the terms of an Advance Care Plan are clear.**
- **Information about the benefits of reviewing Advance Care Plans over time.**

RECOMMENDATION 2

2.74 The Committee recommends that the ACT Government work with members of the ACT's Culturally and Linguistically Diverse communities in order to devise culturally-appropriate strategies to increase the uptake of Advance Care Planning among this sector of the population.

RECOMMENDATION 3

2.75 The Committee recommends that the ACT Government fund the training of volunteer representatives from specific cultural communities to promote Advance Care Planning in their community.

RECOMMENDATION 4

2.76 The Committee recommends that the Minister for Health and Wellbeing publishes the number (without personal details) of Advance Care Plans and Advance Care Directives held by hospitals and care institutions in the ACT.

RECOMMENDATION 5

2.82 The Committee recommends that the ACT Government develop an education campaign for health care professionals using and assessing Advance Care Plans in a hospital setting.

RECOMMENDATION 6

2.83 The Committee recommends that the ACT Government, in consultation with appropriate community, legal professionals, and public guardian bodies, undertake on ongoing program to educate ACT health care professionals about:

- **the nature, purpose and effect of Advance Care Directives and Enduring Powers of Attorney in the ACT;**
- **how to determine and recognise a valid Advance Care Directive; and,**
- **identifying a lawfully appointed substitute decision maker.**

RECOMMENDATION 7

2.91 The Committee recommends the ACT Government liaise with other Australian jurisdictions, particularly the Commonwealth, through the COAG process, to encourage the implementation of the Productivity Commission's recommendation on establishing a Medicare item number to encourage doctors and practice nurses to have more in-depth discussions about Advance Care Planning.

RECOMMENDATION 8

2.111 The Committee recommends that the ACT Government continue to work with other Australian jurisdictions to investigate the feasibility of reforming Power of Attorney legislation or introducing a single, Enduring Power of Attorney across Australia and that report on progress be included in the appropriate agency annual reports

RECOMMENDATION 9

2.120 The Committee recommends the ACT Government works with key stakeholders to:

a) develop a strategy to make Advance Care Plans and Advance Care Directives more widely accessible for people living with dementia and their families and carers.

b) develop a community education campaign for people with dementia, particularly early-on-set dementia, which emphasises the importance of developing or revisiting their Advance Care Plan soon after their diagnosis.

RECOMMENDATION 10

4.12 The Committee recommends the ACT Government consider trialling the funding of "death cafés", including exploring funding existing non-governmental organisations which undertake this work, to establish the initiative in the ACT, with an aim to encourage broader conversations about death and dying and improve death literacy.

RECOMMENDATION 11

6.41 That the ACT Government work cooperatively with Governments from all Australian jurisdictions to implement the proposed reforms advocated by the Productivity Commission report on End-of-life Care in Australia.

RECOMMENDATION 12

6.42 The Committee recommends the ACT Government report to the Legislative Assembly on the timetable and progress of actions to achieve the implementation of the proposed reforms advocated by the Productivity Commission report on End-of-life Care in Australia as part of its response to this report as well as including that information in relevant annual reports.

RECOMMENDATION 13

7.13 The Committee recommends that the ACT Government assess the demand for higher palliative care options in the ACT and investigate the feasibility of funding the extension of in-home palliative care options.

RECOMMENDATION 14

7.14 The Committee recommends that the ACT Government investigate the respite options available to families providing in-home palliative care and whether these options meet the increasing demand for such services.

RECOMMENDATION 15

7.22 The Committee recommends that the Legislative Assembly refer the provision of palliative care to paediatric and adolescent patients in Canberra to the Legislative Assembly Standing Committee on Health, Ageing and Community Services for inquiry and report.

RECOMMENDATION 16

7.30 The Committee recommends that the ACT Government evaluate what level of funding is required for the provision of palliative care within residential aged care facilities and work with the Commonwealth Government to provide this funding.

RECOMMENDATION 17

7.35 The Committee recommends that the ACT Government review whether a dedicated palliative care ward should be established in The Canberra Hospital.

RECOMMENDATION 18

7.39 The Committee recommends that the ACT Government review and improve the counselling and support services available to all healthcare workers involved in palliative care to ensure it is adequate for demand and individual needs.

RECOMMENDATION 19

7.57 The Committee recommends that the ACT Government conduct an independent investigation of Clare Holland House's capacity to meet future demand for palliative care services.

RECOMMENDATION 20

7.58 The Committee recommends that Clare Holland House receive adequate future funding to allow for additional operating costs associated with an expanded Clare Holland House.

RECOMMENDATION 21

7.69 The Committee recommends that the ACT Government consider and seek to reduce or remove the existing barriers to accessing good health care faced by people with a disability, including infrastructure at ACT health facilities, the quality of care provided and the risks of direct or indirect discrimination.

RECOMMENDATION 22

7.83 The Committee recommends that the ACT Government invest in a community awareness campaign about what palliative care is and what it entails, including the choices available to ACT residents.

RECOMMENDATION 23

7.84 The Committee recommends the ACT Government review and report on all aspects of palliative care delivery in the ACT, including programs, demand, funding and delivery and include specific reporting on palliative aged care and child and adolescent palliative care.

RECOMMENDATION 24

7.85 The Committee recommends that the ACT Government assess and review the network of healthcare specialists in the ACT involved in delivering palliative care across all settings, including for paediatrics and adolescents, to:

- **compare the ACT to other jurisdictions;**
- **make improvements to foster better networking and connectivity between patients and their families and carers, healthcare professionals and organisations; and,**
- **ensure timely referrals and access to hospice services.**

1 INTRODUCTION AND CONDUCT OF INQUIRY

INQUIRY REFERRAL AND TERMS OF REFERENCE

1.1 On 30 November 2017, the Legislative Assembly established the Select Committee on End of Life Choices in the ACT (the Committee) to inquire and report on five specific matters related to end of life issues which concern and affect ACT residents. The Resolution appointing the Committee and setting out its terms of reference are noted at the start of this report.

1.2 In particular, the Committee's terms of reference (ToR in this report) directed at specific questions are in two categories. The first category is current practices utilised in the ACT medical community to assist a person in the exercise of their preference in the management of their end of life, including the provision of palliative care.

1.3 The second category relates to questions arising from discussion and examination of approaches to voluntary assisted dying (VAD). These are as follows:

- ACT community views on the desirability of VAD being legislated in the ACT;
- risks to individuals and the ACT community associated with VAD and whether and how these can be managed;
- the applicability of VAD schemes operating in other jurisdictions to the ACT, particularly the Victorian VAD scheme legislated in 2017.

1.4 A distinct aspect of the second category is the effect and impact of the present position governing VAD in the ACT; in particular the current statutory prohibition on enactment of euthanasia legislation in the ACT enacted by Sections 23 (1A) and (1B) of the *Australian Capital Territory (Self-Government) Act 1988.* The ToR asked the Committee to examine the effect of those provisions – enacted by the Federal Parliament in 1997 – on the ACT determining an ACT policy on VAD, and to report on possible process for achieving change to this provision.

1.5 The ToR also required the Committee to report on any other relevant matter that arose during the inquiry.

CONDUCT OF THE INQUIRY

SUBMISSIONS

1.6 The Committee invited submissions for its inquiry on 11 December 2018 by advertisement on the Committee website, on social media sites and by media release to all ACT and a range of interstate media outlets. The Committee directly invited a number and range of organisations and groups and individuals with an interest in the matters before the Committee to provide written submissions.

1.7 The Committee set 23 February 2018 for receipt of submissions, and subsequently extended that date until 23 March 2018.

1.8 The Committee received 488 written submissions, the largest number of written submissions received by an ACT Legislative Assembly Committee inquiry.

1.9 Of these submissions, 61 were from organisations and 427 were from individuals.

1.10 Of submissions made to the inquiry by individuals, 283 were from ACT addresses, 124 were from addresses in other jurisdictions and 20 did not provide an address. All submissions received and published are listed in **Appendix A** and can be downloaded from the Committee website.[4]

HEARINGS

1.11 The Committee held 10 public hearings on this reference. The hearings were held on 17, 18, 24, 25 and 31 May; 1 June; 12 and 26 July; 9 August; and, 26 September 2018.

1.12 A list of witnesses who appeared before the Committee is at **Appendix B**. The transcripts of these public hearings are available on the Legislative Assembly Website.[5]

INTERSTATE VISIT – VICTORIA

1.13 The inquiry ToR required the Committee to – *inter alia* – consider the applicability of VAD schemes that are operating in other jurisdictions, particularly in Victoria.

[4] https://www.parliament.act.gov.au/in-committees/select_committees/end-of-life-choices/inquiry-into-end-of-life-choices-in-the-act#tab-1143329-2

[5] http://www.hansard.act.gov.au/hansard/2017/comms/default.htm#elc

1.14 As a result, the Committee made a visit to Victoria in April 2018 to hold discussions with experienced and expert palliative care practitioners, legislators and administrators and others as follows:

- Geelong and Melbourne – visits to major palliative care institutions – 4 April 2018
- Melbourne – discussions with legislators, medical and health plan administrators, and appointees to the agency task force responsible for the implementation of the Victorian *Voluntary Assisted Dying Act 2017* – 5 April 2018.

1.15 A detailed summary of the Committee's schedule for this visit is at **Appendix C**.

1.16 The Committee thanks the individuals and organisations who gave the Committee the benefit of their experience and practical knowledge during this visit, and for their frank and informative opinions on all aspects of palliative care and VAD in the context of Victorian law and practices.

QUESTIONS ARISING FROM HEARINGS

1.17 During the Committee's hearings, witnesses took a number of questions on notice from the Committee. These questions often sought detailed answers on complex matters relating to end-of-life care.

1.18 These answers to these questions are reproduced on the Committee inquiry website.[6]

COMMITTEE REPORT

1.19 The resolution of the Assembly establishing the Committee required the Committee to report on the reference by the last sitting day of November 2018.

1.20 On 27 November 2018, the Committee Chair advised the Assembly that the Committee had received an overwhelming number of submissions and believed that, to consider all matters raised in an appropriate way, the Committee required a short period of extra time to finalise and present its report.

1.21 The Committee Chair also advised the Assembly that the volume of work that was involved in the inquiry placed pressure on the Assembly committee secretariat.

1.22 The Assembly passed a motion, moved by the Committee Chair, that the resolution of the Assembly of 30 November 2017, which established the Select Committee be

[6] https://www.parliament.act.gov.au/in-committees/select_committees/end-of-life-choices/inquiry-into-end-of-life-choices-in-the-act

amended by omitting a reporting date of the last sitting day in 2018 and substituting a reporting date of the last sitting day in March 2019[7]

STRUCTURE OF THE COMMITTEE'S REPORT

1.23 The Committee's Report comprises seven Chapters as follows:

- Chapter 1 – Introduction and Conduct of the Inquiry
- Chapter 2 – Advance Care Planning
- Chapter 3 – Other Observation and Committee Comment on Advance Care Planning
- Chapter 4 – The Need for Improved Death Literacy
- Chapter 5 – The Need for Safeguards to be Provided to Address Elder Abuse
- Chapter 6 – Palliative Care
- Chapter 7 – Palliative Care Delivery in the ACT
- Chapter 8 – Voluntary Assisted Dying—Background
- Chapter 9 – Voluntary Assisted Dying—Committee Findings and Comment
- Chapter 10 – Committee Conclusions

PREPARATION OF COMMITTEE REPORT

1.24 The Committee met and considered its report on 31 January, 4 February, 8 February, 4 March, 8 March and 18 March 2019.

ACKNOWLEDGMENTS

1.25 The Committee records its appreciation to the many individuals and organisations, particularly members of the ACT community, who made submissions to this inquiry.

1.26 This inquiry gained a great deal from the frank, sometimes personal and painful, evidence it received; the issues raised by this evidence are of importance and significance. Evidence from individual submissions, together with views and perspectives provided by a range of organisations and institutions, enabled the Committee to reach decisions and recommendations on what are difficult and important issues.

[7] ACT Legislative Assembly, *Minutes of Proceedings*, No. 80, 27 November 2018, p. 1140; ACT Legislative Assembly, *Hansard*, 27 November 2018, p. 4807.

1.27 The Committee has developed many of its recommendations based on suggestions by the contributors to the inquiry, and the Committee acknowledges their contributions.

2 ADVANCE CARE PLANNING

INTRODUCTION

2.1 The Committee's ToR (1(a)) require the Committee to consider 'current practices utilised in the medical community to assist a person to exercise their preference in managing the end of their life'. A vitally important part of protecting a person's preference in their end of life care is Advance Care Planning.

2.2 The Australian Medical Association (AMA) defines Advance Care Planning as:

> A process of planning for future health and personal care whereby the person's values, beliefs and preferences are made known so they can guide decision-making at a future time when that person cannot make or communicate his or her decisions.[8]

2.3 The central intent of Advance Care Planning is to protect the self-determination and volition of an individual concerning their treatment options, even when their decision-making capacity has been compromised. According to the Commonwealth Department of Health:

> Advance care planning is intended to enable individuals to make plans for their future care. The process encourages individuals to reflect on what is important to them, on their beliefs, values, goals and preference in life, and how they want to be cared for if they reach a point they cannot communicate decisions about medical care for themselves.[9]

2.4 Under common law, competent adults must consent to all medical treatment they receive, including life-prolonging interventions at the end of life, and have the right to refuse medical treatment on any grounds. Yet, many people approach death at a time when they no longer have the ability to make choices concerning their care options. Unless people have planned for their end of life care in advance, those responsible for their well-being may not make decisions which align with their wishes.

2.5 Dementia Australia informed the Committee, for instance, that:

> A dignified death requires proper planning and support to ensure a person's wishes are respected. It requires an advance care plan and nomination of a guardian in the ACT to enable a person with dementia to ensure their preferences are known, should a

[8] Australian Medical Association, *Submission 406*, Attachment, 'AMA Position Statement on End of Life Care and Advance Care Planning', 2014, p. 2.

[9] Australian Government, Department of Health, 'Palliative Care—Advance Health Planning', 23 October 2018, <http://www.health.gov.au/internet/main/publishing.nsf/Content/acp>, viewed 7 November 2018.

medical or end of life decision need to be made after they have lost the capacity to make that decision.[10]

2.6 While Advance Care Planning is already a well-established feature of health care practice in the ACT, the Committee heard evidence of problems with current practices in the ACT—and nationally—and how these problems could be ameliorated.

IMPORTANCE OF ADVANCE CARE PLANNING

2.7 The Committee heard consistent evidence that adequate Advance Care Planning is essential in ensuring that a person's choices regarding their care, including at the end of their life, are respected at times when they have lost decision-making capacity. Adequate planning can be important for reducing the anxiety, trauma, and fear surrounding death and ensuring, as far as possible, that an individual's preferences are respected.

2.8 The Health Care Consumers' Association (HCCA) informed the Committee about how Advance Care Planning empowers consumers:

> Advance Care Planning can be a powerful tool for consumers to ensure we are able to receive care that is consistent with a person's goals, values, beliefs and preferences. It prepares the person and others to plan for future health care, for a time when the person may no longer be able to communicate those decisions.[11]

2.9 The ACT Health website also underscores the importance of Advance Care Planning:

> Up to 50% of Australians will not be able to make or express their own decisions when they are near death. Doctors and family members will be unaware of any treatment preferences at this time if these have not been discussed and recorded earlier.
>
> …
>
> If there is not a clear statement of a person's wishes, doctors must treat them in the most appropriate way. This can mean aggressive treatments that the person might not have wanted.[12]

2.10 Palliative Care ACT similarly informed the Committee of the significance of a good Advance Care Planning:

---

[10] Ms Patrea Messent, Regional Director and General Manager, Client Services, Dementia Australia, *Transcript of Evidence*, 24 May 2018, p. 170.

[11] Health Care Consumers' Association, *Submission 455*, p. 7.

[12] ACT Health, 'Advance Care Planning', 7 November 2018, <https://health.act.gov.au/services/advance-care-planning>, viewed 8 November 2018.

> When people's preferences are not clear, it is hard to shift from a focus on cure, to a focus on palliative care. ACP is a way that a person can communicate their wishes regarding care and medical treatment.[13]

2.11 Little Company of Mary Health Care Ltd. (Calvary) highlighted the wide recognition of the importance of Advance Care Planning within industry:

> The importance of Advance Care Planning is widely recognised across all sectors and service points in the health and aged care sectors. Nurses, doctors, social workers and counsellors, aged care employees, lawyers and estate planners are all now attuned to the importance and worth of Advance Care Plans.[14]

2.12 The importance of Advance Care Planning in health care planning has also been recognised by Federal and State and Territory governments. A key priority of the *National Palliative Care Strategy 2010: Supporting Australians to live well at the end of life*, is to increase the prevalence of Advance Care Planning.[15] The Strategy calls for action to 'support the national roll out of Advance Care Planning across all sectors (primary, acute, aged care) including addressing any barriers to uptake'.[16]

2.13 In 2011, COAG, through the Clinical, Technical and Ethical Principal Committee of the Australian Health Ministers' Advisory Council, released *A National Framework for Advance Care Directives*. The framework included a 'Code of Ethical Practice and a set of Best Practice Standards' that 'seek to enable policy, legislation and practice to become more consistent across Australia over time and allow for the recognition of ACDs [Advance Care Directives] across jurisdictional boundaries'. The report encouraged 'policy and legal officers in government departments…to review their policies and laws that establish ACDs in light of the Code of Ethical Practice and the Best Practice Standards'.[17]

2.14 Despite these efforts, as recently pointed out by Advance Care Planning Australia, currently 'the legislation and advance care directive documentation across the

---

[13] Palliative Care ACT, *Submission 420*, p. 7.

[14] Little Company of Mary Health Care Ltd. (Calvary), *Submission 452*, p. 10.

[15] Advance Care Planning Australia, 'Review of advance care planning laws across Australia', August 2018, p. 3, <https://www.advancecareplanning.org.au/docs/default-source/acpa-resource-library/acpa-publications/review-of-advance-care-planning-laws-across-australia_short-report-2018-final.pdf?sfvrsn=4>, viewed 9 November 2018.

[16] Commonwealth of Australia, *National Palliative Care Strategy 2010*, Canberra, 2010, <http://www.health.gov.au/internet/main/publishing.nsf/Content/EF57056BDB047E2FCA257BF000206168/$File/NationalPalliativeCareStrategy.pdf>, viewed 19 November 2018.

[17] COAG, the Clinical, Technical and Ethical Principal Committee of the Australian Health Ministers' Advisory Council, *A National Framework for Advance Care Directives*, September 2011, p. 2, <http://www.coaghealthcouncil.gov.au/Portals/0/A%20National%20Framework%20for%20Advance%20Care%20Directives_September%202011.pdf>, viewed 9 November 2018.

jurisdictions lacks consistency'.[18] This issue was raised by witnesses and in submissions and is discussed in more detail below.

2.15 The outcome of Advance Care Planning is an Advance Care Plan (ACP). ACPs can take on a number of forms. According to the AMA, ACPs can include:

a) an Advance Care Directive (ACD) (or other similar instruments);

b) a Medical Enduring Power of Attorney (or other similar instruments);

c) a letter to the person who will be responsible for this decision-making;

d) an entry in the patient medical record;

e) a verbal instruction or other communication which clearly enunciates a patient's view; or,

f) any combination of the above.[19]

LOSS OF CAPACITY AND CARE AT END OF LIFE

2.16 Advance Care Planning is important in providing people with assurances that their wishes concerning their medical care will be respected if they lose decision-making capacity, whether this be at the end of their life or during medical episodes from which they subsequently recover. However, considering that many people die in a state of diminished capacity, actively planning to ensure one's wishes are known to friends, family, and the medical establishment is especially important.

2.17 The AMA defines 'capacity' in the following terms:

Having capacity to make a decision at common law means having the ability to:

- understand and appreciate information about one's own health condition and options for treatment including no treatment;
- make a free and voluntary decision regarding one's own health care; and
- communicate that decision.[20]

[18] Advance Care Planning Australia, 'Review of advance care planning laws across Australia', August 2018, p. 3, <https://www.advancecareplanning.org.au/docs/default-source/acpa-resource-library/acpa-publications/review-of-advance-care-planning-laws-across-australia_short-report-2018-final.pdf?sfvrsn=4>, viewed 9 November 2018.

[19] Australian Medical Association, *Submission 406*, Attachment, 'AMA Position Statement on End of Life Care and Advance Care Planning', 2014, p. 2.

[20] Australian Medical Association, *Submission 406*, Attachment, 'AMA Position Statement on End of Life Care and Advance Care Planning', 2014, p. 2.

2.18 In situations where a person has been declared to lack decision-making capacity—or "competency"—a substitute decision maker will be appointed to make health care decisions on behalf of the person. ACT law provides a hierarchy of people who can be appointed to act on behalf of a person lacking capacity:

1. an Enduring Power of Attorney (EPA);

2. a guardian or guardians appointed by the ACT Civil and Administrative Tribunal (ACAT); and

3. a health attorney (in order of priority, either: a domestic partner, unpaid carer, or close relative or friend).[21]

2.19 If a person has made an ACD and subsequently loses capacity and a guardian or health attorney has been appointed to act on their behalf, 'any power of the guardian or health attorney to consent to medical treatment for the person must be exercised in a way that is consistent with the health direction (unless it is not reasonable to do so)'.[22]

2.20 In cases where an ACD and an EPA have both been made, the attorney 'must comply with the Health Direction when making a decision about a health care matter'. In cases where the ACD and the EPA contain inconsistent instructions concerning health care matters, the attorney must comply with whichever document is most recent.[23]

2.21 In cases where a person does not nominate an attorney under an EPA, the *Guardian and Management of Property Act 1991* 'allows substitute decision makers to be appointed by ACAT to make decisions in various domains of people's lives including decisions about a protected person's health care'. Where an appropriate person cannot be found to act as a guardian, the ACAT can appoint the Public Trustee and Guardian to act in that role.[24]

2.22 Despite a guardian being vested with decision-making power in relation to a protected person's health care options, as noted by the Public Trustee and Guardian, 'a guardian appointed in the ACT cannot make end of life decisions for a protected person. In a landmark case (*ACT v JT*), the ACT Supreme Court decided that a guardian had no authority to cease active life-preserving treatment for a protected person'.[25]

---

[21] Queensland University of Technology, End of Life Law in Australia, 'Australian Capital Territory', < https://end-of-life.qut.edu.au/advance-directives/state-and-territory-laws/australian-capital-territory#547659>, viewed 8 November 2018; Advance Care Planning Australia, 'Advance care planning in the Australian Capital Territory', <https://www.advancecareplanning.org.au/resources/advance-care-planning-for-your-state-territory/act#law>, viewed 9 November 2018.

[22] ACT Government, *Submission 151*, p. 5.

[23] *Medical Treatment (Health Directions) Act 2006*, s. 19.

[24] Public Trustee and Guardian, *Submission 159*, p. 2; Queensland University of Technology, End of Life Law in Australia, 'Australian Capital Territory', < https://end-of-life.qut.edu.au/advance-directives/state-and-territory-laws/australian-capital-territory#547659>, viewed 8 November 2018.

[25] Public Trustee and Guardian, *Submission 159*, p. 2; ACT Government, *Submission 151*, p. 6.

2.23 Similar to a guardian appointed by the ACAT, a health attorney appointed by a health care professional under the *Guardian and Management of Property Act 1991* 'can consent to medical treatment for the person, but does not have specific power to refuse treatment or withdraw consent to treatment'.[26]

2.24 This contrasts to attorneys appointed under an EPA which deals with health care, who, in accordance with the *Powers of Attorney Act 2006*, 'are able to make decisions about withholding or withdrawing life-sustaining treatment, but only in situations where starting the treatment, or continuing it, would be contrary to good medical practice. An attorney cannot ask for treatment to be withheld or withdrawn unless:

- they have consulted a doctor about the person's illness, alternative forms of treatment available and any consequences to the person of remaining untreated; and
- the attorney believes that the person, if they still had capacity and could give serious consideration to his or her own health and wellbeing, would ask for the treatment to be withheld or withdrawn'.[27]

2.25 In short, any guardian or health attorney appointed as a substitute decision maker for someone who has lost capacity does not have power to withhold or withdraw life-sustaining treatment, even if such an action were in accordance with the wishes of the person. Such personal choices can only be protected by adequate end-of-life planning, through ACPs, ACDs, and/or the appointment of an attorney under an EPA which provides health care directions. It is therefore crucial that people make adequate plans for their future health care via Advance Care Planning to ensure their wishes will be respected.

CURRENT PROVISIONS IN THE ACT

2.26 The ACT currently provides for Advance Care Planning through a number of formats. ACT Health lists three ways that Advance Care Planning can be recorded by individuals in the ACT:

- an Advance Care Plan Statement of Choices;
- a Health Direction; and
- an EPA.[28]

[26] Queensland University of Technology, End of Life Law in Australia, 'Australian Capital Territory', < https://end-of-life.qut.edu.au/advance-directives/state-and-territory-laws/australian-capital-territory#547659>, viewed 8 November 2018.

[27] Public Trustee and Guardian, *Submission 159*, p. 2.

[28] ACT Health, 'Advance Care Planning', 7 November 2018, <https://health.act.gov.au/services/advance-care-planning>, viewed 8 November 2018.

2.27 Advice and assistance in Advance Care Planning are currently offered in the ACT via ACT Health's Advance Care Planning Program and The Canberra Hospital's Respecting Patient Choices program.[29] Additionally, information and support on compiling ACPs is offered by HCCA and the Capital Health Network via its Be My Voice website.[30]

2.28 In recent years, the HCCA has partnered with ACT Health to provide Advance Care Planning education and workshops to a range of groups: 'targeting general and multicultural and vulnerable consumer groups, these workshops are aimed at ensuring that choice and control is maintained in all aspects of an individual's health care. HCCA also tailor and deliver this education to health care professionals'. Similarly, the Capital Health Network has 'facilitated training for RACFs [Residential Aged Care Facilities] and GPs in ACPs'.[31]

2.29 Catholic Health Australia (CHA) likewise offers information and support in Advance Care Planning. CHA informed the Committee that 'CHA and our members provide information for people considering their future health care needs and encourage patients to reflect, plan, and appoint a person who will represent them if they are unable to express their wishes'. For this purpose, CHA provides a dedicated website—My Future Care—'where resources are available for members of the community and health professionals'.[32]

ADVANCE CARE PLAN STATEMENT OF CHOICE

2.30 The Advance Care Plan Statement of Choices is a type of ACP that allows a person to record their wishes for their future health care in the ACT.

2.31 According to the Advance Care Statement of Choices form:

> This Advance Care Plan will be used to guide future medical decisions ONLY when you lose the ability to make or communicate your medical treatment decisions yourself. The law requires that this statement of your wishes must be taken into account when determining your treatment.[33]

[29] ACT Health, 'Advance Care Planning', 7 November 2018, <https://health.act.gov.au/services/advance-care-planning>, viewed 8 November 2018; Canberra Hospital, 'Respecting Patient Choices', <http://findahealthservice.act.gov.au/c/fahs?a=apps&ap=hsd&hsd=mobile&mobile=showsite&servicecategory=16&site=66824>, viewed 9 November 2018.

[30] Capital Health Network, *Submission 366*, p.2; Health Care Consumers' Association, 'Advance Health Care Planning', <https://www.hcca.org.au/advance-health-care-planning/>, viewed 12 November 2018; Be My Voice, <http://www.bemyvoice.com.au/Home.aspx>, viewed 12 November 2018.

[31] Capital Health Network, *Submission 366*, p. 2; Health Care Consumers' Association, *Submission 455*, p. 8; Dr Steven Adele, Consumer Representative, Health Care Consumers' Association, *Transcript of Evidence*, 25 May 2018, p. 216.

[32] Catholic Health Australia, *Submission 411*, p. 4. See: <https://myfuturecare.org.au/>, viewed 15 November 2018.

[33] ACT Health, 'Advance Care Plan Statement of Choices', p. 2, <http://www.bemyvoice.com.au/Documents/Advance-Care-Plan-Competent-Mar-2015.aspx>, viewed 9 November 2018.

2.32 ACT Health explains that the Advance Care Plan Statement of Choices 'is used as a supporting document' which provides additional information about the individual's specific wishes regarding health care decisions. [34]

2.33 HCCA explains that the Advance Care Statement of Choices allows people to express their care preferences in relation to a range of treatment options:

- Cardio Pulmonary Resuscitation;
- breathing machines (ventilator);
- kidney machine (dialysis);
- antibiotics; and
- blood transfusions.[35]

2.34 HCCA gives an example of the types of choices the Advance Care Statement of Choices provides for:

> For example, you may say in your Statement of Choices that if you are unable to communicate with or recognise your family, and there is no possibility that you will recover or improve, that you do not want CPR if your heart stops, but only want to be kept comfortable and free from pain.[36]

COMMON LAW AND STATUTORY ADVANCE HEALTH DIRECTIVES

2.35 Advance Care Directives are types of formalised ACPs that place legal obligations on health care professionals to respect the wishes of their patients concerning the withdrawal or withholding of treatment at the end of life.

2.36 While both perform the role of ensuring a patient's views concerning their health care options at a time of diminished capacity are protected, the law distinguishes between common law and statutory Advance Care Directives.

- Common Law Advance Care Directives are ones 'created and governed by the common law (i.e. decisions made by judges and courts)'.
- Statutory Advance Care Directives are ones 'governed by specific legislation in States and Territories. All States and Territories except for New South Wales and Tasmania have legislation creating statutory Advance Directives'.[37]

---

[34] ACT Health, 'Advance Care Planning', 7 November 2018, <https://health.act.gov.au/services/advance-care-planning>, viewed 8 November 2018.

[35] Health Care Consumers' Association, 'Advance Health Care Planning', <https://www.hcca.org.au/advance-health-care-planning/>, viewed 12 November 2018.

[36] Health Care Consumers' Association, 'Advance Health Care Planning', <https://www.hcca.org.au/advance-health-care-planning/>, viewed 12 November 2018.

[37] Queensland University of Technology, End of Life Law in Australia, 'Advance Directives', <https://end-of-life.qut.edu.au/advance-directives>, viewed 7 November 2018.

2.37 The ACT recognises both Common Law Advance Care Directives and Statutory Advance Care Directives.[38]

2.38 In order to make a Common Law Advance Care Directive, a person must:

1. be competent, meaning that the person has decision-making capacity and is able to communicate the directive;

2. make the directive voluntarily.[39]

2.39 According to researchers at the Queensland University of Technology, for a Common Law Advance Care Directive to be valid at a time when the person loses decision-making capacity:

> …the Advance Directive must apply to the medical treatment or health care situation that has arisen.
>
> There is no legal requirement that when making the common law Advance Directive the person receive information about the treatment that he or she is requesting or refusing, or about the medical condition (if any) that the Advance Directive provides instructions about. A direction may be given for any reason, whether religious, social or moral, or on any other grounds.[40]

2.40 A court may determine that a Common Law Advance Care Directive does not apply if

1. a person's circumstances have changed since they made the directive;

2. the terms of the directive are uncertain or ambiguous;

3. the directive was based on incorrect information; and,

4. the directive requests futile or non-beneficial treatment.[41]

2.41 In the ACT, Statutory Advance Health Directives are referred to as Health Directions and are created and governed under the *Medical Treatment (Health Directions) Act 2006*. The objectives of the Act are—

a) to protect the right of patients to refuse unwanted medical treatment; and

[38] Queensland University of Technology, End of Life Law in Australia, 'Australian Capital Territory', < https://end-of-life.qut.edu.au/advance-directives/state-and-territory-laws/australian-capital-territory#547659>, viewed 8 November 2018.

[39] Queensland University of Technology, End of Life Law in Australia, 'Common Law Advance Directives', <https://end-of-life.qut.edu.au/advance-directives/common-law-advance-directives>, viewed 9 November 2018.

[40] Queensland University of Technology, End of Life Law in Australia, 'Common Law Advance Directives', <https://end-of-life.qut.edu.au/advance-directives/common-law-advance-directives>, viewed 9 November 2018.

[41] Queensland University of Technology, End of Life Law in Australia, 'Common Law Advance Directives', <https://end-of-life.qut.edu.au/advance-directives/common-law-advance-directives>, viewed 9 November 2018.

b) to ensure the right of patients to receive relief from pain and suffering to the maximum extent that is reasonable in the circumstances.[42]

2.42 The Act allows a person who has decision-making capacity to make a Health Direction 'in writing, orally or in any other way'.[43] A written Health Direction is valid if:

a) it is signed by the maker of the direction or by someone else in the presence of and at the direction of the person making the directions; and

b) the signature is witnessed by 2 other people; and

c) each witness signs the direction in the presence of the other witness and the person making the direction.[44]

2.43 A non-written Health Direction is valid if 'it is witnessed by 2 health professionals (1 of whom is a doctor) present at the same time'.[45]

2.44 Health Directions can be revoked by the person who made it by 'clearly expressing to a health professional or someone else a decision to revoke the direction'. This revocation can be expressed 'in writing, orally or in any other way'.[46]

2.45 Health professionals are obliged to follow a Health Direction if:

- the direction complies with the Act; and
- the person has not revoked the direction or changed their decision since making the direction.[47]

2.46 Speaking to this point, Advance Care Planning Australia note that

> In the Australian Capital Territory, a health practitioner must reasonably believe that the direction complies with the legislation and the person who made it has not revoked it or changed his or her mind since making it. This puts an obligation on the practitioner to consider the validity of the document and to make enquires about whether the person who made the direction may have changed his or her mind since making it.[48]

2.47 Dr John Boersig, Chief Executive Officer, Legal Aid ACT, explained to the Committee in more detail about the functioning of Health Directions in the ACT:

---

[42] *Medical Treatment (Health Directions) Act 2006*, s. 5.

[43] *Medical Treatment (Health Directions) Act 2006*, s. 7(2).

[44] *Medical Treatment (Health Directions) Act 2006*, s. 8.

[45] *Medical Treatment (Health Directions) Act 2006*, s. 9(1).

[46] *Medical Treatment (Health Directions) Act 2006*, s. 10.

[47] *Medical Treatment (Health Directions) Act 2006*, s. 12.

[48] Advance Care Planning Australia, 'Review of advance care planning laws across Australia', August 2018, p. 11, <https://www.advancecareplanning.org.au/docs/default-source/acpa-resource-library/acpa-publications/review-of-advance-care-planning-laws-across-australia_short-report-2018-final.pdf?sfvrsn=4>, viewed 9 November 2018.

> An advance care directive has evidential value which will be taken into account at the time someone is being medically treated. To give an example, if I made an advance care directive now and then in 20 years it might come into operation, the obligations you see on medical practitioners would be to ensure that an appropriate medical decision was made.
>
> …It is not definitive when you make that advance care plan. It does not mean all the obligations on medical practitioners disappear at the time. There are a whole range of cases where those are looked at in other circumstances and where religious views, for example, prohibit people from having drug transfusions. You will see that in those cases the duty often rests on the court to make an independent decision about that.[49]

2.48 In cases where a person has made a Health Direction, has been declared a person with impaired decision-making capacity by a doctor, and a guardian appointed for the person under the *Guardianship and Management of Property Act 1991* or a health attorney is asked to give a consent under that Act section 32D—

> Any power of the guardian or health attorney to consent to medical treatment for the person, or to the person participating in medical research or low-risk research, must be exercised in a way that is consistent with the health direction.[50]

ENDURING POWER OF ATTORNEY

2.49 The Public Trustee and Guardian describes an EPA as: 'a legal document that gives a trusted person the legal authority to act for you and to make legally binding decisions on your behalf'.[51]

2.50 An EPA differs from a General Power of Attorney in that the former remains valid even if the person who makes it—the "principal"—loses legal capacity, whereas the latter is only valid while the principal maintains legal capacity.[52]

2.51 The principal may designate when the EPA is exercisable. For financial and property matters, this may be immediately. For personal and health care matters, the EPA 'may commence only upon loss of capacity of the person', which must be certified by a medical practitioner.[53]

2.52 As pointed out by the ACT Government in its submission to the Inquiry:

---

[49] Dr John Boersig, Chief Executive Officer, Legal Aid ACT, *Transcript of Evidence*, 18 May 2018, p. 92.

[50] *Medical Treatment (Health Directions) Act 2006*, s. 18(1 and 2).

[51] Public Trustee and Guardian, 'Enduring Powers of Attorney', <https://www.ptg.act.gov.au/powers-of-attorney>, viewed 13 November 2018.

[52] Public Trustee and Guardian, 'Enduring Powers of Attorney', <https://www.ptg.act.gov.au/powers-of-attorney>, viewed 13 November 2018.

[53] Public Trustee and Guardian, 'Enduring Powers of Attorney', <https://www.ptg.act.gov.au/powers-of-attorney>, viewed 13 November 2018.

The *Powers of Attorney Act 2006* provides a framework for individuals to appoint others to make decisions on their behalf in specific areas of their lives, including in relation to their health care. An individual can direct an attorney, under an Enduring Power of Attorney, to—

- Refuse or require the withdrawal of medical treatment generally; or
- Refuse or require the withdrawal of specified forms of medical treatment e.g. blood transfusions; or
- Not to refuse or require the withdrawal of medical treatment generally.[54]

2.53 As noted above, where both an ACD and an EPA which covers health care matters have been made and are found to be inconsistent, the most recent document must take precedence.

ADVANCE CARE DIRECTIVE LEGISLATION IN OTHER AUSTRALIAN JURISDICTIONS

2.54 All Australian States and Territories, except for New South Wales and Tasmania—where common law applies, have legislative provisions governing Advance Care Directives.

2.55 Advance Care Planning Australia have recently released an overview of the legal frameworks for Statutory Advance Care Directives across Australia. They highlight that 'there are inconsistencies across the jurisdictions in terms of terminology, the scope and formalities for advance care directive documents'.[55]

2.56 Table 1 provides a jurisdictional comparison of Advance Care Directive legislations across Australia.

[54] ACT Government, *Submission 151*, p. 6. Also: Public Trustee and Guardian, *Submission 159*, p. 2.

[55] Advance Care Planning Australia, 'Review of advance care planning laws across Australia', August 2018, p. 5, <https://www.advancecareplanning.org.au/docs/default-source/acpa-resource-library/acpa-publications/review-of-advance-care-planning-laws-across-australia_short-report-2018-final.pdf?sfvrsn=4>, viewed 9 November 2018.

Table 1 Advance Care Directives by Jurisdiction[56]

Jurisdiction	**Advance Care Directive Terminology**	**Legislation**
ACT	Health Direction	Medical Treatment (Health Directions) Act 2006
Victoria	Advance care directive	Medical Treatment Planning and Decisions Act 2016
Queensland	Advance health directive	Powers of Attorney Act 1998
Western Australia	Advance health directive	Guardian and Administration Act 1990
South Australia	Advance care directive	Advance Care Directive Act 2013
Northern Territory	Advance personal plan	Advance Personal Planning Act 2013

2.57 While terminology differs across the country, all jurisdictions are broadly consistent in allowing only those with decision-making capacity to make a legitimate directive.[57]

2.58 In the ACT a Health Direction can only be made concerning the refusal or withdrawal of treatment, in Victoria, Queensland, Western Australia, South Australian and the Northern Territory, an Advance Care Directive, however, 'can be given about the administration of treatment as well as the refusal or withdrawal of treatment'.[58]

2.59 The various legislation across Australia generally requires health care professionals to comply with the stipulations of any Advance Care Directive. There are certain subtle differences in the requirements placed on health care professionals across jurisdictions.

[56] Advance Care Planning Australia, 'Review of advance care planning laws across Australia', August 2018, pp. 5-6, <https://www.advancecareplanning.org.au/docs/default-source/acpa-resource-library/acpa-publications/review-of-advance-care-planning-laws-across-australia_short-report-2018-final.pdf?sfvrsn=4>, viewed 9 November 2018.

[57] Advance Care Planning Australia, 'Review of advance care planning laws across Australia', August 2018, p. 6, <https://www.advancecareplanning.org.au/docs/default-source/acpa-resource-library/acpa-publications/review-of-advance-care-planning-laws-across-australia_short-report-2018-final.pdf?sfvrsn=4>, viewed 9 November 2018.

[58] Advance Care Planning Australia, 'Review of advance care planning laws across Australia', August 2018, p. 8, <https://www.advancecareplanning.org.au/docs/default-source/acpa-resource-library/acpa-publications/review-of-advance-care-planning-laws-across-australia_short-report-2018-final.pdf?sfvrsn=4>, viewed 9 November 2018.

2.60 As noted above, in the ACT health care professionals must give effect to an ACD if it complies with the legislation and the professional believes it has not been revoked or changed. Advance Care Planning Australia explain the situation in other jurisdictions:

- In Queensland, there is confusion about whether a health practitioner has an obligation to follow an advance health directive if he or she has reasonable grounds to believe that a direction in it is uncertain or inconsistent with good medical practice, or that circumstances have changed to the extent that the terms of the direction are in appropriate. The legislation states that a health practitioner will not incur any liability in those circumstance.

- South Australian and Victorian legislation recognises that health practitioners should not always be obliged to comply with directions about the administration of treatment. South Australia has adopted the concept of 'binding provisions' (i.e. a provision to refuse particular health care) and 'non-binding provisions' (i.e. all other provisions, such as a provision for the administration of health care). A health practitioner must comply with a binding provision. In relation to a non-binding provision, the health practitioner should, as far as reasonably practicable, comply with it. The new Victorian legislation, states a health practitioner must give effect to any instructional directive in an advance care directive. However, in relation to an instructional directive consenting to administration of treatment, the health practitioner is only obliged to give effect to it if he or she is of the opinion that it is clinically appropriate.[59]

2.61 In terms of the form ACDs take in the various jurisdictions, the ACT and South Australia require that ACDs are made in the prescribed form (except non-written ADCs in the ACT); Queensland and the Norther Territory have prescribed forms, but the legislation does not require that they be used; New South Wales, Victoria and Tasmania do not have prescribed forms, but the health authorities in these jurisdictions have released template forms, which are recommended for use.[60]

ISSUES RAISED BY WITNESSES AND SUBMISSIONS

2.62 There was widespread acknowledgement in submissions and by witnesses that Advance Care Planning is vitally important in ensuring those at the end of life have their care preferences respected. The Committee received a great deal of evidence on how current

[59] Advance Care Planning Australia, 'Review of advance care planning laws across Australia', August 2018, p. 11, <https://www.advancecareplanning.org.au/docs/default-source/acpa-resource-library/acpa-publications/review-of-advance-care-planning-laws-across-australia_short-report-2018-final.pdf?sfvrsn=4>, viewed 9 November 2018.

[60] Advance Care Planning Australia, 'Review of advance care planning laws across Australia', August 2018, pp. 12-13, <https://www.advancecareplanning.org.au/docs/default-source/acpa-resource-library/acpa-publications/review-of-advance-care-planning-laws-across-australia_short-report-2018-final.pdf?sfvrsn=4>, viewed 9 November 2018.

provisions around Advance Care Planning in the ACT currently function and how these could be improved.

LIMITED UPTAKE OF ADVANCE CARE PLANS AND ADVANCE CARE DIRECTIVES

2.63 The widespread reluctance of our society to discuss death has resulted in low levels of adequate advance planning for it. The Productivity Commission has recently highlighted that 'despite efforts to promote advance care planning, less than 15 per cent of Australians have an ACP. People who could be more likely to need an ACP, such as those aged over 65 years, are not more likely to have one'.[61]

2.64 Recently, Advance Care Planning Australia has conducted an Australia-wide survey of the prevalence of ACDs recorded on individual's medical records. Their findings, while indicating a higher prevalence than that shown by the Productivity Commission, still suggest only a limited uptake by Australians:

> The overall prevalence of having at least one Advance Care Directive in the person's health record was 30%. Only 3% of participants had a statutory Advance Care Directive outlining their preference for care. Only 11% of participants had a statutory Advance Care Directive appointing a substitute decision-maker. Rates of non-statutory Advance Care Directives were higher at 21%.[62]

2.65 This finding was echoed by the Australian Catholic Bishops Conference, which noted in its submission to the Inquiry that 'despite significant efforts and fund expended over many years to promote the use of advance care plans, most people do not have them'. On a similar note, Palliative Care ACT noted that 'awareness of Advanced (sic) Care Planning remains low'.[63]

2.66 Lack of Advance Care Planning results in poor outcomes for those facing death and their families. Ms Glenda Stevens, Chief Executive Officer, Palliative Care ACT, notified the Committee that

> We know that about 80 per cent of people want to die at home but only about 14 per cent do. That is due to lack of knowledge of the people around them, not having

[61] Productivity Commission, *Introducing Competition and Informed User Choice into Human Services: Reform to Human Services*, Inquiry Report, No. 85, 27 October 2017, Canberra, p. 12, <https://www.pc.gov.au/inquiries/completed/human-services/reforms/report/human-services-reforms.pdf>, viewed 14 November 2018; Tibetan Buddhist Society of Canberra, *Submission 145*, p. [4].

[62] Advance Care Planning Australia, 'Prevalence of advance care planning documentation in Australian health and residential aged care services', short report, May 2018, p. 4, <https://www.advancecareplanning.org.au/docs/default-source/acpa-resource-library/2018-prevalence-study/report-prevalence-of-advance-care-planning-document-2017_summary-final.pdf?sfvrsn=2>, viewed 20 November 2018.

[63] The Australian Catholic Bishops Conference, *Submission 442*, p. 9; Palliative Care ACT, *Submission 420*, p. 7.

advance care plans in place saying that, and just the system not working as well as it can.[64]

2.67 Doctors of Assisted Dying Choice submitted that while Advance Care Planning options are in place, they are not taken up as much as they should be. They implied that more encouragement for both consumers and the health care professionals is required:

> The problem with advance care planning in the ACT, as in all Australia, is not availability but the inaction of persons in discussing these options and the indolence in failing to complete one or more forms.[65]

2.68 HammondCare suggested that this poor uptake could be addressed by better promotion of planning choices. They submitted: 'Australian governments should promote advance care planning in order to increase its uptake. For advance care planning to become normalised it needs to be promoted across all sectors (primary, acute and aged care) and barriers to uptake need to be addressed'.[66] HCCA made a similar recommendation: 'Advance Care Planning needs to be encouraged and promoted to consumers, and used appropriately by health professionals to enable individual plans for end-of-life care'.[67]

COMMITTEE COMMENT

2.69 The Committee notes the high level of unanimity of submitters and witnesses about the need for more and better Advance Care Planning both in the ACT and across Australia. The Committee notes that the Productivity Commission has considered Advance Care Planning within the context of end-of-life care in a recent report. The Commission's report highlighted the importance of Advance Care Planning and the need to encourage the up-take of such planning.[68] The Committee shares the Commission's view on this matter.

Recommendation 1

2.70 The Committee recommends that the ACT Government develop a community education campaign on Advance Care Planning, or update existing community education resources, including:

---

[64] Ms Glenda Stevens, Chief Executive Officer, Palliative Care ACT, *Transcript of Evidence*, 17 May 2018, p. 40.

[65] Doctors for Assisted Dying Choice, *Submission 81*, p. 6.

[66] HammondCare, *Submission 153*, p. [7].

[67] Health Care Consumers' Association, *Submission 455*, p. 2.

[68] Productivity Commission, *Introducing Competition and Informed User Choice into Human Services: Reform to Human Services*, Inquiry Report, No. 85, 27 October 2017, Canberra, pp. 156-162, <https://www.pc.gov.au/inquiries/completed/human-services/reforms/report/human-services-reforms.pdf>, viewed 14 November 2018.

- **Information about what an Advance Care Plan entails and why it is important.**
- **Information about the benefits of discussing and of like choices and developing a plan early.**
- **Information about the importance of ensuring the terms of an Advance Care Plan are clear.**
- **Information about the benefits of reviewing Advance Care Plans over time.**

2.71 Some sectors of the community have less uptake of Advance Care Planning than others. The Canberra Multicultural Community Forum submitted that 'multicultural community members are underrepresented in using Advance Care Planning and further outreach and education should be supported to address this'.[69]

2.72 The Canberra Multicultural Community Forum's Community Development Manager, Ms Suzanne Eastwood, elaborated on this issue for the Committee:

> There is a really low uptake of advance care directives…within the community. Basically, it is a lack of understanding, it is a lack of information in other languages, and it is a lack of ability for organisations like Canberra Multicultural Community Forum to keep running forums on a voluntary basis. A small investment would really help—or a large one—
>
> …
>
> It would really assist in that ability to disseminate information that people are really interested in receiving.[70]

2.73 Ms Eastwood later expanded on what she believed was necessary to see better uptake of Advance Care Planning in Canberra's Culturally and Linguistically Diverse communities

> For things like advance care directives and palliative care, usually you could produce some resources and the communities themselves work out how it fits in to their context. You do not have to produce a Russian version and an Islamic version; you produce the ACT government version, and the community themselves, when they have access to that information, work out how it is relevant for their context.[71]

[69] Canberra Multicultural Community Forum, *Submission 446*, p. [4].

[70] Ms Suzanne Eastwood, Community Development Manager, Canberra Multicultural Community Forum, *Transcript of Evidence*, 17 May 2018, p. 51.

[71] Ms Suzanne Eastwood, Community Development Manager, Canberra Multicultural Community Forum, *Transcript of Evidence*, 17 May 2018, p. 53.

Recommendation 2

2.74 The Committee recommends that the ACT Government work with members of the ACT's Culturally and Linguistically Diverse communities in order to devise culturally-appropriate strategies to increase the uptake of Advance Care Planning among this sector of the population.

Recommendation 3

2.75 The Committee recommends that the ACT Government fund the training of volunteer representatives from specific cultural communities to promote Advance Care Planning in their community.

Recommendation 4

2.76 The Committee recommends that the Minister for Health and Wellbeing publishes the number (without personal details) of Advance Care Plans and Advance Care Directives held by hospitals and care institutions in the ACT.

NEED FOR EDUCATION AND TRAINING ON ADVANCE CARE PLANNING FOR HEALTH CARE PROFESSIONALS

2.77 Health care professionals are at the frontline of managing the vast majority of deaths. For Advance Care Planning to be effective, it is crucial that health care workers are well acquainted with the provisions governing Advance Care Planning in the ACT and are able to effectively promote its uptake and use. The Committee heard evidence, however, that there is need for more effective training for health care professional on their role in Advance Care Planning.

2.78 Researchers at Queensland University of Technology's Australian Centre for Health Law Research informed the Committee:

> The findings of our research indicate that doctors have poor knowledge of the law, at least in relation to the withholding and withdrawal of treatment at the end of life from adults who lack decision-making capacity.[72]

[72] Professor Lindy Willmott, Professor Ben White, Penny Neller, *Submission 430*, p. 6.

2.79 The Royal Australasian College of Surgeons' submission recognised the need for more education for medical practitioners, but also suggested the need for specialists trained in Advance Care Planning to aid doctors:

> Greater promotion of and education about ACDs among general practitioners and specialists is also needed. Having trained personnel that can help treating doctors when required to discuss end of life decisions and ACDs in the hospital and community setting would help facilitate the decision making process. Not all doctors are comfortable or trained to have these discussions. As they are often busy and overworked, they are not always the best person to have deep and meaningful discussions with patients about end of life care, so support is needed.[73]

2.80 Others expressed similar views on the need for more training. Dr Michael Chapman submitted: 'Healthcare professionals in the ACT need ongoing training to engage in conversations about planning for future care, and to respectfully discuss care preferences'. The Australian and New Zealand Society of Palliative Medicine argued that 'health care professional also need ongoing training to be equipped to engage and support conversations about planning for future care, and to respectfully discuss care preferences'. They recommended the Government to 'ensure staff are trained to communicate and facilitate appropriate and effective Advance Care Planning'.[74]

2.81 In a Position Statement on Advance Care Planning attached to their submission to the Inquiry, Avant Mutual addressed the need for better education on Advance Care Planning by health care professionals. They noted the following:

> In providing end-or-life care, practitioners must be aware of their clinical, ethical and legal responsibilities. Avant is concerned that practitioners lack comprehensive understanding of the law regarding ACDs and this confusion reduces patient autonomy and puts practitioners at risk. This is consistent with Australian research which indicates there are significant knowledge gaps amongst practitioners regarding their legal obligations, particularly when faced with the often fraught decision of withholding or withdrawing life-sustaining treatment.
>
> …
>
> Education targeting doctors' legal responsibilities in this area should begin at university, continue during training and be included as part of continuing professional development provided by the specialist college throughout the career of practitioners. This education should cover relevant legislation, regulatory frameworks and provide

[73] Royal Australasian College of Surgeons, *Submission 483*, p. [1].

[74] Dr Michael Chapman, *Submission 471*, p. 7; Australian and New Zealand Society of Palliative Medicine, *Submission 379*, pp. 6, 11.

the skills to have difficult conversations regarding advance care planning and end-of-life decisions-making.[75]

Recommendation 5

2.82 The Committee recommends that the ACT Government develop an education campaign for health care professionals using and assessing Advance Care Plans in a hospital setting.

Recommendation 6

2.83 The Committee recommends that the ACT Government, in consultation with appropriate community, legal professionals, and public guardian bodies, undertake on ongoing program to educate ACT health care professionals about:

- **the nature, purpose and effect of Advance Care Directives and Enduring Powers of Attorney in the ACT;**
- **how to determine and recognise a valid Advance Care Directive; and,**
- **identifying a lawfully appointed substitute decision maker.**

2.84 The need for better training of staff in RACFs on Advance Care Planning was also recognised. Echoing the Productivity Commission's findings in its *Introducing Competition and Informed User Choice into Human Services* report, the Tibetan Buddhist Society of Canberra informed the Committee that

> The [Productivity] Commission also emphasised the need for additional residential aged care staff trained in caring for people at the end of life and an increase in the rate and quality of advance care planning.[76]

ADVANCE CARE PLANNING SHOULD BE COVERED BY MEDICARE

2.85 Good quality Advance Care Planning requires detailed discussions, usually between a person and their GP, that cover a range of complicated and emotionally-fraught matters. These discussions are necessarily time-consuming for GPs, who are not currently renumerated for this work. Currently, there is no dedicated Medicare Benefits Schedule Item number for advance care planning.[77] Providing adequate financial incentives for

[75] Avant Mutual, *Submission 150*, Attachment, 'Avant Position Paper: Advance care planning and end-of-life decision-making', November 2015, p. [6-7].

[76] Tibetan Buddhist Society of Canberra, *Submission 145*, p. [4].

[77] Advance Care Planning Australia, 'Advance care planning in general practice: Guidance on the use of Medicare Benefits Schedule Items', Factsheet for General Practice, March 2018, <https://www.advancecareplanning.org.au/docs/default-source/acpa-resource-library/acpa-fact-sheets/acpa_mbs-factsheet_2018_online.pdf?sfvrsn=37>, viewed 26 November 2018.

health care professionals to advise on Advance Care Planning is one way to promote its wider adoption by health care consumers.

2.86 Dr David Leaf, State Convenor, Doctors for Assisted Dying Choice, provided the Committee a concrete example of such a discussion with a patient. He noted:

> …today I spent 20 minutes with an elderly lady and handed her the New South Wales government version of the advance healthcare directive. She had never heard of one before. I had to educate her about what it was, how it should be done, and let her go home and do it. That was 20 minutes on the end of a consultation of 15 minutes for other things. I will get no financial recompense for that at all.[78]

2.87 Adjunct Professor Richard Lugg, State Convenor, Doctors for Assisted Dying Choice, noted that one of the reasons for the poor uptake rates of Advance Care Planning was 'that doctors do not have the time for the proper in-depth discussions that are required with patients'.[79]

2.88 As a remedy to this, Professor Lugg advised the Committee that

> What we would advocate—we strongly suggest to the ACT that you pursue this with the Commonwealth—is to get proper medical benefit recognition of the importance of professional discussions with patient over advance care planning matters. With the presence of a medical benefit for advance care planning discussions, we think there would be a much better discussion, much more acceptance in the community, a much wider uptake of those things and a generally beneficial effect when patients come to their end of life episode.[80]

2.89 Dr Leaf also shared this opinion, noting that 'a Medicare benefits item number would be a good idea for that'.[81]

COMMITTEE COMMENT

2.90 The Committee notes that the Productivity Commission has made the following recommendation on this matter:

> The Australian Government should promote advance care planning in primary care by:
>
> - including the initiative of an advance care planning conversation as one of the actions that must be undertaken to claim the '75 plus' health check Medicare item number. At a minimum, this would require a general practitioner to

[78] Dr David Leaf, State Convenor, Doctors for Assisted Dying Choice, *Transcript of Evidence*, 18 May 2018, p. 137.

[79] Adjunct Professor Richard Lugg, State Convenor, Doctors for Assisted Dying Choice, *Transcript of Evidence*, 18 May 2018, p. 137.

[80] Adjunct Professor Richard Lugg, State Convenor, Doctors for Assisted Dying Choice, Transcript of Evidence, 18 May 2018, p. 137.

[81] Dr David Leaf, State Convenor, Doctors for Assisted Dying Choice, *Transcript of Evidence*, 18 May 2018, p. 137.

introduce the concept of advance care planning and provide written information on the purpose and content of an advance care plan

- introducing a new Medicare item number to enable practice nurses to facilitate advance care planning.[82]

Recommendation 7

2.91 The Committee recommends the ACT Government liaise with other Australian jurisdictions, particularly the Commonwealth, through the COAG process, to encourage the implementation of the Productivity Commission's recommendation on establishing a Medicare item number to encourage doctors and practice nurses to have more in-depth discussions about Advance Care Planning.

ADVANCE CARE PLANNING DOCUMENTS NEED TO BE KNOWN AND ACCESSIBLE

2.92 Even the best plans will be fruitless if they are unknown or inaccessible by those responsible for implementing them. In order for Advance Care Planning to be effective, it is essential that any ACPs, ACDs, or EPAs are known by and accessible to health care professionals and substitute decisions makers at times when they are needed.

2.93 The Committee heard evidence that even when a person has an ACP, these are not always given due consideration. In response to a question on whether health consumers have expressed an opinion that ACPs, where in place, 'did not get the attention they could have' by health care professionals at the end of a family member's life, Dr Sarah Spiller, Policy Officer, HCCA, responded: 'Yes, we do. We do, and those experiences are often really grievous for loved ones. Yes, we do. Certainly we hear that with regularity, yes'.[83]

2.94 The Australian Catholic Bishops Conference likewise noted in regard to ACPs, 'the documents often do not get to the relevant medical staff'. In a similar vein, Dr Michael Chapman stressed that 'in the ACT further work is required to support appropriate use of ACDs and ACP processes, and to make sure these are communicated to, understood, and followed by others'.[84]

[82] Productivity Commission, *Introducing Competition and Informed User Choice into Human Services: Reform to Human Services*, Inquiry Report, No. 85, 27 October 2017, Canberra, recommendation 4.4, p. 160, <https://www.pc.gov.au/inquiries/completed/human-services/reforms/report/human-services-reforms.pdf>, viewed 14 November 2018.

[83] Dr Sarah Spiller, Policy Officer, Health Care Consumers' Association, *Transcript of Evidence*, 25 May 2018, p. 225.

[84] The Australian Catholic Bishops Conference, *Submission 442*, p. 9; Dr Michael Chapman, *Submission 471*, p. 7.

2.95 Dr Helen Watchirs, Human Rights Commissioner and President, ACT Human Rights Commission, addressed this issue, informing the Committee that

> People have that legislative framework to make an advance care directive and doctors should have the education to know they exist and actually consult to check them. It would be important to have an education campaign supporting that so that advance care directives are actually put into action more in the ACT. We have the legislation; putting it into practice may be a problem.[85]

2.96 Capital Health Network also noted the importance of ensuring that ACPs are communicated to doctors:

> Emphasis should…be placed on the effective communication and accessibility of an ACP to ensure that this proactively guides any further clinical interventions. It is critically important that an ACP is flagged and linked to the patient's My Health Record and inpatient record.[86]

2.97 The Royal Australasian College of Surgeons similarly suggested that

> ACDs should be linked to hospital and patient records so that they are available when required. Linking ACDs to the hospital system will enable easy access when required and will help avoid futile and unnecessary treatment.[87]

2.98 Dr Michael Chapman suggested that problems with ACT Health's computer system may inhibit doctors and other health care professionals from being aware of the existence of ACDs:

> They [ACDs] are certainly adhered to when they are known. Knowing that they are in existence is more complicated... The system, even within ACT Health's computer system, the system for flagging them, while it is robust and improving, is still miss-able. People can still miss that there is a document there that is available. It requires that document to be known to ACT Health to begin with. And that is just the ACT Health framework.[88]

2.99 The AMA emphasised the role of the patient, or their substitute decision-maker, in proactively ensuring their ACPs are known by the relevant health care professionals. In their Position Statement on End of Life Care and Advance Care Planning (2014), AMA argue:

> Where a patient has a written ACP, it is the responsibility of the patient, or SDM [Substitute Decision Maker], to make the contents of the ACP known. Patients should

[85] Dr Helen Watchirs, Human Rights Commissioner and President, ACT Human Rights Commission, *Transcript of Evidence*, 18 May 2018, p. 110.

[86] Capital Health Network, *Submission 366*, p. 2.

[87] Royal Australasian College of Surgeons, *Submission 483*, p. [1].

[88] Dr Michael Chapman, *Transcript of Evidence*, 12 July 2018, p. 395.

be encouraged to give a copy of any written documents such as an ACD to their doctor, the SDM, to a trusted family member of friend and to their solicitor. It is important for staff in all health care settings to be aware that the patient has made an ACP, and where any written directives can be obtained. The patient may wish to carry notification on their person, stating that they have made an ACP.[89]

NEED FOR NATIONAL STANDARDS FOR ADVANCE CARE DIRECTIVES AND ENDURING POWERS OF ATTORNEY

2.100 Ill-health does not respect Australia's jurisdictional borders; the Advance Care Planning legal framework needs to acknowledge and adapt to this fact of life. Even if someone has diligently planned for their death, cross-jurisdictional legal barriers may inhibit due consideration of these plans by health care professionals and substitute decision-makers when death occurs outside the ACT for Territory residents, or inside the ACT for those from elsewhere in the country.

2.101 Speaking to this point, Ms Jennifer Mobbs, Chief Executive Officer, Council on the Ageing (COTA), informed the Committee that 'if someone from the ACT prepares an advance care plan and then moves to live on the south coast, which many do, the ACT plan does not apply in New South Wales. That national issue needs to be tidied up'.[90]

2.102 In response to a question on the need to harmonise ACT laws on Advance Care Planning with those of NSW, Dr John Boersig, Chief Executive Officer, Legal Aid ACT, expressed a similar opinion to that of Ms Mobbs:

> Clients move back and forth, from our point of view, between Yass, Queanbeyan, Goulburn and Cooma, and indeed, in relation to family matters, we pool right throughout the south and south-west New South Wales. National legislation and national consistency are certainly a best practice objective.[91]

2.103 Avant Mutual addressed the inconsistency of ACDs across Australian jurisdictions in their submission:

> In the context of advance care planning, although ACDs are used in all states and territories, the terminology, format, documentation requirements, the application of ACDs in practice and even the hierarchy of substitute decision-makers, differ markedly from state to state.
>
> …

[89] Australian Medical Association, *Submission 402*, Attachment, 'AMA Position Statement on End of Life Care and Advance Care Planning', 2014, p. 7.

[90] Ms Jennifer Mobbs, Chief Executive Officer, Council on the Ageing, *Transcript of Evidence*, 17 May 2018, p. 26.

[91] Dr John Boersig, Chief Executive Officer, Legal Aid ACT, *Transcript of Evidence*, 18 May 2018, p. 96.

> Lack of consistency between states and territories and legal uncertainty impacts upon the ability of doctors to provide appropriate care at the end of life, and exposes doctors to medico-legal risks including criminal and civil claims and disciplinary or coronial proceedings. The intricacies and varied legal requirements across states and territories surrounding advance care directives and substitute decision-making cause confusion and have significant implications for doctors and patients.
>
> …We believe that the legislation around Australia that impacts on end of life choices should be harmonised.[92]

2.104 Avant Group suggested that COAG's National framework for Advance Care Directives (2011) and the Australian Commission on Safety and Quality in Health Care's National Consensus Statement: Essential Elements for Safe and High-quality End-of-Life Care (2015) 'are a useful start towards a nationally consistent approach to end of life care'.[93]

2.105 This sentiment was shared by other submitters to the Inquiry. The Australian and New Zealand Society for Palliative Medicine recommended that the ACT 'work towards standardising legislative frameworks for the ACPs and ACDs across States and Territories'. COTA called for the ACT Government to advocate for 'national recognition of Advance Care Plans developed in the ACT'. The Public Health Association of Australia highlighted that 'currently health professionals, patients and their loved ones lack the important protection of consistency of legislation regarding advance care planning across the states and territories'. The Canberra Multicultural Community Forum also noted this issue, recommending 'the promotion of a national approach to advance care planning legislation including the development of a common template for advance care directives'.[94]

2.106 The AMA, in their Position Statement on ACDs, specified the areas where greater national consistency, 'in relation to recognising at law ACDs across all States and Territories', was required:

- determining the validity of a ACD;
- providing for an EPA (or similar SDM);
- providing for the recognition of a vail ACD from another State or Territory;
- under what clinical circumstances an ACD comes into effect.

---

[92] Avant Mutual, *Submission 150*, p. 3.

[93] Avant Mutual, *Submission 150*, p. 3. See: COAG, the Clinical, Technical and Ethical Principal Committee of the Australian Health Ministers' Advisory Council, *A National Framework for Advance Care Directives*, September 2011, p. 2, <http://www.coaghealthcouncil.gov.au/Portals/0/A%20National%20Framework%20for%20Advance%20Care%20Directives_September%202011.pdf>, viewed 9 November 2018 and Australian Commission on Safety and Quality in Health Care, *National Consensus Statement: Essential Elements for Safe and High-quality End-of-Life Care*, Sydney: ACSQHC, 2015, <https://www.safetyandquality.gov.au/wp-content/uploads/2015/05/National-Consensus-Statement-Essential-Elements-forsafe-high-quality-end-of-life-care.pdf>, viewed 15 November 2018.

[94] Australian and New Zealand Society of Palliative Medicine, *Submission 379*, p. 11; Council on the Ageing, *Submission 342*, p. 3; Public Health Association of Australia, *Submission 485*, p. 4; Canberra Multicultural Community Forum, *Submission 446*, p. [4].

2.107 Additionally, the AMA called for 'clear, nationally consistent guidance for:

- The preparation, notification and storage of ACDs; and
- The establishment of procedures for identifying an appropriate SDM when there is no ACD or EPA and the patient's medical circumstances are relevant'.[95]

2.108 A similar need for national consistency concerning EPAs was also highlighted by several submissions and witnesses.

2.109 Ms Christina Thompson, Director, Guardianship Unit, Public Trustee and Guardian, notified the Committee about the work of the Australian Guardianship and Administration Council—an incorporated company comprising 'all the public guardians, public trustees, public advocates and heads of tribunals around the country'—concerning a national framework for EPAs:

> They are looking very closely at and advocating for a single consistent enduring power of attorney across the whole country. That is obviously difficult because every jurisdiction thinks they have the best legislation. But I think that would help because doctors and medical professional would actually know where to look and what they are looking for. There would be some consistency in that regard.[96]

2.110 The ACT Government informed the Committee of its participation in discussions on a nationally consistent framework for EPA laws:

> The Australian Law Reform Commission recently completed its Inquiry into Elder Abuse. The Report made a range of recommendations regarding substitute decision making including Powers of Attorney. The Final Report recommends nationally consistent laws for enduring Powers of Attorney and a national register. The ACT Government is participating in a national working group, chaired by the Commonwealth, examining the recommendations of the ALRC report.[97]

Recommendation 8

2.111 The Committee recommends that the ACT Government continue to work with other Australian jurisdictions to investigate the feasibility of reforming Power of Attorney legislation or introducing a single, Enduring Power of Attorney across Australia and that report on progress be included in the appropriate agency annual reports

---

[95] Australian Medical Association, *Submission 402*, Attachment, 'AMA Position Statement on End of Life Care and Advance Care Planning', 2014, p. 7.

[96] Ms Christina Thompson, Director, Guardian Unit, Public trustee and Guardian, *Transcript of Evidence*, 17 May 2018, p. 33.

[97] ACT Government, *Submission 151*, p. 6.

2.112 Mr Andrew Taylor, Public Trustee and Guardian, underscored the necessity for better harmonisation of laws concerning end-of-life issues, especially between the ACT and NSW. This harmonisation is not only important to ensure the care choices of ACT residents are recognised in NSW, but also because Canberra's hospitals support the wider region beyond the Territory's borders:

> A reality with people who find themselves in the ACT in hospital is that the ACT has regional hospitals. In the ACT the Canberra Hospital and Calvary hospital are regional hospitals. They have people brought in here every day—people who are normally resident in New South Wales. Many people who are brought into hospital or other health institutions in the ACT are not going to return home.[98]

DEMENTIA AND ADVANCE CARE PLANNING

2.113 The Committee heard evidence that adequate advance planning for death is particularly needed due to the increasing prevalence of dementia among Australians. As explained by Dementia Australia in their submission to this Inquiry, dementia is a term used to describe a range of progressive neurological diseases 'which cause a progressive decline in a person's functioning including loss of memory, intellect, rationality, social skills and physical functioning'.[99]

2.114 Currently, dementia is the leading cause of death among women and the second leading cause of death in the country. There are more than 425,000 Australians who have been diagnosed with dementia. Without a significant medical breakthrough to curb rates of dementia, by 2056 more than one million Australians will have dementia.[100]

2.115 For the ACT, in 2017 there were 5,369 people diagnosed with dementia, this is expected to increase to 7,353 in 2025, and 16,313 by 2056. Moreover, 'the rates of growth in the number of persons predicted to have dementia are higher than the national average in the ACT'.[101]

2.116 Dementia Australia informed the Committee of the vital importance of Advance Care Planning for sufferers of dementia:

> Dementia Australia is a strong supporter of advance care planning and believes it should be more widely accessible for people living with dementia and their families and carers. Dementia is a progressive disease with symptoms often including issues with memory, understanding and reasoning that generally interfere with cognitive functioning and behaviour. As the disease progresses, there will be a time when the

[98] Mr Andrew Taylor, Public Guardian and Trustee, *Transcript of Evidence*, 17 May 2018, p. 37.
[99] Dementia Australia, *Submission 427*, p. 3.
[100] Dementia Australia, *Submission 427*, p. 3.
[101] Dementia Australia, *Submission 427*, p. 3.

person with dementia loses the capacity to make decisions for themselves. This is why advance care planning can be such a vital support for our consumers to ensure that their end of life wishes are respected and enacted.[102]

2.117 Ms Petrea Messent, Regional Director and General Manager, Client Services, Dementia Australia, emphasised that for cases of dementia planning should happen early:

> We would support early advance care planning in any circumstances, and for anyone with a terminal disease. We would consider it to be extremely important for people with dementia because very often they lose their decision-making capacity and cannot do it at a later stage or find it much more difficult to do as the disease progresses. With doing it early, whether that is through a combination of the points when they see health professionals or services like us, the earlier the better.[103]

2.118 The need for better promotion of Advance Care Planning for people diagnosed with dementia is clearly indicated in Advance Care Australia's findings on the prevalence rates of ACDs for those with dementia in Australia:

> The prevalence of having at least one Advance Care Directive for people with dementia was 47%... However, only 3% had a statutory directive outlining their preferences for care and 14% of people with dementia had a statutory directive appointing a substitute decision-maker to make medical decisions on their behalf if they could not make or communicate decisions themselves.[104]

2.119 The Committee heard from a number of witnesses who spoke about the importance of ensuring ACPs and ACDs are accessible early to ensure people living with impaired decision making can have their wishes recorded.

Recommendation 9

2.120 The Committee recommends the ACT Government works with key stakeholders to:

a) develop a strategy to make Advance Care Plans and Advance Care Directives more widely accessible for people living with dementia and their families and carers.

b) develop a community education campaign for people with dementia, particularly early-on-set dementia, which emphasises the importance of developing or revisiting their Advance Care Plan soon after their diagnosis.

---

[102] Dementia Australia, *Submission 427*, p. 8.

[103] Ms Petrea Messent, regional Director and General Manager, Client Services, Dementia Australia, *Transcript of Evidence*, 24 May 2018, p. 173.

[104] Advance Care Planning Australia, 'Prevalence of advance care planning documentation in Australian health and residential aged care services', short report, May 2018, p. 4, <https://www.advancecareplanning.org.au/docs/default-source/acpa-resource-library/2018-prevalence-study/report-prevalence-of-advance-care-planning-document-2017_summary-final.pdf?sfvrsn=2>, viewed 20 November 2018.

3 OTHER OBSERVATIONS AND COMMITTEE COMMENT ON ADVANCE CARE PLANNING

3.1 The Committee heard a range of other views on Advance Care Planning from witnesses and in submissions. Some of these views are included below.

3.2 HCCA informed the Committee of some consumer views concerning ACPs:

- these are important documents that open conversation about an individual's care preferences with their family and medical staff;
- it is important to keep this conversation ongoing in case things change and one is no longer able to communicate one's wishes;
- it is advisable to have multiple easily-accessible copies of your ACP, including one for the paramedics;
- people need to choose an advocate or Enduring Power of Attorney very carefully. They need to be someone who respects the individual's views and won't impose their own; and
- having an ACP helps ensure your wishes are not dismissed.[105]

3.3 The Committee heard evidence that effective Advance Care Planning needs to start early and continue as an ongoing process. A person's situation changes throughout their life and their planning for death must be updated regularly to remain in alignment with their values and wishes concerning their end of life care. Ms Jennifer Mobbs (COTA) opined that

> We really do have to get the word out to people about planning for your life and that the end of life needs to be planned. I am not sure how we get that message out to people in their 30s, 40s and 50s, but we must, because if we do not, we will end up with a lot of people in that situation where they will have things done to them that perhaps 20 years ago they would never have agreed to.[106]

3.4 Mr Paul Feldman (COTA), reflecting on the impact of neurodegenerative diseases on a person's decision-making capacity, highlighted the importance for older Australians to keep their ACPs updated and relevant:

[105] Health Care Consumers' Association, *Submission 455*, p. 8.
[106] Ms Jennifer Mobbs, Chief Executive Officer, Council on the Ageing, *Transcript of Evidence*, 17 May 2018, p. 25.

> This…underscores the importance of people in their 50s framing advance care plans and reviewing them regularly, and for these advance care plans to be expressed in a way that is simple enough for them to be able to grasp the essentials as they look at it year by year.[107]

COMMITTEE COMMENT

3.5 The Committee shares the views expressed in submission and by witnesses on the crucially important role of Advance Care Planning in ensuring that the care choices of ACT residents and visitors to the Territory are respected.

3.6 While acknowledging the positive function Advance Care Planning already plays as an integral part of end of life care in the Territory, the Committee also agrees that current provisions can be improved.

3.7 The Committee believes there needs to be greater awareness among the general population of the Advance Care Planning options available and believes the Government can more effectively communicate the advantages of good planning to all sectors of the community.

3.8 The Committee also believes that there is scope for more effective training and education of health care professionals on their roles in actively aiding patients in planning for their end of life via Advance Care Planning. Health care professionals must have appropriate training on the legality of Advance Care Planning and their roles in that framework.

3.9 The Committee recognises that, legally speaking, the ACT is an island within the State of New South Wales. Our borders are not closed and thousands of people move freely into and out of the Territory on a daily basis. Some of these people may experience sudden deaths involving a loss of capacity. The Committee therefore acknowledges the importance of promoting legal consistency across all Australian jurisdictions concerning Advance Care Planning and Power of Attorney laws to ensure, no matter where a person dies, their end of life choices are respected.

3.10 The Committee recognises that Advance Care Planning for those diagnosed with dementia is especially important. Dementia, inevitably, results in the diminished decision-making capacity of the person. It is vital that those diagnosed with dementia, in particular those with early on-set dementia, are encouraged to plan early and keep those plans updated regularly.

[107] Mr Paul Feldman, Chair, Policy Committee, Council on the Ageing, *Transcript of Evidence*, 17 May 2018, p. 25.

4 THE NEED FOR IMPROVED DEATH LITERACY

4.1 As discussed in Chapter 2, Advance Care Planning starts with conversations around death. These conversations must be between a person and their family, friends, carers, and their health care professionals—centrally their GP. More fundamentally, these conversations need to be fostered at the societal level. The Committee heard, however, that there currently exists a community-wide reluctance to engage in open and frank discussion of death, resulting in poor advance planning and poor outcomes for individuals and their loved ones.

4.2 The Committee heard that conversation around death are often shrouded by taboo. Ms Judith Dodd touched on this:

> As a nurse, I have seen many occasions where people do not have a clear idea of what death will be because we are so divorced from death in this society. We are afraid of it. It is locked away. It is not something we discuss. We cannot even say "death" or "died"; we use euphemisms. I have seen families afraid of using the word, let alone coming to grips with the fact that they have a loved one that is going to die.[108]

4.3 The Committee heard that much of the taboo associated with death and the unwillingness of the community to engage in conversations around death stem from the changing nature of death and people's relationship to this within modern society. Professor Jane Phillips, President, Palliative Care Nurses Australia, reflected on this issue for the Committee:

> …death has become very institutionalised. Whereas once our grandparents would have grown up in an era where they were probably quite exposed to multiple deaths, with new technology and new developments, and our reliance on advanced treatments, many Australians will actually end up dying in an acute care setting.
>
> …not everybody is ready to talk about death, even though it is inevitable for all of us. In some respects we live in quite a death-denying society. It is also, too, about the way death is portrayed in the media. It is often the only reference people have to what death actually looks like.[109]

4.4 Mr Brian Corley, Chief Executive Officer, Community Options Inc., likewise highlighted that 'as a society, we are probably not as resilient as we might once have been to cope with death. Many years ago death in a family was a regular occurrence'. Mr Mark Green, National Director of Mission, Little Company of Mary Health, similarly noted that 'in our world that we live and move in, death is much more remote from us. It is managed

[108] Ms Judith Dodd, *Transcript of Evidence*, 24 May 2018, p. 179.
[109] Professor Jane Phillips, President, Palliative Care Nurses Australia, *Transcript of Evidence*, 12 July 2018, p. 410.

differently. It is not a personal, familial thing…We have found ways, if you like, to separate ourselves from the experience'.[110]

4.5 Ms Judith Dodd elaborated on what she believes is necessary for society to do to improve understanding and acceptance of, and planning for, death:

> …we need, as a community, to have a really long, thorough discussion about end of life…
>
> We need to have things in place. We need to have options for people. We need to all come together and tackle what is almost the taboo that is death. It is a taboo, and it is not healthy. We need to all be made aware of the fact that death is not just something that happens on a particular day. It takes weeks, months and sometimes years for some people. We need to address how we are going to tackle any particular scenarios that might crop up and give people some sort of overall plan.
>
> …
>
> …I think we need to tackle not just the actual end of life but the procedure and the lead-up that go along with that and lead to that end of life. It is more than just the end of life. We need ways of tackling that short, medium or long-term range of options that people might be facing with their deaths or end of life.[111]

4.6 In essence, better advance planning requires better and more widespread 'death literacy'. This theme was taken up by Dr Michael Chapman, who pointed out to the Committee some 'recognised gaps within the ACT at the moment':

> Those would be, in no specific order, the need to focus on community awareness, and community awareness around death literacy, understanding of death and dying, and death and dying as a natural process, to address misconceptions and fears, and facilitate better awareness of the choices available and engagement in conversation around those choices. That is a clear need.
>
> Improving death literacy and normalising natural dying are urgently required. It is something that I think we as a community really need to take on.[112]

4.7 The Little Company of Mary Health Care Ltd. (Calvary) expressed its support for more open discussions on end of life planning:

> The introduction of any initiative that improves the opportunities for the general community, health, social or aged care staff to be empowered and resourced to initiate and support conversations that allow for honest and open sharing of information,

[110] Mr Brian Corley, Chief Executive Officer, Community Options Inc., *Transcript of Evidence*, 12 July 2018, p. 385.

[111] Ms Judith Dodd, *Transcript of Evidence*, 24 May 2018, p. 184.

[112] Dr Michael Chapman, *Transcript of Evidence*, 12 July 2018, p. 391; Mr Mark Green, National Director of Mission, Little Company of Mary Health, *Transcript of Evidence*, 17 May 2018, p. 16.

communication of goals and preferences and development of shared understanding of approaches to care can only ever be supported.[113]

4.8 HCCA suggested that wider publicity campaigns targeting health care consumers on Advance Care Planning could help ensure that personal choice in end-of-life care was protected:

> Improving **health literacy** and promoting effective and supported use of **Advanced Care Planning** provides opportunities for consumers to consider the issues for themselves, and to articulate their own wishes for future health care.[114]

4.9 HCCA emphasised that what was needed were 'conversations about death and dying'. They submitted:

> Talking about death and dying can be difficult. Both consumers and health professionals need to have more respectful and honest conversations regarding end-of-life choices, death and dying. We all need to be as realistic as possible so that consumers, their families, friends and carers, as well as health professionals, can work together through the choices available for end-of-life care. Ultimately, it is the consumer's right to determine their health care, but we need to be supported with sufficient information to empower us to make these decisions.[115]

4.10 One potential format for discussions around death is the so-called "death café". The death café movement started in Switzerland as a way of breaking down inhibitions to discuss and plan for death more freely. The premise of a death café is that a group of people meet to talk about death—including end of life care and funeral options and experiences with death and ways of coping with loss—over coffee, tea and cakes.[116]

4.11 The Committee heard of recent attempts by Illawarra Retirement Trust, partnering with Palliative Care ACT, to promote death cafés for their residents as a means of 'trying to get the stigma off the residents and family with death and dying'. Ms Hilde de Raadt-Abma, Social Welfare Officer, Illawarra Retirement Trust, explained the rationale behind the initiative: 'We feel that, very gently, we would like to break down those barriers and have people start thinking about things more, so it does not all have to happen at the very end'.[117]

---

[113] Little Company of Mary Health Care Ltd. (Calvary), *Submission 452*, p. 9.

[114] Health Care Consumers' Association, *Submission 455*, p. 1. Emphasis in original.

[115] Health Care Consumers' Association, *Submission 455*, p. 8.

[116] Funeralzone, 'Australians breaking the taboo at death cafés', 2 December 2016, <https://www.funeralzone.com.au/blog/australian-death-cafe-movement>, viewed 21 November 2018.

[117] Ms Andrea Mabalo, Facilities Care Manager, Illawarra Retirement Trust and Ms Hilde de Raadt-Abma, Social Welfare Officer, Illawarra Retirement Trust, *Transcript of Evidence*, 26 September 2018, pp. 444-5.

Recommendation 10

4.12 The Committee recommends the ACT Government consider trialling the funding of "death cafés", including exploring funding existing non-governmental organisations which undertake this work, to establish the initiative in the ACT, with an aim to encourage broader conversations about death and dying and improve death literacy.

5 THE NEED FOR SAFEGUARDS TO BE PROVIDED TO ADDRESS ELDER ABUSE

5.1 The Committee heard from a number of witnesses and submissions on measures around Advance Care Planning which may help in reducing the risk of elder abuse.

5.2 Mr Timothy Morton informed the Committee that:

> Part of strengthening the law in relation to elder abuse—I would personally advocate for this—is strengthening witnessing requirements and potentially even requiring an attorney accepting an appointment to accept that appointment in front of a lawyer who gives a certificate setting out what their obligations are.[118]

5.3 While some witnesses and submissions recommended that Advance Care Planning discussions be mandated for RACF while admitting new clients, the Little Company of Mary Health Care cautioned that:

> There is a risk, if completion of an end of life care plan (or as more commonly practiced—directive) is mandated an entry requirement to a residential aged care facility…older people will feel pressured or coerced. This is particularly true if the focus of the advance care plan is on transfer to hospital or withholding/withdrawing of treatment. The ongoing communication around goals of care, their clarification and/or amendment should be the focus of any recommendation and mandated requirement—rather than the completion of a document at any single point in time.[119]

5.4 Mr Andrew Taylor, Public Trustee and Guardian, informed the Committee that a move away from guardianship towards supported decision-making paradigms could serve to reduce instances of elder abuse and abuse of other vulnerable peoples:

> There is movement internationally as well as locally to remove guardianship in favour of upholding the United Nations convention on the rights of people with a disability, particularly article 12, and moving towards more of a supported decision-making environment. That works well with the advance care planning.[120]

COMMITTEE COMMENT

5.5 The Committee shares witnesses' concerns over the issue of elder abuse as this relates to Advance Care Planning, but also believes this is an area of serious concern covering a

[118] Mr Timothy Morton, *Transcript of Evidence*, 31 May 2018, p. 334.
[119] Little Company of Mary Health Care Ltd (Calvary), *Submission 452*, p. 10.
[120] Mr Andrew Taylor, Public Trustee and Guardian, *Transcript of Evidence*, 17 May 2018, pp. 32-3.

wide-spectrum of setting—from palliative care and RACF settings, to within the family home. The Committee is also particularly concerned about the potential for elder abuse as this relates to the issue of VAD.

5.6 The Committee recognises that elder abuse is an issue of national concern and notes with satisfaction the establishment of the Royal Commission into Aged Care Quality and Safety by the Commonwealth Government on 8 October 2018.[121]

5.7 The Committee also notes comments made by Mr Gordon Ramsay MLA, Attorney-General, to the Legislative Assembly on 21 August 2018 that the 'ACT Government is committed to tackling [elder abuse] here and cooperatively with other jurisdictions'. The Attorney-General provided further details on the ACT Government's efforts in this space:

> The 2018-19 budget also includes funding to establish a seniors rights service, based in Legal Aid. This will provide targeted support for older Canberrans who are experiencing or vulnerable to elder abuse.
>
> The 2018-19 budget also includes an allocation for an increase in the staffing resources of the office of veterans and seniors. The office, working alongside the Justice and Community Safety Directorate, provides the ACT Government's representation on the Council of Attorney-General's working group on protecting the rights of older Canberrans. This working group is overseeing the national response on the implementation of the recommendations resulting from the Australian Law Reform Commission's report *Elder Abuse—A National Legal Response* and is leading the development of a national plan on elder abuse.[122]

5.8 Elsewhere, the Attorney-General has commented on the Government's work with the Ministerial Advisory Council on Ageing in developing strategies for the ACT Government to address the problem of elder abuse.[123] The Committee supports and encourages this work.

5.9 The Committee urges the ACT Government to continue and strengthen these efforts to address elder abuse within the ACT, and nationally, in cooperation with other jurisdictions.

5.10 The Committee considers that, given the significance of the issue of elder abuse, that a stand-alone inquiry by the appropriate committee of the Legislative Assembly be undertaken on the issue.

---

[121] Royal Commission into Aged Care Quality and Safety, https://agedcare.royalcommission.gov.au/Pages/default.aspx, viewed 15 February 2019.

[122] ACT Legislative Assembly, *Hansard*, 21 August 2018, p. 3342.

[123] Mr Gordon Ramsay MLA, Attorney-General, comments to 2CC Radio, 6 February 2019. On the Ministerial Advisory Council on Ageing, see: ACT Government, 'ACT Ministerial Advisory Council on Ageing', https://www.communityservices.act.gov.au/wac/seniors/advisory_council_on_ageing, viewed 15 February 2019.

6 PALLIATIVE CARE

INTRODUCTION

6.1 The Committee has been asked to report on current practices utilised in the medical community to assist a person to exercise their preference in managing the end of their life, including palliative care.

6.2 In this chapter, the Committee discusses the elements of palliative care, as it has developed as practice of medical and health services in modern society, both in Australia and in other jurisdictions.

6.3 The Committee concentrates its discussion in this chapter on the broad definition and characterisation of palliative care, and also concentrates on the Australian national approach to palliative care.

6.4 In the next chapter, the Committee examines and discusses palliative care in the ACT which has its own characteristics and practices.

6.5 From an aspect of medical care which arose from the need to provide a different and new category of care to individuals with terminal cancer, palliative care is perceived and practised as the means of providing care to the aged, infirm, terminally ill and those with particular degenerative diseases.

6.6 Palliative care has developed to provide a spectrum of care regimes to individuals requiring a wide variety of care and treatment care responses. Of particular emphasis and focus is the development of treatment regimes that deal, amongst other needs, with the gamut of, mental and other factors affecting the psychological state confronting patients which inevitably arise at the end-of-life.

6.7 The Committee draws on the submissions and evidence it received – together with a very considerable body of published literature and research – directed at identification, better definition and analysis of issues arising for palliative care – as a basis for current and future programs of palliative care in Australia.

6.8 In the context of developing palliative care programs and funding as a function of Commonwealth-State and Territory responsibilities are several major studies of palliative care.

6.9 One is the study of two elements of palliative care; 'End of Life Care', and 'Reforms to End-of-Life Care' within the Productivity Commission's 2017 report on *Introducing Competition and Informed User Choice into Human Services: Reforms to Human*

Services.'[124] The Committee refers to this publication – and in particular the palliative care chapters – as the Productivity Commission report.

6.10 Second, Australian palliative care is the subject of an October 2018 review by the Australian Institute of Health and Welfare (AIHW) entitled *Palliative Care in Australia*. The Committee refers to this report as the AIHW report.[125]

6.11 In later parts of this chapter, the Committee also refers to the current – and proposed – updates for palliative care standards and strategies in Australia to ensure palliative care, as a central element of Australian health care, is addressed and suitably recognised and resourced.

DEFINITIONS

6.12 The Committee considers that palliative care is an issue dealt with from several perspectives. Views of palliative care in the community at large, as has been pointed out in other inquiries, vary with the standpoint and involvement of the individual and/or the individual's family or support. Views also vary, understandably, depending on the development, establishment and implementation of palliative care programs.

6.13 So:

> Palliative care is an important and measured approach to manage a person's pain or suffering and provide them comfort during the end of their life. It encompasses medical, physical, mental and spiritual comfort for not only patients, but also their relatives, carers and friends.[126]

6.14 The definition of palliative care which encompasses palliative care in all its elements, and which is accepted as the basis of contemporary palliative care, is that adopted by the World Health Organization (WHO).

6.15 The World Health Organization describes palliative care as an approach that

> …improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

---

[124] See: Chapters 3 &4, Productivity Commission 2017, *Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services*, Report No. 85, Canberra. Chapter 3 (pp. 109 to 129) and Chapter 4 (pp. 129 to 135). https://www.pc.gov.au/inquiries/completed/human-services/reforms/report/01-human-services-reforms-life.pdf (Productivity Commission Report)

[125] https://www.aihw.gov.au/reports-data/health-welfare-services/palliative-care-services/overview

[126] Victorian Parliament, *Legislative Council Select Committee on End of Life Choices*, Report, June 2016, p. 17. https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient's illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.[127]

The definition has been adopted as the basis of the Australian National Palliative Care Strategy (ANPCS).

6.16 The WHO definition is inclusive of long and short-term illness, including illness which may extend over a long period of development and gradual deterioration before approaching end-of-life stage. The Committee notes that definitions of palliative care do encompass long-term care requirements as part of therapy and care. For example, the submission to this inquiry from Dementia Australia, notes that

> Quality of life is improved through prevention and relief of suffering by means of early identification and assessment and treatment of pain, as well as addressing physical, psychosocial and spiritual concerns.
>
> On average, people with dementia survive for three to ten years from the point of diagnosis10. However, survival prognosis is very difficult in dementia and is influenced by various factors including age, gender, type of dementia, the person's comorbidities, and the severity of the illness at the time of diagnosis[128].

6.17 Similarly, support groups for a range of conditions of life-limiting nature have identified the extended palliative care as being situations where patients receive palliative care at any stage of an illness and that receiving palliative care doesn't necessarily mean a person is going to die soon; some people receiving palliative care for years.

[127] World Health Organization, *'WHO definition of palliative care'*, viewed 10 November 2018. http://www.who.int/cancer/palliative/definition/en/

[128] Submission 427, Dementia Australia, p.4.

> Palliative care is provided as part of treatments, therapies and medicines aimed at controlling and ameliorating illness,

As the emphasis in palliative care is the end of life, the definition of end-of-life care is a logical additional matter for definition. As is the case in discussions in other reports[129], the Committee notes the definition by the Australian Commission on Safety and Quality in Health Care (ACSQHC) as follows:

> [End-of-life care] includes physical, spiritual and psychosocial assessment, and care and treatment delivered by health professionals and ancillary staff. It also includes support of families and carers, and care of the patient's body after their death. People are 'approaching the end of life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:
>
> - advanced, progressive, incurable conditions
> - general frailty and co-existing conditions that mean that they are expected to die within 12 months
> - existing conditions, if they are at risk of dying from a sudden acute crisis in their condition
> - life-threatening acute conditions caused by sudden catastrophic events.[130]

6.18 The Productivity Commission report has a shorter definition of end-of-life care which draws on the WHO and ACSQHC definitions. The Productivity Commission report also acknowledges that palliative care and end-of-life care definitions (and descriptions) do not include euthanasia, assisted suicide or voluntary assisted dying.[131]

PALLIATIVE CARE IN AUSTRALIA

6.19 The Productivity Commission report has highlighted the following aspects of palliative care in Australia. These points are from the Productivity Commission inquiry, and reflect the Australian situation in 2017:

- End-of-life care is provided to people who have a medical condition that means they are likely to die within the next 12 months
- Most of the 160 000 people who die in Australia each year would benefit from end-of-life care but many do not receive care that fully reflects their choices

[129] See, e,g,. Victorian Parliament, *Legislative Council Select Committee on End of Life Choices*, Report, June 2016, p. 18;

[130] Australian Commission on Safety and Quality in Health Care, *National Consensus Statement: Essential elements from safe and high-quality end-of-life care*, Australian Government, Sydney, 2015, p. 33. https://www.safetyandquality.gov.au/wp-content/uploads/2015/05/National-Consensus-Statement-Essential-Elements-forsafe-high-quality-end-of-life-care.pdf

[131] Productivity Commission Report, p. 110.

or meets their needs. Demand for care will grow rapidly in coming years as more people enter the older age groups in which most deaths occur.

- Where it is available, the quality of end-of-life care services in Australia is often excellent. But services are not available everywhere and to everyone who would benefit.
- Hospitals play an important role in the delivery of end-of-life care. Hospital accreditation standards will, from 2019, prescribe a range of best-practice elements for end-of-life care.
- About 60 000 people die in residential aged care facilities each year. End-of-life care should be core business for residential aged care providers but the quality of end-of-life care in residential aged care is patchy at best.
- Many people are unable to communicate their wishes for end-of-life care at the time the care is provided.
- While Governments have recognised community concern about end-of-life care, progress is being hindered by poor stewardship, including conflict over responsibilities and how service provision is coordinated across different settings.[132]

6.20 Of these observations, a number are dealt with in the following chapter which provides analysis and canvasses submissions and recommendations for ACT palliative care received during the inquiry.

6.21 Submissions to the Committee conceded the broad point made by the Productivity Commission, and highlighted the level of gaps, confusion and lack of strategy and planning which is within the finding:

> While the quality of end-of-life care services in Australia is often excellent, they perform less well on equity considerations, as too many people approaching the end of life end up with little real choice about the care they receive. Similarly, while some services are effective, offering only hospital services to many people who would prefer to be, and could be, well cared for at home, reduces the overall effectiveness of end-of-life care in Australia. It also means that end-of-life care services are not as responsive as they should be to users' needs and choices.
>
> Poor stewardship by governments is a major barrier to the delivery of better end-of-life care in Australia. Inadequate planning, overlapping and uncertain funding and other responsibilities between different levels of government, and limited use of data to monitor and improve services, are all impediments to change.[133]

[132] Productivity Commission Report, Chapter 3, p. 109.
[133] Productivity Commission Report, Chapter 3, p. 127.

6.22 The Committee does note, however, the observation made by the Productivity Commission, that:

> The problems resulting from the lack of cross-jurisdiction co-operation have been particularly evident for residents of aged care facilities. They may miss out on specialist palliative care because it is unclear whether it is the Australian Government's responsibility as steward of the aged care system, or the role of State and Territory Governments as providers of specialist palliative care.
>
> - The Australian Government rarely acknowledges that providing end-of-life care is (or should be) core business for residential aged care and has, for many years, failed to ensure that residential aged care providers receive sufficient funding for delivering palliative care.
> - State and Territory Governments can be reluctant to fund palliative care for people aged over 65 years who, by virtue of their age, could also be eligible for aged care funded by the Australian Government. Some State and Territory Governments have end-of-life and palliative care policies that omit the needs of those in aged care, or focus only on specialist palliative care (ignoring the end-of-life care needs of frail elderly people who do not require specialist care).[134]

PALLIATIVE CARE AS A CENTRAL ELEMENT IN AUSTRALIA'S HEALTH-CARE PROGRAM

6.23 The current Australian National Strategy (ANS) for palliative care is the plan agreed to in 2010.

6.24 The current ANS is currently in the course of being re-drafted and is the subject of discussion and proposed updating by all Australian jurisdictions.

6.25 National standards for palliative care have also been published in 2018 by Palliative Care Australia (PCA) as a set of standards for palliative care practitioners.[135]

6.26 As a further point of reference and guidance for palliative care nationally, the Consensus Statement on Palliative Care has two particular parts which identify an aspect of palliative care which reflect on other observations (such as that by the Productivity Commission): that palliative care in Australia is still developing as major element in health care;

---

[134] Productivity Commission Report, Chapter 3, p. 127.

[135] Palliative Care Australia, *National Palliative Care Standards (5th edition)*, 2018. https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/02/PalliativeCare-National-Standards-2018_web-3.pdf national consensus statement: essential elements for safe and high-quality end-of-life care

> The Consensus Statement reflects the views of health consumers and carers, experts in the field, and the Australian Commission on Safety and Quality in Health Care (the Commission). It has been derived from expert experience and published evidence, and developed in partnership with carers and consumers, and representatives from public and private hospitals and health services, professional colleges, state and territory health departments, and other government agencies.

and

> Some actions within the Consensus Statement are currently aspirational. It is likely to take time for health services to develop and implement systems that enable care to be consistently delivered in accordance with all the principles and elements outlined in this document.[136]

6.27 The Australian National Strategy for Palliative Care (ANS) has been developed and reviewed during the period 2001 to present (with the latest version of the ANS being dated 2010). A principal factor and consideration in all reviews and discussion of palliative care is the increase in demand for palliative care services.

6.28 This demand is summarised in the Draft Updated ANS for palliative care as:

Demand for palliative care is increasing

- In 2015-2016, almost 14,300 patients received a Medicare Benefits Scheme subsidised palliative medicine specialist services, an increase of 84.8% from 2010-2011.
- In 2015-2016, Medicare Benefits Scheme-subsidised palliative medicine specialist services were estimated at $5.6 million, an increase of nearly 60% over the previous five years.
- In 2014-2015, there were 65,000 palliative care-related hospitalisations, an increase of 19.2% since 2010-2011.
- It is anticipated that by 2066 around 25% of the population will be over 65. As around 80% of Australians who die in any given year are over 65, the number of people dying each year will increase consistently.
- Australia has one of the highest rates of institutionalised death in the developed world, with 80% of people dying in hospital or residential aged care facilities.[137]

---

[136] National Consensus statement: Essential Elements for Safe and High Quality end of life care, Introduction, p. 1, https://www.safetyandquality.gov.au/wp-content/uploads/2015/05/National-Consensus-Statement-Essential-Elements-forsafe-high-quality-end-of-life-care.pdf

[137] Updated National Palliative Care Strategy 2017 Draft 2.1, Department of Health, p. 2.
https://www.hcasa.asn.au/documents/565-updated-national-palliative-care-strategy-2-1/file

6.29 The 2017 Draft ANS notes as a basis for the need to formulate an updated ANS, that:

> The discipline of specialist palliative care has grown in Australia since the 1980s, and every state and territory government health department funds and delivers palliative care services for its residents. In the last few decades, palliative care has become available within almost every health care setting, including neonatal units, paediatric services, general practices, acute hospitals, residential and community aged care services, and generalist community services. Palliative care is also provided through specialist palliative care services which operate from a variety of settings, including specialist inpatient consulting services, specialist inpatient settings, hospices and community-based specialist services.[138]

6.30 The development of demand and other growth drivers for palliative care, particularly in the residential care sector, underlies the need for an updated ANS for palliative care:

> Concurrently, most jurisdictions have either updated or produced new policy frameworks for palliative and end-of-life care. Since the previous National Strategy was released in 2010, there has been ongoing discussion regarding the language used to refer to care at the end of life. This National Strategy has maintained the term 'palliative care' but notes that there is not a national consensus regarding terminology and that there is overlap between concepts of palliative and end-of-life care.
>
> Also since 2010, significant change has taken place in related service sectors such as aged care, chronic disease, and disability, as well as an increasing recognition of the need for services to be person-centred. This update of the National Strategy has sought to align with strategic frameworks in the primary, community and aged care sectors, and other components of the health system.[139]

6.31 The development of the updated ANS for palliative care is planned to operate in the following manner:

> The implementation of the National Strategy will be guided by an Implementation Plan, to be developed once the goals and priorities of the updated National Strategy have been agreed. The Plan will identify the stakeholders involved as well as the timing and accountability for activities.
>
> A Monitoring and Evaluation Plan will also be developed that will identify how the National Strategy's progress will be measured and reported. A process of consultation will be undertaken with jurisdictions and other stakeholders with key responsibilities for the provision and development of palliative care services, to inform the framework

[138] Updated National Palliative Care Strategy 2017 Draft 2.1, Department of Health, p.2.
https://www.hcasa.asn.au/documents/565-updated-national-palliative-care-strategy-2-1/file

[139] Updated National Palliative Care Strategy 2017 Draft 2.1, Department of Health, p.3.
https://www.hcasa.asn.au/documents/565-updated-national-palliative-care-strategy-2-1/file

for implementation, monitoring and evaluation of the National Strategy Committee Comment, Findings and recommendations.[140]

COMMITTEE COMMENT AND RECOMMENDATIONS

6.32 Palliative care in Australia is an element in the Australian – and ACT – health care system and programs which has developed rapidly, and – as highlighted by the Productivity Commission Report, is subject to a number of pressures and growth factors which have led to a current recognition that palliative care is a central element in the health care system, and takes its role in conjunction with other areas of health care. This is particularly the case for residential care and for acute care sections, as appropriate, of modern hospitals.

6.33 The Committee discusses how palliative care in the ACT is currently organised and how it is provided in the next chapter.

6.34 However, the Committee – noting the process that is currently underway to revise and update the National Strategy for palliative care - considers it important to the future and continuing development of palliative care elements in the ACT health system that the ACT plays a role in this process. This need for emphasis on developing a national (and coordinated) approach to palliative and end-of-life- care is discussed as a question of 'Shared stewardship between governments' in the Productivity Commission report.[141]

6.35 A comment made by the Productivity Commission report in relation to shared stewardship is that:

> To achieve better planning and resource allocation, there will need to be greater collaboration between the Australian, State and Territory Governments. As noted …, there is currently overlap in the roles of the different levels of government, ***which has led to uncertainty and buck passing*** [Committee emphasis added] over how stewardship is shared and service provision is coordinated across different settings.[142]

6.36 In its submission to the committee, the ACT Government adverted to its role in the development of national approach and in the ANS process as a focus on an End of Life working group established by the Australian Health Ministers Advisory Committee (AHMAC), which is established to make recommendations to AHMAC related to

---

[140] Updated National Palliative Care Strategy 2017 Draft 2.1, Department of Health, p.7. https://www.hcasa.asn.au/documents/565-updated-national-palliative-care-strategy-2-1/file

[141] Productivity Commission report – Chapter 3.4, p. 127.

[142] [142] See: Chapters 3 &4, Productivity Commission 2017, *Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services*, Report No. 85, Canberra. Chapter 3 (pp. 109 to 129) and Chapter 4 (pp. 129 to 135). https://www.pc.gov.au/inquiries/completed/human-services/reforms/report/01-human-services-reforms-life.pdf (Productivity Commission Report)

common language, common tools and strategies to raise awareness at a national level.[143]

6.37 The Committee considers that the continual development, review and implementation of a national strategy (in conjunction with standards such as those developed by Palliative Care Australia and others) is an essential part of public health policy, and that the ACT must contribute to this process.

6.38 An important element in current analysis of the implementation of palliative care nationally is the barriers identified by the Productivity Commission report and identified in paragraph 6.35 above.

6.39 The emphasis on the recommendations that are made by the Productivity Commission are included in proposed reforms to end-of-life care in Australia. They are:

- State and Territory Governments to increase the availability of community-based palliative care so that people with a preference to die at home can access support to do so.
- The Australian Government to remove current restrictions on the availability and duration of funding for palliative care in residential aged care, and provide sufficient additional funding so that people living in residential aged care receive end-of-life care that aligns with the quality of that available to other Australians.
- Governments to co-operate to:

- plan, fund, deliver and set standards for end-of-life care across different settings and jurisdictions
- develop and implement a strategy for end-of-life care data, including developing a national minimum data set for end-of-life care
- Review the effectiveness of end-of-life care across all settings.[144]

6.40 The Committee has two recommendations to make which endorse the overall direction of the Productivity Commission recommendations. It is important, in the Committee's view, that these matters be both observed by the ACT government, and that the ACT government have regard to these recommendations and act on them as a priority.

[143] ACT Government, *Submission 151*, p. 11.

[144] , Productivity Commission report, 'Overview of proposed reforms to end-of-life care', para 4.1, p. 131.

Recommendation 11

6.41 That the ACT Government work cooperatively with Governments from all Australian jurisdictions to implement the proposed reforms advocated by the Productivity Commission report on End-of-life Care in Australia.

Recommendation 12

6.42 The Committee recommends the ACT Government report to the Legislative Assembly on the timetable and progress of actions to achieve the implementation of the proposed reforms advocated by the Productivity Commission report on End-of-life Care in Australia as part of its response to this report as well as including that information in relevant annual reports.

7 PALLIATIVE CARE DELIVERY IN THE ACT

INTRODUCTION

7.1 In Chapter 6 the Committee has discussed and described the current state, and developments in implementation, of palliative care in Australia. The Committee has drawn attention to the recent analysis by the Productivity Commission's 2017 report which included considerable discussion of on end-of-life care, and the AIHW survey in October 2018 of palliative care in Australia. The Committee also drew attention to the current, and ongoing, development of the national strategy, standards and recognition of palliative care as a priority area of health care in Australia.

7.2 During this inquiry, the Committee has focussed on matters raised with it by submissions and in evidence which have provided current perspectives and concerns about the development of palliative care programs in the ACT.

7.3 The analysis and recommendations made by the Committee in this chapter have focussed on matters which go to current organisation, administration, staffing, planning, expertise, training and support for the continuing development of ACT palliative care. The Committee also deals with particular elements of the palliative care delivery system which were addressed during the inquiry.

7.4 These matters include the Committee's account and recommendations regarding matters of concern expressed to it. The Committee has made recommendations throughout this chapter to address matters which the Committee considers should be matters of priority and which, if addressed, can provide a way to better, responsive and appropriate palliative care.

CURRENT PALLIATIVE CARE ARRANGEMENTS IN THE ACT

7.5 The ACT Government and providers of hospital, in-home and residential care provided the Committee with a description of the current organisation of palliative care in the ACT. Its description is of a system of palliative care which is describes a palliative care delivery which reflects the size of the community and organisation of the ACT health care system.

7.6 The elements of ACT palliative care are:

- **Specialist palliative care services** The Calvary Public Hospital Bruce Palliative Care Service operates from Clare Holland House, a hospice serving the ACT

and the region. This is a nineteen bed inpatient palliative care unit where a specially trained team cares for people with a life-threatening illness.

- **Specialist Palliative Care Consult service** currently exists for inpatient and outpatient referrals to support palliative management including end of life care and serves as a link to the palliative care network of services in the ACT. The team comprises medical, nursing and allied health professionals. Referrals are taken from all specialties across Canberra Hospital and Health Services to assist in the planning and treatment of patients with life limiting illnesses. The team also provides outpatient services at the Canberra Region Cancer Centre, Canberra Hospital.
- **Paediatric palliative care for hospital inpatients and outpatients** Palliative care for children represents a special, albeit closely related field to adult palliative care.
- **Home based palliative care through the End-of-Life Care at Home Program** The Home Based Palliative Care supports and maintains patients living with a life limiting illness in their own home. The main objective being to enable each patient to be cared for and to die at home, if this is their choice.
- **Palliative care volunteer and community support services.** The community sector is increasingly caring for people at home rather than in hospital. Palliative Care ACT receives approximately $650,000 per annum from ACT Health to ensure the delivery of palliative care volunteer support services both within Canberra Hospital and Health Services (CHHS) and in the community. This element includes the role of the GP, as primary care providers, often take on the responsibility to coordinate palliative care treatment having had a part of the patients care from diagnosis to end of life care. (GPs often coordinate sometimes fragmented and competing community services and advocate on behalf of patients, their families and carers for community based palliative care).
- **Research** ACT Health also funds research projects across the ACT looking at the role and advancement of palliative care services.[145]

PALLIATIVE CARE DELIVERY IN THE ACT - HOSPITALS

7.7 There are two major hospitals in the ACT where palliative care is delivered to patients who require it: The Canberra Hospital and Calvary Hospital.

[145] ACT Government, *Submission 151*, pp. 8-11.

7.8 In detail, there is no current dedicated palliative care unit at The Canberra Hospital or Calvary Hospital, although palliative care is organised and provided to patients in particular areas of medical treatment as required.

7.9 In Calvary Hospital, palliative care is provided at Calvary John James Hospital, the Calvary Public Hospital, Bruce and Calvary Bruce Private Hospital. In both The Canberra Hospital, and Calvary hospitals the reference of cases and delivery of palliative care appears similar. A consultancy service sees patients who are deemed palliative. If a treating team decides that there are limited or no future care options for that patient, that they are reaching end-of-life and that they require palliative care, an appropriate team is called who will assess and assist patients and provide advice for management of symptoms or care needed. If the patient requires transfer to Clare Holland House then a referral to Clare Holland House can occur.

PALLIATIVE CARE DELIVERY IN THE ACT – AT HOME

7.10 The provision of palliative care in home is delivered in the ACT under a model which focusses on personal care programs which take into account individual needs and medical condition.

7.11 The model is that Palliative Care Programs complement the existing palliative care system in the ACT and provide home based palliative care services as a separate form of care. (The Palliative Care Program works in conjunction with the home palliative care at Clare Holland House). Through this arrangement, in-home care and support (non-clinical support with activities of daily living) are provided by the care organisation. Clinical home based palliative care services, including nursing care for pain and other physical symptom are delivered by the home palliative care teams.

7.12 The funding of in-home palliative care is drawn principally from:

- ACT Health grant assistance for case management services delivered through this Program to ACT residents of all ages diagnosed with terminal (end-stage) illnesses;
- ACT Health Community Assistance and Support Program (CASP) for in-home support (non-clinical) services delivered to people diagnosed with terminal (end-stage) illnesses aged under 65; and,
- Commonwealth Home Support Program (CHSP) for in-home support (non-clinical) services delivered to people diagnosed with terminal (end-stage) illnesses aged 65 and over.[146]

[146] See, Community Options, *Submission 365*, pp. 4-5; Catholic Health, *Submission 411*, p. 5.

Recommendation 13

7.13 The Committee recommends that the ACT Government assess the demand for higher palliative care options in the ACT and investigate the feasibility of funding the extension of in-home palliative care options.

Recommendation 14

7.14 The Committee recommends that the ACT Government investigate the respite options available to families providing in-home palliative care and whether these options meet the increasing demand for such services.

PALLIATIVE CARE IN THE ACT – PAEDIATRIC CARE

7.15 The committee received limited specific comment regarding current levels and detail of paediatric palliative care services in the ACT during its inquiry.

7.16 In evidence to the committee, the Minister provided detail of budget initiatives on paediatric palliative care initiated in recent time as follows:

> We did not have specialist paediatric palliative care support. That was funded two budgets ago, after feedback from families who had lost children, around their experience in palliative care—a couple of families in particular, who also then contributed to some of the design work around what that service might look like and the recruitment of new staff to that area. There were also discussions with Clare Holland House. Generally, it is for adults, but occasionally they do have children there with their families. It is about being able to be sensitive to a family's experience, particularly when there is a child involved. So that is one, but there are a range of others.[147]

7.17 The Committee notes the *Model for Palliative Care in the ACT and Regions* has not specifically addressed paediatric palliative care as a separate aspect of palliative care.

7.18 In its submission, the Australian Medical Association provides in its current position statement the following:

- Children and young people under the age of 18 may be considered at law to have limited rather than impaired (unless otherwise relevant) decision-making capacity.

[147] *Transcript of Evidence*, 1 June 2018, p. 355.

- Children and young people experiencing end of life care should be involved as much as possible in clinical decision-making as appropriate to their mental and emotional maturity as determined by a doctor.
- Guidance should be offered to parents about how to communicate with their child and their siblings, where appropriate, regarding the child's condition[148]

7.19 Submissions and evidence to the Committee which addressed palliative care did so, in general, without specific reference to paediatric palliative care as a separate palliative care category. However, the committee observes that - given the advice – received from the Minister, increased funding and added resources for paediatric palliative care in the ACT should be provided to ensure that palliative care for children and young people is enhanced.

7.20 The Committee considers provision of paediatric palliative care in Canberra should be examined in more detail than allowed by this inquiry. Paediatric palliative care should be considered as a category of palliative care which may require different care arrangements. Paediatrics as a medical discipline or specialisation is separate to general medical, nursing and hospital specialties care, so paediatric palliative care should be viewed and treated as a separate form of treatment. Special considerations which apply in developed palliative care treatment such as dealing with age-determined constraints on patient decision-making, assistance and the role played by a support persons are of a different quality and require different support in both level and quality to palliative care for adults.

7.21 The Committee believes that this matter should be subject of a specific inquiry, particularly in the context of palliative care designed (as part of palliative care in general). The Committee recommends accordingly.

Recommendation 15

7.22 The Committee recommends that the Legislative Assembly refer the provision of palliative care to paediatric and adolescent patients in Canberra to the Legislative Assembly Standing Committee on Health, Ageing and Community Services for inquiry and report.

[148] Submission 406, Australian Medical Association, *(from 'Position Statement on End of Life Care and Advance Care Planning, 2014',* p. 6.

PALLIATIVE CARE DELIVERY IN THE ACT – RESIDENTIAL CARE

7.23 In general, providers of palliative care to outpatient or in home packages also provide care (in consultation with and reliance on staff) at residential care facilities in the ACT.

7.24 The committee had discussions with one provider of residential care requiring palliative care services, IRT. The elements of the model employed for establishing palliative care for an individual at the IRT residential care were:

- The goal is to improve the engagement with residents, families and staff and to be able to pick up at an early stage where and when palliative care is provided whether on a first phase, second phase or third phase of palliation.
- A triage is conducted to determine projected life expectancy which determines a priority list we will have a look at what are the advanced care directives we have with the families.
- Conference of GPs, registered nurses and social workers to seek from families and individuals long and short-term goals for treatment including medical procedure, medical investigation, or to ensure a better quality of life within palliative care practices. This includes providing for quality of life, stay at home and then ensuring a patient is pain free and at home.

COMMITTEE COMMENT

7.25 The Committee has described the several categories of current palliative program delivered currently in the ACT. During its inquiry, the Committee considered and heard comments and observations on the organisation of ACT palliative care services in the categories described. From the ACT Government and from Clare Holland House on the range of practitioners, services and programs currently applied to residential aged care. [149] The Committee has addressed its recommendations to those areas of palliative care delivery and administration in the ACT which the Committee considers should be addressed.

7.26 Evidence received by the Committee was that difficulties in the funding of residential care often requires the transfer of residents from residential care facilities to hospital for palliative care. The Committee believes that palliative care should be better integrated into residential aged care.

[149] See, , *Transcript of evidence*, 12 July 2018 , p. 365; and 'Specialist Palliative Care Services', *Submission 151* , ACT Government, p. 11.

7.27 The Committee notes that this matter is before the Royal Commission on Aged Care Quality and Safety for inquiry and report. The Committee has conveyed its views on this issue to the Royal Commission. Its letter to the Royal Commission, dated 20 March 2019, is attached as **Appendix D** to this report.

7.28 The Committee notes also that, in relation to the issue of palliative care in residential aged care facilities, the Committee experienced difficulty in engaging with the ACT residential aged care sector during its inquiry.

7.29 In relation to current programs for palliative care professional personnel, the Committee acknowledges the work by the ACT Government with practice nurses; a program which could be further developed to ensure continuing development of high-level palliative care.

Recommendation 16

7.30 The Committee recommends that the ACT Government evaluate what level of funding is required for the provision of palliative care within residential aged care facilities and work with the Commonwealth Government to provide this funding.

LACK OF A DEDICATED PALLIATIVE CARE UNIT IN THE CANBERRA HOSPITAL

7.31 A principal issue the Committee did pursue, is the current lack of a dedicated palliative care unit or ward at The Canberra Hospital. In his evidence to the Committee, Dr Michael Chapman, the current Director of Palliative Care at Canberra Hospital and Chair of the ACT Palliative Care Clinical Network, told the Committee that, whilst the question had been raised the matter was unresolved:

> It is not that it is a completely novel idea. There has been a sort of draft plan for how that might look and how that might work and the resources required for that circulating within ACT Health, but there are no actual beds at the moment.[150]

7.32 At a later hearing Dr Chapman advised the committee:

> From my perspective, the merit of not having a palliative care ward at Canberra Hospital, for instance, is that if there is not a palliative care ward then it remains everybody's business to provide palliative care. And that is a merit. We do need to continue to encourage people. One of the challenges of specialist palliative care

[150] *Transcript of Evidence*, 1 June 2018, p. 343

provision is that the more that you do, potentially the less others do. And there are clear tensions around that. I think that there is a merit there.

There is also a merit in the sense that any hypothetical palliative care ward at Canberra Hospital would need to be very carefully avoiding duplicating services that were already in existence, for instance at Clare Holland House. Not having one avoids the possibility of duplication, and that is a merit as well.

Having said that, I think that there are lots of reasons why having a ward would be a really good idea, from my own personal perspective. I think that there are clearly palliative care needs in Canberra Hospital, from my own position, that are unmet and unable to be met within the current structures that are available to us and the resources available to us.

Canberra Hospital is an acute hospital. With the evolving understanding of palliative care being more than just care for people who are close to dying, that in fact there are some people who have palliative needs and who also have acute needs, those will never be able to be adequately met in a subacute or hospice-type environment because their needs are too acute for that environment.[151]

7.33 In further comment, Dr Chapman noted that;

Further on that, unfortunately, again my personal impression is that the current services and palliative care services in Canberra Hospital are stretched, they are under pressure and some kind of additional resourcing for those services is quite sorely needed. A palliative care ward would be one way of doing that but, if that is not the way that it is going to be enacted, another way certainly needs to be enacted, because there is a very genuine need.[152]

7.34 The Committee also heard evidence from the current manager of Clare Holland house that a dedicated palliative care ward may not be a necessity:

I am not really sure that there is enough need for a dedicated ward at both Calvary and TCH for palliative care patients. I think we have got to understand that palliative care is a very broad topic. The philosophy is that patients should be referred to palliative care early. Not everybody that is a palliative care patient actually requires to be in a ward or in a bed.[153]

[151] *Transcript of Evidence*, 12 July 2018, p. 396
[152] *Transcript of Evidence*, 12 July 2018, p. 398.
[153] *Transcript of Evidence*, 12 July 2018, p. 366

Recommendation 17

7.35 The Committee recommends that the ACT Government review whether a dedicated palliative care ward should be established in The Canberra Hospital.

SUPPORT FOR PALLIATIVE CARE STAFF

7.36 The committee has discussed at some length the configuration of current palliative care provision in the ACT, and proposals for its improvement and the need for a different approach to the structure and future development of palliative care, including establishment of a dedicated palliative care facility at The Canberra Hospital.

7.37 During this inquiry the Committee did hear of particular and persistent problems with present palliative care arrangements in The Canberra Hospital, including an over-emphasis on geriatric ward treatment , the lack of specialised palliative care nursing staff either in each area of the hospital likely to treat terminal patients requiring palliative care, the shortage of specialty clinical nursing staff with principal responsibility for palliative care and several accounts of delay, wrong or non-existent treatment and failure to have palliative care as an ongoing, properly recognised nursing specialty. The Committee should add that several of these comments were made confidentially, but were constant and from several experienced current health personnel.

7.38 The pressure on hospital staff carrying out palliative care is stressful, demanding and requires a suite of skills which go beyond specialist nursing care training and experience. A representative of the Australian Nursing and Midwifery Federation summed up the challenges of palliative care nursing – and staffing pressures associated with that work as follows:

> You have got the family that comes through the door and are in distress and you want to spend time with them and you want to talk to them about what is going on for their family member, where you see things are at, at this point. They want to speak to the doctor, so you need to try and get hold of the team managing the care to come and talk to the family. It is heavily resource intensive. Nurses do it because that is the essence of nursing. But the pressures can really be very difficult to manage. They provide, in some cases, the level of care that you believe this person deserves. That is while a person is moving into death. And then there are a whole range of things that need to go on after that. The level of staffing around that is often not up to what you need to provide the level of care. [154]

[154] Transcript of Evidence, 17 May 2018, p. 67.

COMMITTEE COMMENT

Palliative care continues to be a stressful, demanding and often traumatic form of health care, and submissions given to the committee by nursing, medical, in-home care providers and others indicated that such support is essential.

Recommendation 18

7.39 The Committee recommends that the ACT Government review and improve the counselling and support services available to all healthcare workers involved in palliative care to ensure it is adequate for demand and individual needs.

ACCESS AND REFERRAL TO CLARE HOLLAND HOUSE

7.40 The Committee heard contrasting evidence regarding access and referrals to Clare Holland House. Some witnesses suggested that they knew of, or had personal experience with, difficulty accessing Clare Holland House. Other witnesses claimed that there are no serious access issue and that Clare Holland House is capable of meeting demands for beds. The Committee also heard that the referral process between The Canberra Hospital and Clare Holland House could be improved.

7.41 Ms Glenda Stevens, Chief Executive Officer, Palliative Care ACT, expressed concerns regarding this issue:

> Access to Clare Holland House is a problem. There appear to be issues with referral pathways and issues with bed numbers. We do not have another hospice here in the ACT, and we do not have a short-term hospice which is non-clinical, somewhere where someone can just go for a rest. Clare Holland is a clinical environment, which means that there are a lot of medical interventions.[155]

7.42 Dr Adele Stevens, Consumer Representative, Health Care Consumers' Association, suggested that, while there was previously an access problem to Clare Holland House, the situation has recently improved. She informed the Committee that

> …there was a period where it was really difficult to get people into Clare Holland House and they started using National Capital Private Hospital for palliative care. That has happened in the last couple of years, using services in the private sector when people are in Canberra Hospital and cannot get into Clare Holland House. I think it is a bit better at the moment, but there was a time a couple of years back when it was really

[155] Ms Glenda Stevens, Chief Executive Officer, Palliative Care ACT, *Transcript of Evidence*, 17 May 2018, pp. 40-1.

difficult and they started using the private sector. It is good for people with private health insurance but not for others.[156]

7.43 Other witnesses suggested that access to Clare Holland House remains a current problem, resulting in unnecessary trauma for those at the end of their life and their families. The Higgs-Hein family recounted to the Committee their problems gaining access to the hospice for a family member who died early in 2018 until a religious minister intervened on their behalf. Mrs Michelle Heine detailed their access problems:

> I went and visited them. I put in submissions and spoke with the staff at the hospital. We just kept being pushed back, "No, no, no, no, no, no, no," until eventually we asked the minister to come and read the last rites to my dad. He came back the next day and said, "What is going on?" That is when we explained what had been happening in the lead-up to the situation we were in. Within 45 minutes of speaking with him, we had a call to say that there was a bed for him. They said, "We will send an ambulance at 5 o'clock." He said, "No, send the ambulance now."[157]

7.44 Mrs Heine explained that she had contacted the head of Clare Holland House on the morning her father was admitted to the hospice and

> …was told emphatically, "I'm sorry, there are no beds whatsoever". That was at 9 o'clock that morning. And then once the chaplain came in, we already knew by 11 o'clock my dad was going to be moving after he had stepped in'.
>
> We had social workers, we had people suddenly just descend on that room. I would go, "Why didn't we have that beforehand?..." My dad had the death rattle for four or five days. To sleep in a room and hear this 24/7 is heartbreaking.[158]

7.45 When asked what was needed to improve the provision of palliative care services in the ACT, Mrs Heine responded:

> …definitely more places like Clare Holland House. I cannot tell you the difference it made to our family. The minute we walked through that front door at Clare Holland House, I felt such relief at the fact that he was actually there. The staff are incredible. They are absolutely incredible at Clare Holland House. I just wish we could have had a bit more of that and not just literally have gone there overnight.[159]

7.46 Dr Michael Chapman, Director of Palliative Care, Division of Cancer, Ambulatory and Community Health Support, Canberra Hospital and Health Services, explained that the

---

[156] Dr Adele Stevens, Consumer Representative, Health Care Consumers' Association, *Transcript of Evidence*, 25 May 2018, p. 225.

[157] Mrs Michelle Heine, *Transcript of Evidence*, 31 May 2018, p. 281.

[158] Mrs Michelle Heine, *Transcript of Evidence*, 31 May 2018, p. 284.

[159] Mrs Michelle Heine, *Transcript of Evidence*, 31 May 2018, p. 282.

limited number of beds and short-term nature of the care offered by Clare Holland House result in the difficulty in negotiating a place at Clare Holland House:

> It is 19 beds and, like the acute hospital, it is a short-term facility. It is not a place a person can go to for a long, long time. That often puts people in the unenviable situation of recognising that they would like to be at Clare Holland House and they would like to be there as soon as they can be and yet, because of the context of the needs they have or the uncertainty of exactly how long they might need that bed for, it is difficult to determine exactly when would be the right time for them to go.[160]

7.47 Dr Chapman elaborated on how Clare Holland House has become a victim of its own success, with strong demand for places, even from those whose needs may not qualify them for a bed:

> …if we recognise that Clare Holland House is the gold standard of care that provides an excellent service—just about everyone I have ever spoken to thinks that the care is excellent—lots of people want to go there. And yet if, for instance, a person's care needs are such that they do not necessarily need to be at Clare Holland House anymore because their needs have changed, there is no good next step available.[161]

7.48 On the ability of Clare Holland House to meet demand for beds, Dr Chapman informed the Committee that 'the occupancy rate of that service [Clare Holland House] is often around 80 per cent, so there is often capacity within that service in terms of physical beds'. He also suggested, however, that 'it is likely that the need is much greater than we recognise'.[162]

7.49 In response to a Question Taken on Notice concerning the adequacy of bed availability at Clare Holland House, the Minister for Health and Wellbeing, Meegan Fitzharris MLA, informed the Committee that

> The current and past bed occupancy at Clare Holland House is adequate to meet demands placed upon it.[163]

7.50 Ms Jane Etchells, Manager, Clare Holland House, echoed this position. She informed the Committee that

---

[160] Dr Michael Chapman, Director of Palliative Care, Division of Cancer, Ambulatory and Community Health Support, Canberra Hospital and Health Services, *Transcript of Evidence*, 1 June 2018, p. 344.

[161] Dr Michael Chapman, Director of Palliative Care, Division of Cancer, Ambulatory and Community Health Support, Canberra Hospital and Health Services, *Transcript of Evidence*, 1 June 2018, pp. 344-5.

[162] Dr Michael Chapman, Director of Palliative Care, Division of Cancer, Ambulatory and Community Health Support, Canberra Hospital and Health Services, *Transcript of Evidence*, 1 June 2018, p. 342.

[163] Mr Chris Bone, Deputy Director-General, Canberra Hospital and Health Services, ACT Health, *Transcript of Evidence*, 1 June 2018, p. 359; Minister for Health and Wellbeing, Meegan Fitzharris MLA, Answer to Question Taken on Notice, Committee Public Hearing 1 June 2018, 21 June 2018.

> We use palliative care outcomes collaborative data, and that says we get 90 per cent of patients into Clare Holland House within 24 hours of referral. I think the evidence is quite strong that beds are available.
>
> …
>
> My personal opinion is there is not a huge issue with patients getting beds in Clare Holland House.[164]

7.51 Ms Glenda Stevens, however, suggested that lack of bed availability may not be the only factor inhibiting people from accessing Clare Holland House. She explained what she conceived as a factor in the access issue to the hospice:

> …difficulty accessing Clare Holland House does appear to be a problem and we do know that it is not always the access issue—I am trying to be politically correct—it is not always a bed issue, that other factors are affecting the non-acceptance of patients. Last week we had a phone call from the Canberra Hospital from one of their palliative nurses, "We've been trying since Monday to get this man into Clare Holland. He is very close to death. He is a young man and he needs to not be in hospital for this and why can we not get him in there?" They rang us to see if we had any ability and after out phone call he was admitted the next day. But we did know that during that period he had not been admitted there were beds available.[165]

7.52 As recently announced, Clare Holland House is set to undergo a $6 million expansion, its first since opening in 1995, which will add eight to 12 beds to its current capacity of 19. The Federal Government will provide $4 million and the Snow Foundation $2 million to facilitate the expansion, while the ACT Government will fund the extra staff for the expanded facility.[166]

7.53 Clare Holland House informed the Committee of potential issues with the referral process form The Canberra Hospital to Clare Holland House. Ms Jane Etchells, Manager, Clare Holland House, told the Committee that

> …TCH probably does not have enough medical consultants to look after the patients who are in their team. Often they do not get to see their patients and make their referrals until the end of the week. Sometimes we might get three referrals on a Friday afternoon, at which time it is very difficult for us to necessarily take those people in the Clare Holland House because we do not have medical staff on 24 hours a day; we have medical staff on Monday to Friday, 8 till 5.30, and then on call after hours.
>
> …

---

[164] Ms Jane Etchells, Manager, Clare Holland House, *Transcript of Evidence*, 12 July 2018, pp. 367-8.

[165] Ms Glenda Stevens, Chief Executive Officer, Palliative Care ACT, *Transcript of Evidence*, 17 May 2018, p. 47.

[166] Katie Burgess, 'Up to 12 new beds in $6 million expansion of Clare Holland House', *Canberra Times* (Canberra, 25 September 2018), <https://www.canberratimes.com.au/politics/act/up-to-12-new-beds-in-6-million-expansion-of-clare-holland-house-20180924-p505px.html>, viewed 21 November 2018.

> …if they had more medical staff and their rounds were done more frequently, earlier in the week, they would be making referrals earlier in the week and we could plan better into Clare Holland House.[167]

7.54 The Health Care Consumers' Association addressed the issue of access and referral to Clare Holland House in a report attached to their submission to the Inquiry. Reflecting the feedback of health care consumers, they noted that

> …timely and predictable access to hospice as an alternative to hospital-based palliative care was highly valued, as were smooth transitions between these sites. Given that delayed transfers from TCH to the Clare Holland House was a concern for some consumers and carers, it is suggested that these agencies collaborate on an ongoing basis to ensure protocols and practices deliver seamless transfers between these sites of care, and report regularly to consumer organisations about progress on this issue.[168]

7.55 When asked about admissions into Clare Holland House and if people are ever refused admission, Ms Etchells noted that

> …we have admission criteria for Clare Holland House, and the admission criteria for Clare Holland House may not accord with the wish of the patients who want to come into Clare Holland House…
>
> The fact is that we have 19 beds and we are under the restriction of activity-based funding. We cannot have people come to Clare Holland House and stay for months and months. We have to use our admission criteria to say, "This person has a high symptom burden and they need to come over because they need our expertise," or "This person is reaching the last two to three weeks of their life and they can't be managed at home, so they need to come to Clare Holland House."[169]

7.56 When asked whether it was Clare Holland House policy to respond to requests for admission coming from priests, Ms Etchells and Ms Suzanne Greenwood, Chief Executive Officer, Catholic Health Australia, responded that it was not. Alluding to the experiences of the Higgs-Heine family mentioned above, Ms Greenwood suggested that

> With what the family may have been seeing in that situation, where they interpreted it as being delays in Canberra Hospital referring them on, it may have actually been Canberra Hospital assessing the clinical needs of the person at that point in time as not, as you say, meeting the criteria for entry into Clare Holland House. It may have just been a coincidence—you do call a priest when it is the end days—so it had probably

---

[167] Ms Jane Etchells, Manager, Clare Holland House, *Transcript of Evidence*, 12 July 2018, pp. 367-8.

[168] Health Care Consumers' Association, *Submission 455*, attachment, Spiller, Sarah, 'Consumer and Carer Experiences and Expectations of Home-based Palliative Care in the ACT', 22 December 2017, ACT: Health Care Consumers' Association, p. 23.

[169] Ms Jane Etchells, Manager, Clare Holland House, *Transcript of Evidence*, 12 July 2018, pp. 368-9.

just naturally reached a point where it was appropriate for the clinicians at the hospital to transfer to Clare Holland.[170]

Recommendation 19

7.57 The Committee recommends that the ACT Government conduct an independent investigation of Clare Holland House's capacity to meet future demand for palliative care services.

Recommendation 20

7.58 The Committee recommends that Clare Holland House receive adequate future funding to allow for additional operating costs associated with an expanded Clare Holland House.

PALLIATIVE CARE FOR PEOPLE WITH DISABILITIES

7.59 People with disability face discrimination and inequality in almost all facets of life, including in the medical and end of life care they receive. The Committee heard evidence that while people with disability should have better—equal—access to palliative care, there is also a fundamental need to improve equality of access to medical treatment at all stages of life, to ensure that people with disability are not rushed into facing the need for palliative care earlier than other members of the community.

7.60 ADACAS explained the systemic discrimination faced by people with disability:

> People with disability often experience systemic discrimination based on the values that society holds. These values may not be explicit but they lead to behaviours which indicate that the worth of the life of a person with disability is somehow less than the life of other people in the community. This discrimination is already felt by people with disability interacting with the service system and with the health system, where they may for instance not be considered suitable candidates for particular treatment options because of they live with disability.[171]

7.61 This discrimination acts as a barrier for people with disability in accessing medical treatment, generally. ADACAS submitted that 'current medical practices do not offer access to support, when and where it is needed, for participation in care choices at any point in life'. Mr Craig Wallace, National Convenor, Lives Worth Living, similarly

[170] Ms Suzanne Greenwood, Chief Executive Officer, Catholic Health Australia, *Transcript of Evidence*, 12 July 2018, p. 369.
[171] ACT Disability Aged and Carer Advocacy Service, *Submission 231*, p. 1.

informed the Committee that 'for many people with disability we have actually got really poor access to health care and health support'.[172]

7.62 Mr Wallace provided concrete examples of the type of barriers that people with disability face daily in accessing equal medical treatment:

> Most doctors do not have height adjustable exam beds, so I cannot get out of wheelchair and get up and have a full examination where they poke around and say 'Are things going on in your abdomen that we need to be concerned about in terms of cancer?' They bowel screening kits that the commonwealth government sends out to over 55s have sharp implements in them and they are not in braille, so blind people cannot use them.[173]

7.63 Ms Helen Connolly, Projects Coordinator, ADACAS, informed the Committee that, specifically in relation to palliative care, 'the additional support that people with disability might require to access those services, to understand those services and to consider the options attached to that is not available'. She further commented, that 'guardians, family members, have certainly contacted us about their concern that palliation was not discussed, was not offered or was offered too quickly'.[174]

7.64 Both Lives Worth Living and ADACAS informed the Committee that Australia has obligations under the United Nations Convention on the Rights of Persons with Disabilities to ensure that the equal rights of people with disability in Australia are respected and promoted, including access to best-quality medical treatment.[175]

7.65 Australia ratified the United Nations Convention on the Rights of Persons with Disabilities on 17 July 2008, thereby agreeing to 'adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognized in the present Convention'.[176]

7.66 The provisions of the Convention include, *inter alia*, that

- States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others;

---

[172] ACT Disability Aged and Carer Advocacy Services, *Submission 231*, p. 2; Mr Craig Wallace, National Convenor, Lives Worth Living, *Transcript of Evidence*, 25 May 2018, p. 210.

[173] Mr Craig Wallace, National Convenor, Lives Worth Living, *Transcript of Evidence*, 25 May 2018, p. 214.

[174] Ms Helen Connolly, Projects Coordinator, ACT Disability Aged Carer Advocacy Service, *Transcript of Evidence*, 25 May 2018, p. 205.

[175] ACT Disability Aged and Carer Advocacy Services, *Submission 231*; Lives Worth Living, *Submission 314*.

[176] United Nations, 'Convention on the Rights of Persons with Disabilities', <https://treaties.un.org/Pages/ViewDetails.aspx?src=IND&mtdsg_no=IV-15&chapter=4&lang=en#EndDec>, viewed 30 November 2018.

- States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability.[177]

7.67 In fulfilment of Australia's international obligations, members of our community with disability should have equal access to palliative care—as an equal right. These obligations extend much further, however. As Mr Craig Wallace emphasised, this equality of access should, as a matter of priority, cover all spheres of the health system to ensure people with disability do not require palliative care prematurely, but are able to live for as long and healthily as possible. He argued:

> My point is that the end of life comes to people with disability as a result of inherent discrimination and blockages in the health and other systems that would stop them getting sick. At the moment we have people with disabilities who cannot access annual health checks to find out if they have a cancer that is developing and that could be managed.[178]

7.68 While expressing opposition to any attempt to implement VAD for disable people in the ACT, Lives Worth Living elaborated on what they see should be the priority for Government:

> We would prefer that Parliaments addressed secondary comorbidity, barriers and lack of supports experienced by people with a disability rather than provide a mechanism for suicide because of them. Instead of safeguards, we need to be talking about preconditions. Like the precondition that half of us no longer live in poverty, have good access to medical treatment and palliative care, that we have the care and support to live a good life.[179]

Recommendation 21

7.69 The Committee recommends that the ACT Government consider and seek to reduce or remove the existing barriers to accessing good health care faced by people with a disability, including infrastructure at ACT health facilities, the quality of care provided and the risks of direct or indirect discrimination.

[177] United Nations Convention on the Rights of Persons with Disability, Articles 10 and 25, <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>, viewed 30 November 2018.

[178] Mr Craig Wallace, National Convenor, Lives Worth Living, *Transcript of Evidence*, 25 May 2018, p. 212.

[179] Lives Worth Living, *Submission 314*, p. 7.

PALLIATIVE CARE MODEL FOR THE ACT – IMPLEMENTATION

7.70 The Committee has discussed the plan to finalise and implement a Model of Palliative Care for the ACT during the inquiry.

7.71 ACT Government submission has noted:

> ACT Palliative Care Network, headed by a Clinical Leader involves clinicians working flexibly across the various service delivery settings to provide a cohesive service and address operational issues as they arise. Under the guidance of the Network, ACT Health developed a Model of Palliative Care for the ACT and Surrounding Region (Model), and Model of Palliative Care – Implementation Roadmap (Roadmap), which were completed in 2016. The Model and associated Roadmap will be used to inform the development of a new Territory-wide Model of Palliative Care Specialist Services Plan, which will effectively replace the ACT Palliative Care Services Plan 2013-17.[180]

7.72 The model is contained in the publication Development of a Model of Palliative Care for the ACT and Surrounding Region (March 2016).

7.73 In addition, ACT Health is proposing the following programs, including a specialised service plan for palliative care:

> ACT Health will be developing a SSP for Palliative Care. Significant consultation will occur during the development of the Palliative Care SSP, including internal and external stakeholders to ACT Health. It is expected that the wider community (service providers, nongovernment organisations and advocacy groups) will have the opportunity to participate in the SSP development process through a consultation period currently planned for late April 2018. In considering the SSP for Palliative Care, ACT Health will also consider broader management of end of life care, including the management of chronic pain, as well as continuing to improve inpatient care.

7.74 The Committee notes that the Committee discussed the Model plan with the Minister and officials to ascertain its scope and timing:

> There is a process where, over 12 months, it will be implemented. The first component of it is looking at the governance of services across the ACT and how to improve that networking of services to ensure that there are a range of people working to provide that front-line service to the community. That acknowledges that it is made up of GP services, community services, hospital-based services, and palliative care through Calvary. It is about really focusing on a holistic approach to palliative care.[181]

---

[180] ACT Government, *Submission 151*, p. 10.

[180]

[181]

7.75 The plan is published by the Committee, it having been provided to the Committee as a document provided as part of answer to a Question on Notice at the Committee's discussions with the Minister.

OTHER OBSERVATIONS

7.76 The Committee heard evidence that there was concern among sections of the community regarding the fact that the ACT's only hospice is managed by a religious organisation, leaving those who would prefer a purely secular option with no choice. In response to a question on whether some people are reluctant to go to Clare Holland House due to its religious affiliation, Ms Glenda Stevens answered, 'anecdotally we hear that'. This opinion was also expressed by COTA, which submitted that 'while feedback on services provided by Clare Holland House is very positive, some people have expressed a preference to access hospice services provided by a non-religious service provider'.[182]

7.77 Dementia Australia informed the Committee of the limited use of specialist palliative care services for those suffering with dementia: 'in comparison to patients with cancer, the proportion of people with a diagnosis of dementia using specialist palliative care services is low (75.4% versus 2.4%)'. They continued:

> …people with dementia still struggle to access palliative care or receive care in a timely fashion; they are given inappropriate life-sustaining or intrusive procedures; and they receive inadequate pain management. Encouraging improvements in the quality and appropriateness of care keep us hopeful, yet there is still much work to be done to improve the quality of care provided to people with dementia at the end of their lives.[183]

7.78 Dementia Australia also pointed out that many people with dementia will spend their final days in a residential aged care facility. Due to this fact, they note, 'it is therefore imperative that residential aged care staff are appropriately skill and trained to deliver palliative care to people with dementia'.[184] Elaborating on this point before the Committee, Ms Petrea Messent, Regional Director and General Manager, Client Services, Dementia Australia, suggested:

> I guess the level of education and support provided in that environment is probably the main area where we see a gap. That is probably something that is a bit more

[182] Ms Glenda Stevens, Chief Executive Officer, Palliative Care ACT, *Transcript of Evidence*, 17 May 2018, p. 47; Council of the Ageing, *Submission 342*, pp. 2-3.

[183] Dementia Australia, *Submission 427*, p. 5.

[184] Dementia Australia, *Submission 427*, p. 6.

quantifiable—the level of expertise, skill and knowledge around palliative care and particularly around pain management.[185]

7.79 The Committee heard from witnesses about the complicated interactions between cases of neurodegenerative conditions—such as dementia— and mental illness and the provision of palliative care services. As Ms Petrea Messent noted: 'Obviously, there are some particular challenges around palliative care and what services and so forth you are providing for people who [are] having difficulty making decisions, accepting treatment and accepting assistance full stop'.[186]

7.80 Speaking to this issue, Mr Matthew Daniel, Secretary, Australian Nursing and Midwifery Federation (ACT), informed the Committee of the difficulty in assessing such patient's mental capacity and how this impacts their treatment:

> I myself nursed someone who was being palliated on an acute care ward, and there were all sorts of questions swirling around about whether this person had capacity, because of mental illness, with that condition at that particular time, of wanting to refuse treatment. That was no quick fix. It is difficult.[187]

7.81 Mr Daniel suggested that, while such situations are complicated, improvements can be made. He noted:

> …if I can draw on that one example to provide what I believe would have been the fix in that situation, it is quicker access to specialist services. At that point, it probably went on for a week, not knowing whether this person had the capacity to decline medical and nursing interventions. We needed a psychiatric review, and that took too long. We need specialist services that might come along with that, such as social workers to talk with families about their understanding of the situation. We need arrangements so that those things that needed to happen, and eventually did happen, occur in a much more timely manner.[188]

COMMITTEE COMMENT

7.82 The development of the model plan for palliative care provides a basis for a range of issues which the Committee considers should be addressed as an aspect of proposed improvement and change to palliative care in the ACT

---

[185] Ms Petrea Messent, Regional Director and General Manager, Client Services, Dementia Australia, *Transcript of Evidence*, 24 May 2018, p. 172.

[186] Ms Petrea Messent, Regional Director and General Manager, Client Services, Dementia Australia, *Transcript of Evidence*, 24 May 2018, p. 171.

[187] Mr Matthew Daniel, Secretary, Australian Nursing and Midwifery Federation (ACT), *Transcript of Evidence*, 17 May 2018, p. 62.

[188] Mr Matthew Daniel, Secretary, Australian Nursing and Midwifery Federation (ACT), *Transcript of Evidence*, 17 May 2018, p. 62.

Recommendation 22

7.83 The Committee recommends that the ACT Government invest in a community awareness campaign about what palliative care is and what it entails, including the choices available to ACT residents.

Recommendation 23

7.84 The Committee recommends the ACT Government review and report on all aspects of palliative care delivery in the ACT, including programs, demand, funding and delivery and include specific reporting on palliative aged care and child and adolescent palliative care.

Recommendation 24

7.85 The Committee recommends that the ACT Government assess and review the network of healthcare specialists in the ACT involved in delivering palliative care across all settings, including for paediatrics and adolescents, to:

- **compare the ACT to other jurisdictions;**
- **make improvements to foster better networking and connectivity between patients and their families and carers, healthcare professionals and organisations; and,**
- **ensure timely referrals and access to hospice services.**

8 VOLUNTARY ASSISTED DYING—BACKGROUND

INTRODUCTION

8.1 This chapter provides an overview of the history of legislation concerning Voluntary Assisted Dying (VAD) within the ACT Legislative Assembly and more widely in other Australian jurisdictions. As is discussed below, VAD has been the subject of prolonged and intensive debate within the Assembly for more than a quarter of a century. As exemplified in this report, the Committee's inquiry process and recent debates in the Legislative Assembly and the Australian Senate, this discussion continues.

HISTORY OF LEGISLATIVE APPROACHES TO VOLUNTARY ASSISTED DYING BY THE ACT LEGISLATIVE ASSEMBLY

8.2 In terms of legislation specifically aiming to introduce VAD into the Territory, the Legislative Assembly has dealt with three attempts, dating back to 1993. These bills were:

- Voluntary and Natural Death Bill 1993
- Medical Treatment (Amendment) Bill 1995
- Medical Treatment (Amendment) Bill 1997.

8.3 All of these bills were private members' bills introduced by independent MLA Mr Michael Moore.

8.4 The first bill was presented to the Assembly on 16 June 1993 and referred to committee for inquiry and report.[189] That committee, the Select Committee on Euthanasia, tabled its report out-or-session on 17 March 1994.[190]

8.5 In its report, the Select Committee recommended that the proposed Voluntary and Natural Death Bill 1993 not proceed, concluding that it was

[189] ACT Legislative Assembly, *Hansard*, 16 June 1993, pp.1878, 1884.
[190] ACT Legislative Assembly, *Hansard*, 14 April 1994, p. 817.

> …politically inopportune to proceed with those provisions of the Bill which empower a private citizen, in the terminal phase of a terminal illness, to make a reasoned choice concerning the ending of their life and to seek medical assistance to that end.[191]

8.6 This first attempt to legislate on the issue of VAD ended on 11 May 1994. At that time, in light of the Select Committee's findings, Mr Moore moved in the Assembly that the Voluntary and Natural Death Bill 1993 be removed from the *Notice Paper*.[192]

8.7 The second attempt occurred with the tabling of the Medical Treatment (Amendment) Bill 1995, on 20 September 1995. This bill was preceded by the release of an exposure draft of the bill which was subject to community consultation, debate and feedback.[193]

8.8 Following an intensive debate in the Assembly, the bill was voted down 7 votes to 10 on 22 November 1995.[194]

8.9 The third attempt to introduce VAD to the ACT is discussed in the next section.

AMENDMENT TO THE *ACT SELF-GOVERNMENT ACT 1988* BY THE COMMONWEALTH PARLIAMENT

8.10 On 22 February 1995, Northern Territory Chief Minister Marshall Perron tabled a private members' bill—the Rights of the Terminally Ill Bill 1995—to the NT Legislative Assembly. The bill was passed by the Assembly on 25 May 1995 and on 1 July 1996, the NT became the first jurisdiction in the world to introduce a legislated VAD scheme, when the *Rights of the Terminally Ill Act 1996* came into force.[195]

8.11 In response to the passing of the NT legislation, Mr Kevin Andrews, Member for Menzies in the House of Representatives, introduced a private members' bill—the Euthanasia Laws Bill 1996—into the Federal Parliament on 9 September 1996. This bill, widely referred to as the Andrews Bill, contained three schedules to amend the self-government acts of the ACT and the NT and the *Norfolk Island Act 1979* to place prohibitions on the legislatures of the ACT, the NT and Norfolk Island in passing any legislation to introduce a VAD scheme into those jurisdictions.

---

[191] Select Committee on Euthanasia, *Voluntary and Natural Death Bill 1993*, Report, Canberra: ACT Legislative Assembly, March 1994, pp. 6-7.

[192] ACT Legislative Assembly, *Hansard*, 11 May 1994, p. 1377.

[193] ACT Legislative Assembly, *Hansard*, 20 September 1995, p. 1524.

[194] ACT Legislative Assembly, *Hansard*, 22 November 1995, pp. 2245-2272, 2289-2309.

[195] Jennifer Norberry and Natasha Cica, 'Bills Digest 45 1996-97 Euthanasia Laws Bill 1996', Bills Digest Service, Parliamentary Research Service, Parliamentary Library, 17 October 1996, <https://www.aph.gov.au/Parliamentary_Business/Bills_Legislation/bd/BD9697/97bd045>, viewed 6 December 2018.

8.12 In protest to the introduction of the Andrews Bill, on 27 October 1996 the NT parliament presented a Remonstrance to the President of the Senate and the Speaker of the House of Representatives. The Remonstrance included seven grievances, the first of which noted:

> The Northern Territory having been granted self-governing powers, the duly elected representatives of the people of the Northern Territory are aggrieved that there should be any attempt to diminish these self-governing powers by the proposed enactment of the Euthanasia Laws Bill 1996.[196]

8.13 The Andrews Bill was referred to the Senate Legal and Constitutional Legislation Committee for inquiry. The ACT Government, represented by Chief Minister Ms Kate Carnell MLA and Attorney-General Mr Gary Humphries MLA, contributed to the Committee's inquiry process and strongly argued against the Bill as anti-democratic and discriminatory for the residents of Australia's territories.[197]

8.14 The ACT Government's submission to Senate Committee's inquiry pointed out the discriminatory nature of the bill. It highlighted the:

> …incongruous situation…that the Representatives and Senators who vote in favour of it will reserve to their own States the power to make laws permitting euthanasia at any time, while denying that power to the Territories—jurisdictions that they do not represent.[198]

8.15 The Senate Committee's report was tabled in March 1997. The Committee made no recommendations on the Euthanasia Laws Bill 'because it is a private member's Bill and is subject to a "conscience vote"'.[199]

8.16 Following amendments and a conscience vote, the Andrews Bill was given assent by the Parliament on 27 March 1997. The resultant *Euthanasia Laws Act 1997* amended the *Australian Capital Territory (Self-Government) Act 1988* with the addition of two clauses to subsection 23(1):

> 1A The Assembly has no power to make laws permitting or having the effect of permitting (whether subject to conditions or not) the form of intentional killing of another called euthanasia (which includes mercy killing) or the assisting of a person to terminate his or her life.

---

[196] Legislative Assembly of the Northern Territory, *The Remonstrance*, 10 October 1996, p. 2, <http://www.territorystories.nt.gov.au/jspui/bitstream/10070/288883/1/A_proposed_Remonstrance_for_presentation_to_the_Federal_Parliament.PDF>, viewed 7 December 2018.

[197] Senate Legal and Constitutional Legislation Committee, *Euthanasia Laws Bill 1996*, Canberra: Parliament House, March 1997.

[198] ACT Government cited in Senate Legal and Constitutional Legislation Committee, *Euthanasia Laws Bill 1996*, Canberra: Parliament House, March 1997, p. 20.

[199] Senate Legal and Constitutional Legislation Committee, *Euthanasia Laws Bill 1996*, Canberra: Parliament House, March 1997, p. 114

1B The Assembly does have power to make laws with respect to:

(a) the withdrawal or withholding or medical treatment or surgical measures for prolonging the life of a patient but not so as to permit the intentional killing of the patient; and

(b) medical treatment in the provision of palliative care to a dying patient, but not so as to permit the intentional killing of the patient; and

(c) the appointment of an agent by a patient who is authorised to make decisions about the withdrawal or withholding of treatment; and

(d) the repealing of legal sanctions against attempted suicide.[200]

8.17 Prior to the release of the Senate Committee's findings on the Andrews Bill and the subsequent passage of that bill through Federal Parliament, the third and final attempt to pass VAD legislation in the ACT Legislative Assembly occurred. On 19 February 1997, Mr Michael Moore tabled a private members' bill—the Medical Treatment (Amendment) Bill 1997.[201]

8.18 The Bill was debated in the Assembly chamber on 26 February 1997 and discharged from the *Notice Paper* by Mr Moore on 9 April 1997.[202] Mr Moore noted at the time that

> The discharge of this legislation is a sad day for individual and for Territory rights. Discharge of the Medical Treatment (Amendment) Bill marks the end in this Assembly of the debate on voluntary active euthanasia.[203]

8.19 Appearing before the Committee, Mr Moore reflected on his final attempt to introduce legislation for VAD in the ACT and the passing of the Andrews Bill:

> If I can go back to 1997, when that legislation was passed, and the ACT was on the cusp of supporting voluntary active euthanasia, or not supporting it, it was actually impossible—and I can tell you, as it was my legislation, I was counting the votes—I to know what the outcome was going to be; it was that close, when the Andrews Bill was introduced. At that point I sought leave to remove my legislation because, in discussion with the other members of the Assembly, we did not want the community to believe that we would somehow have the power to do it. It was very clear that the self-government act had been changed, and we did not have the power.[204]

[200] *Euthanasia Laws Act 1997*, Schedule 2.

[201] ACT Legislative Assembly, *Hansard*, 19 February 1997, p. 84.

[202] ACT Legislative Assembly, *Hansard*, 26 February 1997, pp. 430-453, 489-508; ACT Legislative Assembly, *Hansard*, 9 April 1997, p. 743.

[203] ACT Legislative Assembly, *Hansard*, 9 April 1997, p. 744.

[204] Mr Michael Moore, *Transcript of Evidence*, 12 July 2018, p. 400.

8.20 At several point in the Inquiry, the Committee sought statements from expert witnesses on the legitimacy of the federal legislation prohibiting the ACT's ability to legalise VAD. All witnesses were unequivocal on the absolute constitutional jurisdiction of the Commonwealth to pass laws in relation to the territories. Dr Terence Dwyer, for instance, explained:

> Commonwealth power over the territories is plenary…Fundamentally, if there is a clear Commonwealth law binding the territory—the territory is not a state—it is fully subject. Under, I think it is, clause 122 of the constitution, the Commonwealth can do what it likes. The Commonwealth Parliament can do what it likes.
>
> This parliament could be abolished tomorrow and all its acts…reduced to ordinances and altered by ministerial signature. There is no question of the competence and the constitutional validity of the commonwealth law.[205]

8.21 ACT Attorney-General, Mr Gordon Ramsay MLA, also explained the legal situation of the ACT:

> …the ACT cannot currently legislate for voluntary assisted dying due to the law-making restrictions that have been placed on the ACT Legislative Assembly by the Commonwealth Parliament. Section 122 of the Australian Constitution enables the Commonwealth Parliament to override any territory law, which it did be enacting the *Euthanasia Laws Act 1997*.[206]

8.22 Similarly, Mr Marshall Perron, former Chief Minister of the Northern Territory, informed the Committee:

> Section 122 of the Constitution certainly gives the Commonwealth Parliament the power to make laws for the territories. That is standing and unquestioned in my view.[207]

8.23 Mr Perron, however, also went on to argue that

> The Euthanasia Laws Act is a valid act of Federal Parliament; it is just morally wrong in my opinion and democratically wrong for obvious reasons. The 660,000 Australians who have decided to live in the territories should not be discriminated against compared to the 24 million who do not live in the territories. It is as simple as that to me.[208]

8.24 Mr Perron's view is one that is shared by the ACT Government. ACT Attorney-General, Mr Ramsay, informed the Committee of the ACT Government's view:

---

[205] Dr Terence Dwyer, *Transcript of Evidence*, 25 May 2018, p. 192.
[206] Mr Gordon Ramsay MLA, ACT Attorney-General, *Transcript of Evidence*, 12 July 2018, p. 373.
[207] Mr Marshall Perron, *Transcript of Evidence*, 26 July 2018, p. 423.
[208] Mr Marshall Perron, *Transcript of Evidence*, 26 July 2018, p. 423.

> The Government is strongly of the view that, regardless of one's views on voluntary assisted dying, Canberrans should be afforded equality under the law to legislate on this issue if the community desires. And we have agitated this view with our Commonwealth counterparts repeatedly over the years since the Euthanasia Laws Act was passed.[209]

8.25 There have been several attempts at the federal level to repeal the *Euthanasia Laws Act 1997*. In February 2008, for instance, Senator Bob Brown introduced the Rights of the Terminally Ill (Euthanasia Laws Repeal) Bill 2008. This bill did not achieve the required support to pass through the Senate and lapsed at the end of 42nd Parliament in 2010.

8.26 Following the convening of the 43rd Federal Parliament, Senator Brown tabled two bills designed to extend territory rights. Introduced on 29 September 2010, These bills were

- Restoring Territory Rights (Voluntary Euthanasia Legislation) Bill 2010; and
- Australian Capital Territory (Self-Government) Amendment (Disallowance and Amendment Power of the Commonwealth) Bill 2010 (later called the Territories Self-Government Legislation Amendment [Disallowance and Amendment of Laws] Bill 2011).[210]

8.27 On 4 December 2011, the latter bill was passed by the Federal Parliament, thereby amending the *Australian Capital Territory (Self-Government) Act 1988*. This Act repealed section 35 of the ACT Self-Government Act, thus removing

> …the Governor-General's power under the *Australian Capital Territory (Self-Government) Act 1988* to disallow or amend any Act of the Legislative Assembly for the Australian Capital Territory.[211]

8.28 This Act did not remove the prohibition placed on the ACT Legislative Assembly in passing legislation to introduce VAD (Self-Government Act subsections 23[1A] and [1B]), nor did it affect the prerogative of the Federal Parliament to pass laws overriding territory law, which is guaranteed under section 122 of the Constitution. The Act removed the discretionary power of federal ministers to intervene to disallow laws passed by the Legislative Assembly.[212]

---

[209] Mr Gordon Ramsay MLA, ACT Attorney-General, *Transcript of Evidence*, 12 July 2018, p. 373.

[210] Australian Parliament House, Restoring Territory Rights (Voluntary Euthanasia Legislation) Bill 2010, <https://www.aph.gov.au/Parliamentary_Business/Bills_Legislation/Bills_Search_Results/Result?bId=s787>, viewed 7 December 2018; Australian Parliament House, Territories Self-Government Legislation Amendment (Disallowance and Amendment of Laws) Bill 2011, <https://www.aph.gov.au/Parliamentary_Business/Bills_Legislation/Bills_Search_Results/Result?bId=s769>, viewed 7 December 2018.

[211] *Territories Self-Government Legislation Amendment (Disallowance and Amendment of Laws) Act 2011*, s. 4.

[212] Diane Spooner, 'Australian Capital Territory (Self-Government) Amendment (Disallowance and Amendment Power of the Commonwealth) Bill 2010', Bills Digest, 73 2010-11, Canberra: Parliamentary Library, 2 March 2011, <https://www.aph.gov.au/Parliamentary_Business/Bills_Legislation/bd/bd1011a/11bd073>, viewed 7 December 2018.

8.29 The Restoring Territory Rights Bill, by contrast, had sought to repeal the Andrews Bill, therefore removing subsections 23(1A) and (1B) from the ACT Self-Government Act. This bill, however, but did not gain the numbers to pass through the Senate. It was removed from the Senate *Notice Paper* on 22 November 2012.[213]

8.30 Of significance, during the Senate Legal and Constitutional Affairs Legislative Committee's inquiry into the proposed ACT (Self-Government) Amendment Bill, that committee heard evidence from commonwealth public servants from the territories division of the Department of Regional Australia who noted that

> What I can say though is that the Australian government has provided advice to the ACT government that the review of the self-government act is something that the ACT government could undertake of itself and that it would welcome any advice of the results of that review and would give it consideration.[214]

8.31 As a result of this statement and independent reviews of the governance structure in the ACT by Professor John Halligan and Dr Allan Hawke conducted in 2011, the Legislative Assembly's Standing Committee on Administration and Procedure resolved to

> …review the *Australian Capital Territory (Self-Government) Act 1988* and any associated regulations, and make recommendations as to whether the Act should be modified since it was enacted by the Commonwealth Parliament on 6 December 1988.[215]

8.32 In its 2012 report, that committee recommended, *inter alia*, the removal of the federal prohibition against VAD legislation in the ACT by the repeal of sections 23(A1) and 23(A2) from the ACT Self-Government Act. The report noted:

> The Committee considers that the ACT Government has demonstrated its maturity in respect to law making over the 23 years of self-government. As a result, the ACT should have equal law making powers to that of the States. This principle of equality with the States dictates that both subsections (1A) and (1B) should be removed.[216]

8.33 More recently, the Assembly has passed several motions requesting the Federal Parliament to repeal the *Euthanasia Laws Act 1997*.

8.34 On 18 September 2014, the Assembly passed a motion calling on the Speaker to

---

[213] Australian Parliament House, Restoring Territory Rights (Voluntary Euthanasia Legislation) Bill 2010, <https://www.aph.gov.au/Parliamentary_Business/Bills_Legislation/Bills_Search_Results/Result?bId=s787>, viewed 7 December 2018.

[214] As cited in ACT Legislative Assembly, *Hansard*, 8 December 2011, p. 6006.

[215] ACT Legislative Assembly, *Hansard*, 8 December 2011, p. 6006; Standing Committee on Administration and Procedure, *Review of the* Australian Capital Territory (Self-Government) Act 1988 *(Cwlth)*, Report 5, Canberra: ACT Legislative Assembly, August 2012, pp. 1-2.

[216] Standing Committee on Administration and Procedure, *Review of the* Australian Capital Territory (Self-Government) Act 1988 *(Cwlth)*, Report 5, Canberra: ACT Legislative Assembly, August 2012, p. 32.

> …write to the Australian Prime Minister and Minister for Health, requesting on behalf of the ACT Legislative Assembly, that the Australian Parliament repeal the limitation imposed by the *Euthanasia Laws Act 1997* and to restore the right of the ACT and other Territories to consider laws on the issue of euthanasia.[217]

8.35 Similarly on 1 November 2017, the Assembly passed a motion for 'the ACT Government and each member of the Legislative Assembly:

a) to raise with Federal political colleagues and counterparts, as appropriate, the increasing paternalistic and unreasonable curtailment of the ACT Legislative Assembly legislative powers, and how poorly this reflects on the Commonwealth Parliament's understanding of the ACT's capacity to govern itself;

b) to convey to the Commonwealth Government and Opposition, at every available and appropriate forum, the need to repeal the *Euthanasia Laws Act 1997* and restore to the Territories the right to make laws in respect to voluntary euthanasia and voluntary assisted dying; and

c) to consider as soon as practicable, upon the passage of a scheme in any Australian State to allow voluntary assisted dying, whether and how the ACT community can have input on a possible model for such a scheme in the ACT'.[218]

PROPOSED REPEAL OF THE PROHIBITION ON EUTHANASIA

8.36 At the federal level, too, there has been a recent attempt to repeal the *Euthanasia Laws Act 1997*. To this end, in December 2015, Senator David Leyonhjelm introduced a private members' bill, the Restoring Territory Rights (Assisted Suicide Legislation) Bill 2015.

8.37 This bill had four stated objects:

a) to reduce Commonwealth interference with the laws of the Australian Capital Territory and the Northern Territory; and

b) to facilitate competitive federalism in law-making; and

c) to recognise the rights of the Australian Capital Territory and the Northern Territory to legislate for assisted suicide within their jurisdiction; and

[217] ACT Legislative Assembly, *Minutes of Proceedings*, No. 70, 18 September 2014, p. 767.
[218] ACT Legislative Assembly, *Minutes of Proceedings*, No. 39, 1 November 2017, p. 522.

d) to repeal the *Euthanasia Laws Act 1997* the enactment of which was inimical to the objects stated in paragraphs (a) to (c).[219]

8.38 The ACT Government welcomed the tabling of this bill, yet was careful to clarify that the Government was not actively considering the introduction of VAD legislation, if the Restoring Territory Rights Bill was to pass the Parliament. Attorney-General, Mr Ramsay, explained this position to the Committee:

> …the ACT Government has not yet formed a view, has not actively considered the area around voluntary assisted dying. It is not a matter that the Government has reached any particular view on and had active conversations about, primarily because we have no legislative authority to pass laws in that matter anyway.[220]

8.39 Mr Ramsay also explained to the Committee, that if the federal prohibition were to be removed and if the ACT Government were to consider the issue, the types of steps which would be necessary. He noted:

> …any consideration of whether or not to legislate for assisted dying would necessarily require thorough exploration of community views and robust consideration of what safeguards might need to be in place to support a scheme for assisted dying in the Territory.
>
> Any such safeguards would have to be closely mindful of the protections contained in the ACT Human Rights Act as a yardstick against which to compare various options.[221]

8.40 This bill was subjected to a conscience vote in the Senate and was defeated at the second reading stage 36 votes to 34 on 15 August 2018.[222]

8.41 In a response to the failure of the Restoring Territory Rights Bill to pass the Senate, the ACT Legislative Assembly passed a motion on 16 August 2018 to present Senator Scott Ryan, the President of the Senate, with a Remonstrance. The Remonstrance was the first in the Assembly's 29-year history.[223]

8.42 The Remonstrance contained five grievances:

1. the Federal Parliament should never determine the rights of Australian citizens based on their postcodes;

---

[219] Restoring Territory Rights (Assisted Suicide Legislation) Bill 2015, s. 3.

[220] Mr Gordon Ramsay MLA, ACT Attorney-General, *Transcript of Evidence*, 12 July 2018, p. 376.

[221] Mr Gordon Ramsay MLA, ACT Attorney-General, *Transcript of Evidence*, 12 July 2018, p. 374.

[222] Senate, *Hansard*, 15 August 2018, p. 4942.

[223] In June 2009, one previous Remonstrance was moved in the Assembly, this was later amended and passed as a regular motion. ACT Legislative Assembly, 'News archive', <https://www.parliament.act.gov.au/Publications/news-archive2>, viewed 10 December 2018.

2. during the debate on the Restoring Territory Rights (Assisted Suicide Legislation) Bill 2015, numerous Senators did one or more of:

    a) conflate their personal views on voluntary assisted dying with restoring Territory rights;

    b) misrepresented the intentions of the Territory parliament if the Bill happened to pass;

    c) quoted one or more debunked sources as a reference point; and

    d) reneged on the position that they had stated to their electors;

3. the Senate has denied the Legislative Assembly for the Australian Capital Territory the ability to debate what is a health and legal issue thanks to Senator's individual personal viewpoints, when the Legislative Assembly for the Australian Capital Territory otherwise freely debates and determines policy on health and justice issues without federal interference;

4. the Senate has refused to properly seek, let alone take into account, the views of 420 000 citizens of the Australian Capital Territory during its debate about Territory rights; and

5. The Senate's unjustifiable position has resulted in the distress of citizens of the Australian Capital Territory.[224]

8.43 Legislative Assembly Speaker, Ms Joy Burch MLA, accompanied by some members of the Legislative Assembly formally presented the Remonstrance to the President of the Senate, Senator Ryan on 13 September 2018. Members of the Northern Territory Legislative Assembly presented that Assembly's Remonstrance to the President of the Senate at the same time.[225]

RECENT HISTORY IN OTHER AUSTRALIAN JURISDICTIONS

8.44 Between June 1993 and the end of 2015 there were 51 attempts to pass bills relating to VAD in parliaments across the country. While some of these bills were for matters such as referenda on the issue, 39 specifically aimed to introduce VAD legislation. Of these

[224] ACT Legislative Assembly, *Minutes of Proceedings*, No. 67, 16 August 2018, p. 952.

[225] ACT Legislative Assembly, 'News archive', <https://www.parliament.act.gov.au/Publications/news-archive2>, viewed 10 December 2018.

attempts, all but the short-lived Northern Territory *Rights of the Terminally Ill Act 1996*, met with failure.[226]

8.45 Since the beginning of 2016, four further VAD bills have been introduced in Australian parliaments: in South Australia, the Death with Dignity Bill 2016; in Tasmania, the Voluntary Assisted Dying Bill 2016; in New South Wales, the Voluntary Assisted Dying Bill 2017; and in Victoria, the Voluntary Assisted Dying Bill 2017. All of these attempts failed, except for the Victorian bill.[227]

8.46 Under the Victorian Act, Australian citizens or permanent residents, ordinarily resident in Victorian, who are 18 years of age or more, can access voluntary assisted dying if

- they have decision-making capacity;
- are diagnosed with a disease, illness or medical condition that—
  - is incurable; and
  - is advanced, progressive and will cause death; and
  - is expected to cause death within weeks or months, not exceeding 6 months (except for neurodegenerative diseases, in which case, not exceeding 12 months); and
  - is causing suffering to the person that cannot be relived in a manner that the person considers tolerable.[228]

8.47 Additionally, since 2015, five Australian State and Territory legislatures have undertaken, or are in the process of conducting, inquiries into the law and policy surrounding end of life choices and palliative care—Victoria, Tasmania (palliative care and advance care planning only), Western Australia, the Australian Capital Territory, and Queensland.[229]

8.48 The Victorian report—*Inquiry into end of life choices*—was tabled in June 2016 by the Legislative Council's Legal and Social Issues Committee. The Committee recommended,

---

[226] Joint Select Committee on End of Life Choices, Parliament of Western Australia, *My Life, My Choice*, August 2018, p. 184; Ben White and Lindy Willmott, 'Future of assisted dying reform in Australia', *Australian Health Review*, 23 November 2018, p. B, <http://www.publish.csiro.au/ah/pdf/AH18199>, viewed 29 November 2018.

[227] Joint Select Committee on End of Life Choices, Parliament of Western Australia, *My Life, My Choice*, August 2018, p. 184; Ben White and Lindy Willmott, 'Future of assisted dying reform in Australia', *Australian Health Review*, 23 November 2018, p. B, <http://www.publish.csiro.au/ah/pdf/AH18199>, viewed 29 November 2018; Queensland University of Technology, End of Life Law in Australia, Recent Developments, 29 November 2018, <https://end-of-life.qut.edu.au/about/recent-developments>, viewed 29 November 2018.

[228] *Voluntary Assisted Dying Act 2017* (Vic.), s. 9.

[229] Queensland University of Technology, End of Life Law in Australia, Recent Developments, 29 November 2018, <https://end-of-life.qut.edu.au/about/recent-developments>, viewed 29 November 2018.

inter alia, that Victoria legislate to introduce VAD. This recommendation was realised in the *Voluntary Assisted Dying Act 2017*.[230]

8.49 In Tasmania, the Standing Committee on Community Development, released its report into palliative care on 13 April 2018. While the report did not deal with VAD, it did provide a wide range of recommendations on Advance Care Planning and palliative care to improve end-of-life choices for Tasmanians.[231]

8.50 On 23 August 2017, both Houses of the WA parliament agreed to establish a joint committee to examine and report on the issue of end of life choices. The Joint Select Committee on End of Life Choices tabled its report—*My Life, My Choice*—in August 2018, recommending the State legislate to introduce VAD.[232]

8.51 In relation to the eligibility criteria for access to VAD, the WA report recommended that

> …the eligibility requirement in the legislation include that the person is experiencing grievous and irremediable suffering related to an advance and progressive terminal, chronic or neurodegenerative condition that cannot be alleviated in a manner acceptable to the person.[233]

8.52 The WA Government has since announced its intention to introduce a VAD bill to the WA Parliament by the second half of 2019. In line with recommendations made by the Joint Select Committee, State Premier Mark McGowan announced that an expert panel will draft a proposed bill. The panel will be chaired by former WA Governor Malcolm McCusker QC and consist of 10 members—experts in aged care, medicine and law.[234]

8.53 In September 2018, Queensland Premier Annastacia Palaszczuk announced a parliamentary inquiry into aged care, end of life and palliative care. On 14 November 2018, the Queensland Legislative Assembly referred the inquiry to the Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee.[235]

---

[230] Legislative Council Legal and Social Issues Committee, Parliament of Victoria, *Inquiry into End of Life Choice*, Final Report, June 2016.

[231] House of Assembly Standing Committee on Community Development, Parliament of Tasmania, *Inquiry into Palliative Care*, April 2017.

[232] Joint Select Committee on End of Life Choices, Parliament of Western Australia, *My Life, My Choice*, August 2018.

[233] Joint Select Committee on End of Life Choices, Parliament of Western Australia, *My Life, My Choice*, August 2018, recommendation 23.

[234] Eliza Laschon, 'Voluntary euthanasia bill set to be introduced to WA Parliament in bid to legalise assisted dying', *ABC News*, 12 November 2018, <https://www.abc.net.au/news/2018-11-12/voluntary-euthanasia-legislation-announced-by-wa-government/10488400>, viewed 29 November 2018.

[235] Gail Burke and Laura Gartry, 'Voluntary euthanasia inquiry announced in Queensland, issue must be confronted Premier says', *ABC News*, 2 September 2018, <https://www.abc.net.au/news/2018-09-02/voluntary-euthanasia-inquiry-in-queensland/10192716>, viewed 29 November 2018; Queensland Parliament, Inquiry into aged care, end-of-life and palliative care, <https://www.parliament.qld.gov.au/work-of-committees/committees/HCDSDFVPC/inquiries/current-inquiries/AgedCareEOLPC>, viewed 29 November 2018.

8.54 The Committee will examine, *inter alia*, 'Queensland community and relevant health practitioners' views on the desirability of supporting voluntary assisted dying, including provisions for it being legalised in Queensland and any necessary safeguards to protect vulnerable persons'. The Committee is set to report by 30 November 2019.[236]

[236] Queensland Parliament, Inquiry into aged care, end-of-life and palliative care, <https://www.parliament.qld.gov.au/work-of-committees/committees/HCDSDFVPC/inquiries/current-inquiries/AgedCareEOLPC>, viewed 29 November 2018.

9 VOLUNTARY ASSISTED DYING—COMMITTEE FINDINGS AND COMMENT

INTRODUCTION

9.1 The Committee has provided an account of how discussion, debate and other matters related to Voluntary Assisted Dying (VAD) in the ACT jurisdiction has been dealt with in Chapter 5.

9.2 The Committee's terms of reference asked the committee to address matters related to VAD in the following terms:

- current practices utilised in the medical community to assist a person to exercise their preference in managing the end of their life, including palliative care;
- ACT community views on the desirability of voluntary assisted dying being legislated in the ACT;
- risks to individuals and the community associated with voluntary assisted dying and whether and how these can be managed;

9.3 In Chapters 3 and Chapter 4, the Committee discusses the elements of palliative care, both as a form of end-of-life care, and current practices utilised in the Canberra medical community to provide a person with care and assistance in managing their end-of-life care needs. In this chapter, the Committee provides a discussion and analysis of the other two ToRs it has been asked to report on, to do with the desirability of VAD being legislated in the ACT and the perceived risks to individuals and the community associated with VAD and whether and how these can be managed.

9.4 In doing so, the Committee has concentrated on the views of individual residents of the ACT, and on views from government, from public health, from palliative care, from support and religious organisations as they address VAD during the Committee's inquiry.

9.5 The Committee observes that it is clear that, until such time as the applicable sections of the Australian Capital Territory Self-Government Act are amended to allow a scheme for voluntary assisted dying to be considered by the Legislative Assembly, no legislative action can be taken to enact a VAD scheme in the ACT. It is also important to note that the implementation of VAD legislation in Victoria, the introduction of VAD legislation in Western Australia, and the possible introduction of VAD legislation in other states and New Zealand will be relevant to decision on ACT VAD

9.6 The Committee ToR also asked the Committee to inquire into and report on:

9.7 the applicability of voluntary assisted dying schemes operating in other jurisdictions to the ACT, particularly the Victorian scheme;

9.8 As noted in Chapter 5, the Committee examines and reports on the applicability of VAD schemes (both enacted and in course of preparation) in other jurisdictions, principally in Victoria. The Committee describes how the Victorian legislation was examined, analysed by an implementation task force and then enacted by the Victorian Parliament in 2017. That process - as highlighted elsewhere in the report - followed the recommendation by the Victorian parliamentary select committee on End Of life Choices that Government act to introduce appropriate VAD legislation in Victoria.

9.9 The Committee – as noted earlier in this report – had the benefit of discussions with members of the task force established for the purpose of implementing the Victorian VAD scheme which is to commence in mid-2019.[237]

9.10 The Committee also notes that a panel has been established in Western Australia to prepare and advise government on appropriate legislation to enact VAD in Western Australia[238] following recommendation of the WA Parliament Select committee on End of Life choices.

9.11 The Committee has considered a wide range of submissions and evidence both for and against VAD. These views cover current specialists who work in palliative care as well as individual members of the community, community organisations and service providers.

VIEWS ON VOLUNTARY ASSISTED DYING PROVIDED IN SUBMISSIONS AND EVIDENCE

9.12 The number of submissions received by the Committee from individuals who gave as their residence an ACT address is 274. Of those submissions, the distribution of those who support VAD in the ACT, and those who did not support VAD is in the following table:

[237] Victorian Government (Health Vic), *Ministerial Advisory Panel on Voluntary Assisted Dying: Final Report*, 31 July 2017.https://www2.health.vic.gov.au/about/publications/researchandreports/ministerial-advisory-panel-on-voluntary-assisted-dying-final-report

[238] Western Australia, Minister for Health, statement, *Government to Introduce Bill to Legalise Voluntary Assisted dying and improve end-of-life choices for West Australians*, November 2018
https://www.mediastatements.wa.gov.au/Pages/McGowan/2018/11/Government-to-introduce-Bill-to-legalise-voluntary-assisted-dying-and-improve-end-of-life-choices-for-Western-Australians.aspx

Opposed to VAD	Support VAD	Neither support or oppose VAD
160	108	6

VIEWS FROM ORGANISATIONS ON VOLUNTARY ASSISTED DYING

9.13 The Committee received a range of views on VAD from a number of care, medical and concerned organisations involved in all levels of palliative care and in relation to VAD. These views ranged from outright opposition to VAD to strong support for VAD, with some organisation neither opposing nor supporting the principle of VAD.

OPPOSITION TO VOLUNTARY ASSISTED DYING

9.14 The Australian Medical Association provided the Committee with their organisation's Position Statement on VAD. Their Statement read:

> The AMA believes that doctors should not be involved in interventions that have as their primary intention the ending of a person's life. This does not include the discontinuation of treatments that are of no medical benefit to a dying patient.[239]

9.15 Having stated this opposition, the AMA also indicated that if Governments were to go ahead with the implementation of any VAD scheme, that the AMA should be consulted:

> If governments decide that laws should be changed to allow for the practice of euthanasia and/or physician assisted suicide, the medical profession must be involved in the development of relevant legislation, regulations and guidelines which protect:
>
> - all doctors acting within the law;
> - vulnerable patients—such as those who may be coerced or be susceptible to undue influence, or those who may consider themselves to be a burden to their families, carers or society;
> - patients and doctors who do not want to participate; and
> - the functioning of the health system as a whole.[240]

9.16 Catholic Health Australia (CHA), likewise expressed unequivocal opposition to the consideration of any VAD scheme. They submitted:

> CHA believes that there is no form of legislation that would enable VAD to be implemented in a way that ensures public safety. The risks of VAD are wide-ranging

[239] Australian Medical Association, *Submission 406*, attachment: AMA Position Statement: Euthanasia and Physician Assisted Suicide', p. 2.

[240] Australian Medical Association, *Submission 406*, attachment: AMA Position Statement: Euthanasia and Physician Assisted Suicide', p. 2.

> and uncontrollable, threatening the health and safety of vulnerable groups, individuals, and communities, as well as fundamentally undermining the values and ethics that form the fabric of Australian society. It is CHA's belief that there in no way to adequately manage the risks of VAD.[241]

9.17 Similarly, Calvary Health Care noted their opposition:

> Calvary cannot support the notion that assisting a person to suicide, or to end their life directly and intentionally, is an expression of care. We strive to eliminate suffering, but not the people who are experiencing the pain or physical incapability that may inform their suffering.[242]

9.18 HammondCare expressed a similar position:

> HammondCare does not support physician-assisted suicide or euthanasia. The risks these practices pose are significant and legislated safeguards designed to protect vulnerable citizens are subject to abuse and erosion over time. Rather than introducing such a framework, we urge the ACT parliament to continue to invest in high quality palliative care services and to identify opportunities for increasing equitable access to these services for all citizens.[243]

9.19 The Australian and New Zealand Society of Palliative Medicine was also opposed to VAD, yet noted—similar to the AMA—that if VAD was to be implemented, the medical community must be part of the process:

> ANZSPM does not support the legalisation of euthanasia or physician assisted suicide, but recognises that ultimately these are matters for government to decide having regard to the will of the community and, critically, informed by appropriate research and consultation with the medical community, including palliative medicine practitioners.[244]

SUPPORT FOR VOLUNTARY ASSISTED DYING

9.20 Some medical practitioners were strongly in favour of VAD. Doctors for Assisted Dying submitted their support:

> …we believe that rational adults, who for reasons of intolerable suffering with no realistic chance of cure or relief, wish to gently end their lives, should have the right to access legal assisted dying, at a time and place of their choosing, in the company of friends and loved ones of their choice.[245]

---

[241] Catholic Health Australia, *Submission 411*, p. 6.
[242] Calvary Health Care, *Submission 452*, p. 18.
[243] HammondCare, *Submission 153*, p. [7].
[244] Australian and New Zealand Society of Palliative Medicine, *Submission 379*, p. 9.
[245] Doctors for Assisted Dying, *Submission 81*, p. 17.

9.21 The Australian Nursing and Midwifery Federation provided a detailed Position Statement supporting VAD, including a potential framework for eligibility for access to any VAD scheme:

> We support legislative reform so that persons who have an incurable physical illness that creates unrelieved, unbearable and profound suffering shall have the right to choose to die with dignity in a manner acceptable to them and shall not be compelled to suffer beyond their wishes.
>
> For people who have an incurable physical illness that creates unrelieved, unbearable and profound suffering to obtain and use prescriptions from their treating doctor for the self-administration of lethal medication ending one's life in accordance with any state or territory law which does not constitute suicide, the following criteria must be met: The person must:
>
> a) be a resident of the state or territory where the request is made;
>
> b) be 18 years or older;
>
> c) be deemed 'capable' of making decisions:
>
> - have the ability to make and communicate healthcare decisions.
> - have the appreciation of the relevant facts including medical diagnosis and prognosis.
> - be aware of the risks involved in taking the lethal medication.
> - be aware of any feasible treatment alternatives; and d) have made a voluntary, well considered request.[246]

9.22 In a similar vein, the Australian College of Nursing expressed their support for the implementation of VAD:

> The Australian College of Nursing (ACN) strongly believes that an individual's dignity and choice are vital for end of life (EOL) care. Quality nursing care provided during EOL profoundly influences a person's quality of life, comfort and dignity during this vulnerable time. Care should be delivered in partnership with health professionals, individuals and their families and be responsive to changing needs and circumstances, whilst maintaining a person centred focus. EOL is one of four inaugural Policy Chapters endorsed by ACN. ACN's National Policy Summit held in April 2017, called for governments to invest in initiatives supporting individuals' choice regarding EOL care. This also echoes the nursing profession's health policy priorities. Specifically, ACN is in favour of changes to health policy reflecting community preferences in terms of both when and where terminally ill individuals prefer to die with dignity.[247]

[246] Australian Nursing and Midwifery Federation, *Submission 482*, attachment: 'ANMF Position Statement: Assisted Dying', p. [2].

[247] Australian College of Nursing, *Submission 416*, p. 2.

VIEWS THAT NEITHER OPPOSED NOR SUPPORTED VOLUNTARY ASSISTED DYING

9.23 Other organisations did not have an official position either supporting or opposing VAD.

9.24 The Australian Psychological Society, for instance, submitted that:

> The APS takes a similar position to that of the American Psychological Association (APA), which neither endorses nor opposes assisted dying given the complex multitude of issues involved. In their recent Resolution on Palliative Care and End-of-life Issues, the APA also advocates for quality end of life care for all individuals; promotes research on assisted dying; promotes policies that reduce suffering; and supports research on ethical dilemmas faced by clinicians and researchers. Both the APS and APA foreground the need to protect first and foremost the wellbeing of the individual concerned. Consideration should also be given to the needs of family members and professionals involved.[248]

9.25 The Royal Australasian College of Surgeons also submitted that their organisation has no official position on VAD, noting however, that 'members are required to act in accordance with the law'.[249] The Royal College of Physicians, likewise, submitted that their organisation does not have a position on VAD, as yet, noting that 'the RACP has convened a Working Party which is currently developing a position in these issues in consultation with our membership'.[250]

9.26 Capital Health Network also expressed an ambiguous position on VAD, noting that because VAD 'is a highly emotive and personal issue it is difficult to find consensus opinion'. They did provide some consideration of necessary safeguards for any VAD scheme, if it were to be introduced. They submitted:

> If such legislation is introduced primarily on the basis of patient autonomy and choice, it may well be assumed that all GPs are willing, professionally skilled and competent to manage these issues. The rights and autonomy of medical practitioners (Specialist and GPs alike) should be safeguarded and respected in a similar way to that of clinician participation in the management of patients seeking abortions. These rights should not be eroded nor abused—no medical practitioner should be forced to be involved in any such procedure, whether arranging it or taking part.[251]

9.27 Capital Health Network concluded their submission with the following statement:

> CHN strongly supports the implementation of changes to the ACT health system that will enhance end of life care, including better advanced care planning, strengthening

[248] Australian Psychological Society, *Submission 440*, p. 12.
[249] Royal Australasian College of Surgeons, *Submission 483*, p. [2].
[250] Royal Australasian College of Physicians, *Submission 177*, p. 2.
[251] Capital Health Network, *Submission 366*, p. 5.

the availability of, and access to, palliative care and an informed discussion on the merits of assisted dying both from a patient and clinician perspective.[252]

INDIVIDUAL EXPERIENCES OF DEATH

9.28 Several witnesses to appear before the Committee recounted their direct experience with one or more traumatic deaths. The Committee expresses its sincere thanks to witnesses for their candour in publicly sharing these difficult experiences.

9.29 For several witnesses, their experiences affirmed their strong support for the introduction of a VAD scheme to the ACT. The Committee draws attention in particular to evidence of the Higgs-Heine family and Ms Katarina Pavkovic. Both families stressed they believed that had their loved one had access to a VAD scheme, the loved one and the family may have been able to plan for a less traumatic death, with certainty as to when it would occur.

9.30 In recounting the death of Mr Phillip Higgs, his daughter Mrs Heine stated:

> For me, when the doctors came to us and said, "There's no hope. He's never going to get better. He's actually just going to pass away," I would have preferred at that point in time for us to have has something together as a family—wherever he was, had a little moment together—and then have him euthanised, so that he would then have just peacefully slipped away. We would have all been there supporting him, and he would have known that we were there. I think he would have understood that, because he said to us that he did not want to live anymore.[253]

9.31 In recounting the death of her father, Ms Pavkovic agreed that:

> If I had known [a date in which he intended to die] then I would have been able to organise work properly. I would have been able to care for him properly, given him the love and the affection that he needed, rather than him being so distressed. I suppose the horrible thing about it was that for about three of four weeks he was under this palliative sedation…. "That's not my dad". He was just…locked in a shell. He wanted to come out, obviously. If we had known, we would have had better communication in the end. We would have been able to say goodbye properly.[254]

[252] Capital Health Network, *Submission 366*, p. 6.
[253] Ms Philippa Higgs and Mrs Michelle Heine, *Transcript of Evidence*, 31 May 2018, p. 288.
[254] Ms Katarina Pavkovic, *Transcript of Evidence*, 24 May 2018, p. 183.

9.32 The Committee notes the full transcripts of these appearances are available here (Higgs-Heine family)[255] and here (Ms Pavkovic)[256].

9.33 Equally, the Committee notes some individuals gave evidence about witnessing traumatic deaths but this had not led them to advocate for VAD.[257]

A FUTURE APPROACH TO VOLUNTARY ASSISTED DYING IN THE ACT

COMMITTEE COMMENT

9.34 In Chapter 8, the Committee detailed the current legislative position regarding VAD in the ACT; that is, that the ACT Legislative Assembly is currently unable to legislate for VAD.

9.35 In noting the ACT is able to determine its own laws on most other areas of policy, a majority of Committee members support the ACT Government in its work with the Northern Territory in lobbying the Commonwealth Government for the Territories to be able to determine their own laws regarding VAD and urge that this be continued. However, not all members of the Committee agree.

9.36 As outlined above, the Committee received a lot of evidence both in support of and opposed to VAD.

9.37 There is considerable belief across areas of the community that no scheme will ever have strict enough provisions or safeguards for the community to be confident in its implementation and application.[258]

9.38 On the other hand, many organisations and individuals expressed support of VAD and put forward what could be the principles or tenets of VAD scheme.

9.39 The suggestions put forward about how a VAD scheme might look were quite varied. The Committee notes evidence from a range of individuals and organisations that personal freedom was the paramount consideration for a scheme's operation.[259]

---

[255] See, *Transcript of Evidence*, 31 May 2018, pp. 280-291.

[256] See, *Transcript of Evidence*, 24 May 2018, pp. 178-188.

[257] See, for example, Archbishop Christopher Prowse, *Transcript of Evidence*, 18 May 2018, pp. 139-148.

[258] See, for example: Major General Peter Phillips (Rtd), *Transcript of Evidence*, 17 May 2018, p.3; Dr Elisabeth Taylor, Australian Christian Lobby, *Transcript of Evidence*, 31 May 2018, p. 250; Ms Rachael Wong, Women's Forum Australia, *Transcript of Evidence*, 18 May 2018, p. 125.

[259] See, for example: Mr G Cornwell, *Transcript of Evidence*, 18 May 2018, pp. 82-83; Ms Judith Dodd, *Transcript of Evidence*, 24 May 2018, pp. 178-179; Ms Philippa Higgs, *Transcript of Evidence*, 31 May 2018, p. 288; Ms Petrea Messent,

However, a considerable number of other themes and/or proposals emerged to guide the operation of the scheme, particularly around safeguards.

9.40 A majority of the Committee [260]strongly suggests that if there is a time when the legislative position changes and the ACT Legislative Assembly gives serious consideration to VAD and establishing an appropriate scheme, the following safeguards or criteria would be necessary to have confidence in the operation of such a scheme:

- that the person is 18 years or older[261];
- that the person has been diagnosed with a terminal illness or a serious condition that cannot be sufficiently relieved by palliative care, and that a timeframe be considered[262];
- that the person is independently assessed by at least one general practitioner to determine that the person is of sound mind to make a decision regarding voluntary assisted dying[263];
- that the person has been given adequate information about the voluntary assisted dying scheme and the implications of their decision[264]; and
- that the person has access to counselling and other appropriate support[265].

- Further, the Committee consistently received or heard evidence that in designing the scheme the ACT Legislative Assembly should, at a minimum:
  - consider the risks to elderly patients, including elder abuse, and ensure appropriate safeguards are in place to mitigate these risks[266];
  - consider the risks to people with a disability and ensure appropriate safeguards are in place to mitigate these risks[267];
  - include provisions for healthcare professionals who do not wish to be involved in any voluntary assisted dying scheme, including referral processes[268];

Dementia Australia, *Transcript of Evidence*, 24 May 2018, p. 170; Mr Timothy Morton, *Transcript of Evidence*, 31 May 2018, pp. 334-335; Dr David Swanton, EXIT ACT, *Transcript of Evidence*, 18 May 2018, p. 151.

[260] Mrs Dunne MLA and Mrs Kikkert MLA dissent from this Committee comment.

[261] See, for example: ACT Human Rights Commission, *Submission 477*, p. 4; Mr Michael Boesen, *Transcript of Evidence*, 31 May 2018, p. 299.

[262] Legal Aid ACT, *Submission 158*, p. 7; Dr Helen Watchirs OAM, ACT Human Rights Commissioner, *Transcript of Evidence*, 18 May 2018, pp. 101-102.

[263] Dr Balaji Bikshandi, Australian Medical Association (ACT), *Transcript of Evidence*, 31 May 2018, p. 278; Australian Psychological Society, *Submission 440*, pp. 6-7; Mr Michael Boesen, *Transcript of Evidence,* 31 May 2018, pp. 295, 298-299; Judith Dodd, *Transcript of Evidence*, 24 May 2018, pp. 178-179; Ms Philippa Higgs, *Transcript of Evidence*, 31 May 2018, p. 288; Legal Aid ACT, *Submission 158*, p. 8; Ms Petrea Messent, Dementia Australia, *Transcript of Evidence*, 24 May 2018, p. 174.

[264] ADACAS, *Submission* 231, p. 2; Dying with Dignity ACT, *Submission 118*, p. 5; Legal Aid ACT, *Submission 158*, p. 9; Dr Sarah Spiller, Health Care Consumers Association, *Transcript of Evidence*, 25 May 2018, p. 221.

[265] Australian Psychological Society, *Submission 440*, p. 2; Dying with Dignity ACT, *Submission 118*, pp. 5-6.

[266] COTA, *Submission 342,* p. 4; Dr Siobhan Gibbons, *Transcript of Evidence*, 31 May 2018, p. 328; Legal Aid ACT, *Submission 158*, p. 6; Ms Petrea Messent, Dementia Australia, *Transcript of Evidence*, 24 May 2018, p. 175; Mr Timothy Morton, *Transcript of Evidence*, 31 May 2018, pp. 331, 333.

[267] ADACAS, *Submission* 231, p 1; Mr Gev Khambata, Health Care Consumers Association, *Transcript of Evidence*, 25 May 2018, p. 223.

[268] Australian Psychological Society, *Submission 440*, p. 8; Dr Helen Watchirs OAM, ACT Human Rights Commissioner, *Transcript of Evidence*, 18 May 2018, pp. 102-103.

- ensure all healthcare workers involved in the scheme have access to appropriate training, facilities, support and counselling[269];
- establish an independent position or body to record and assess data on patients accessing voluntary assisted dying, so that any scheme can be rigorously and frequently evaluated[270]; and
- increase palliative care funding[271].

9.41 There are some members of the Committee who do not consider that these criteria offer the safeguards imagined and do not support any further work on VAD.

[269] Ms Heather Gridley, Australian Psychological Society, *Transcript of Evidence*, 17 May 2018, pp. 72-73.

[270] Legal Aid ACT, *Submission 158*, p. 10; Dr Helen Watchirs OAM, ACT Human Rights Commissioner, *Transcript of Evidence*, 18 May 2018, pp. 101-102.

[271] Dr Balaji Bikshandi, Australian Medical Association (ACT), *Transcript of Evidence*, 31 May 2018, p. 277; Dr Sarah Spiller, Health Care Consumers Association, *Transcript of Evidence*, 25 May 2018, p. 217.

10 COMMITTEE CONCLUSIONS

10.1 The Committee undertook this inquiry with great care, bearing in mind that individuals who prepared written submissions to the inquiry could be expected to include details of the most difficult and confronting issues people face in their life – both for themselves and for family members. This proved to be so, as a reading of the individual submissions which are published with this report shows.

10.2 The Committee - as required by its terms of reference – also examines and reports on the current position with regard to palliative care, community views on end-of-life choices and the current position with regard to voluntary assisted dying in the ACT.

10.3 The Committee considered the findings and recommendations from recent reports by committees of other Australian Parliaments which addressed end-of-life choices with conscientiousness and sensitivity.

10.4 The Committee has also, in common with other parliaments, focussed on issues covering advanced care planning and directive arrangements, a continuing need for better-developed and responsive palliative care, the importance of managing and supporting end-of-life choices in residential care and other end-of-life care and support which the community considers increasingly important.

10.5 The Committee has considered the evidence presented to it through submissions, public hearings, and a wide range of reports and research.

10.6 This report makes 24 recommendations.

10.7 The Committee particularly wishes to acknowledge and thank all individuals, organisations, care and support groups, health advancement and support organisations and public agencies for the candid and supportive responses provided to the Committee, particularly to questions raised by the Committee.

10.8 The Committee considered a Draft Report at meetings on 31 January, 4 February, 8 February, 4 March, 8 March and 18 March 2019. The Committee adopted the Report on 18 March 2019.

Bec Cody MLA
Chair
21 March 2019

APPENDIX A – LIST OF WRITTEN SUBMISSIONS

Submissions received by the Committee to the Inquiry[272]:

[272] https://www.parliament.act.gov.au/in-committees/select_committees/end-of-life-choices/inquiry-into-end-of-life-choices-in-the-act#tab-1143329-2

Submission No / Submitters	Submission No / Submitters	Submission No / Submitters
001 - Frank Long	026 - John Lance Keogh	051 - Judith Leslie
002 - Bill Alcock	027 - Terri Margaritis	052 - Jos Hall
003 - Valerie Davies	028 - Helen Dennis	053 - Julian Tertini
004 - Clare Phillips	029 - Marshall Perron	054 - Lidia Bilbatua
005 - Donald Baker	030 - Marjorie Edwards	055 - Lyndall Hough
006 - John & Patricia Hurworth	031 - Elizabeth Keogh	056 - Max Prince
007 - Joy Molineux Kelly	032 - RB Thompson	057 - Ruth Haig
008 - Carol Cronk	033 - Greg Cornwell	058 - Shaheen Badat
010 - Paul Bennett	034 - Sylvia Henshaw	059 - Yvonne Michael.
011 - Roger Pearson	035 - Amanda & Douglas McFarlanc	060 - Confidential
012 - Yvonne Little	036 - Arthur & Helen Milne	061 - Carole Gamble
013 - Faye Girsh	037 - Bernadette Davies	062 - Hendrik de Vries
014 - Nancy Wood	038 - Dorothy Long	063 - Jonathon Cook
015 - Susan Stern	039 - Imelda Aslett	064 - John Brook
016 - Timothy Pascoe	040 - John Kelly	065 - Confidential
017 - Barbara Mummery	041 - Mark Vegar	066 - Mina Singh Batra
018 - Phyllis Sequeira	042 - Penny Hackett	067 - Sue Clancy
019 - Susan MacDougall	043 - Confidential	068 - Anna Tchernetsov
020 - Marion Howard	044 - Veronica Selwyn	069 - Anthony Talbot
021 - Steph McCarthy	045 - Confidential	070 - Heather Robinson
022 - Beverley McIntyre	046 - Rita Joseph	071 - Meraiah Foley
023 - Christians Supporting Choice f Voluntary Euthanasia	047 - Sue Hayward	072 - Mia Campioni
024 - Julia Bailey	048 - Walter Marsh	073 - Robert Wilce
025 - Stanley Mangalson	049 - Richard & Phillip Stuckey	074 - Western Australia Chapter of Exit International
	050 - Brigitte Tucholski	

Submission No / Submitters	Submission No / Submitters	Submission No / Submitters
075 - Andrew Cumbo	098 - ACT Humanist Society	123 - Annette Hamilton
076 - Name Withheld	099 - Bruce Taggart	124 - Angela Woollacott
077 - Christina Brooks	101 - Janet Clifford	125 - Atila Nagy
078 - Name Withheld	102 - John Shannon	126 - Robert Pollnitz
079 - Wendy Williams	103 - Sylvia Grey	127 - Ian Robinson
080 - Christa Weber	104-Don-Gray.pdf	128 - FamilyVoice Australia
081 - Doctors for Assisted Dying Choice	105 - WB Larkin	129 - Wendy Christian
082 - Ellen Bannister	106 - Moya Homan	130 - David Miller
083 - Janet Burgess	107 - Rachel Carling-Jenkins	131 - Patricia Woolcock
084 - South Australian Voluntary Euthanasia Society	108 - Tina Christensen	132 - Granville Mawer
085 - Dying with Dignity Victoria	109 - Hugh Dakin	133 - Christine Wilson
086 - Susan Leggo	110 - Patrick McNamara	134 - Gail Wyatt
087 - Elvira de Neeff	111 - Mark Taylor	135 - Anne Zrich
088 - Shannon West	112 - Michael Boesen & Noel Atcherley with 10 signatories	136 - Name Withheld
089 - Terry Dwyer	113 - John Wayne Martin	137 - Catherine Wallace
090 - Women's Forum Australia	114 - Karin Geiselhart	138 - Eris Kennedy
091 - Joy Shannon	115 - Geoff Wall	139 - Ralph & Jane Wingfield
092 - Milton March	116 - Christine Finn	140 - Helene Axelby
093 - Monica Green	117 - Judith Blundell	141 - Katrina Haller
094 - Pamela Martin	118 - Dying with Dignity ACT	142 - Audrey Donnithorne
094 - Pamela Martin	119 - Graham Stitz	143 - Euthanasia NO (ACT)
096 - Susan Kirk	120 - Karen Webb	144 - Patricia Loughlan
097 - Tony di Michiel	121 - Gosta Lynga	145 - Tibetan Buddhist Society of Canberra
	122 - Confidential	146 - Confidential

Submission No / Submitters	Submission No / Submitters	Submission No / Submitters
147 - Sally Cuff	170 - Peter Parsons	194 - Kellie Inman
148 - William & Sandra Tento	171 - R Menkarska	195 - Andre Wheeley
149 - Cariba Heine	172 - Elizabeth Coghile	196 - Ivan Mewett
150 - Avant Mutual Group	173 - Brian Hanvin	197 - Peter Frogley
151 - ACT Government	174 - Katarina Pavkovic	198 - Judy Nixon
152 - Helen Connor	175 - Jan Whyte	199 - Name Withheld
153 - HammondCare	176 - GR Varley	200 - Hugh Brady
154 - Confidential	177 - Royal Australiasian College of Physicians	201 - Wendy Evans
155 - Malcolm Knight	178 - Pauline Hally-Burton	202 - Raymond Kirkpatrick
156 - Confidential	179 - Anne Yuille	203 - Llywellyn O'Brien
157 - Paul Burt	180 - Marianne Forshaw	204 - Mary Ringrose
158 - Legal Aid ACT	181 - John Cashman	205 - Danny Castro
159 - Public Trustee and Guardian	182 - Garry Eldridge	206 - Gillian Punch
160 - Ukrainian Autocephalic Orthodox Church in Australia and N Zealand	183 - Nick Stuparich	207 - Keith Weeks
161 - Palliative Care Nurses Australi	184 - Kevin Goatley	208 - Patricia Spaul
162 - Joan Sallecchia	185 - Right to Life Australia	209 - Peter & Sophie Hill
163 - Margaret Otlowski	186 - Sheelagh Egan	210 - Peter Phillips
164 - Albert Alyta	187 - Anne de Smet	211 - Chris Emery
165 - Michael Solomko	188 - Tony Whelan	212 - Sue Dyer
166 - Confidential	189 - Prudence Gordon	213 - Confidential
167 - Geoffrey Williams	190 - Bob Perkins	214 - John Popplewell
168 - Elizabeth Dyer	191 - Greg Donnelly	216 - Peter Hatcher
169 - Carolyn O'Loughlin	192 - Ashley Byrne	217 - Tracey Radbourne
	193 - Murray Thomas	218 - Debra Cheyne
		220 - Mike Sarah

Submission No / Submitters	Submission No / Submitters	Submission No / Submitters
221 - Tracey Preston	247 - Jude Dodd	272 - Confidential
222 - Ivan Sparks	248 - Margaret Boyd	273 - Dennis Glanville
223 - Fairlie Everingham	249 - Stuart Bullock	274 - Stanley Silverwood
224 - Pete Milne	250 - Lola Bootle	275 - Martin Keast
225 - Luis & Minda Cruz	251-Lyn-Keating.pdf	276 - Sarah Abramowski
226 - Paul Lasshko	252 - Arthur Schuster	277 - Kate Roffey
227 - Giles Walters	253 - Brian Medway.	278 - Jacqueline Jenkins
228 - Jane Andrews	254 - Confidential	279 - Ingrid Ross
229 - Monica Murray	255 - Ian Brearley	280 - Graeme Church
230 - Elizabeth Montgomery	256 - Peter Laughlin	281 - Eileen Currie
231 - ADACAS	257 - Judith White	282 - I Morzone
232 - John Edge	258 - Diane Eager	283 - Tom & Catherine Brimage
233 - Herman van de Brug	259 - Janice Hodgson	284 - Alicia Manzano
234 - Stan Fleetwood	260 - Wesley Gates	285 - Hendrik de Groot
236 - Roger Beddis	261 - John Sheldrick	286 - Tom Sharp
237 - Liz Sweaney	262 - Tony & Carolyn Allen	287 - Eloise Bright
238 - Linda Hort	263 - Allen Seed	288 - Shinta Benilda
239 - Matt Leonard	264 - Winston Newman	289 - Heather Whiteley
240 - Sean Lang	265 - Andrew Muir	290 - Kerrie Mitchell
241 - Gill Graham	266 - Mike McAuliffe	291 - Hillas MacLean
242 - Craig Johnson	267 - James Grieve	292 - Judy Seach
243 - Jodie Bradby	268 - John McKeough	293 - Maurice Boland
244 - Josephine Roberts	269 - Christopher Crowley	294 - Gordon Matton-Johnson
245 - David Roberts	270 - Michaela Samman	295 - Lynn McKee
246 - Sam Hussey-Smith	271 - Jordan Serena	296 - Greg Cadman

Submission No / Submitters	Submission No / Submitters	Submission No / Submitters
297 - Sarah Avery	322 - Clara Curtis	347 - Timothy Morton
298 - Mark Bailey	323 - Gabrielle van der Spek	348 - Janet Rickwood.
299 - Mary Stirzaker	324 - Brian & Margaret Studley	349 - Sadie McHugh
300 - Christian Medical & Dental Fellowship of Australia	325 - Dira Horne	350 - John Smith
301 - Catriona Pickett	326 - Dying with Dignity NSW	351 - Gregory Lloyd
303 - Julie Schranz	327 - Andrew Blanckensee	352 - Stephanie Norris
304 - Carmel Walshe	328 - Bronwyn Copp	353 - Robert Altamore
305 - David Hutchins	329 - William Dovers	354 - Joseph de Riva O'Phelan
306 - Chris Dennis	330 - Jacqueline Halgren	355 - Audrey Miller
307 - Angela Shanahan	331 - Michelle Heine	356 - Leslie Hood
308 - Rowan Shann	332 - Marie Higgs	357 - Michael Allam
309 - Dave Aked	333 - Barbara Browning	358 - Mary Bryant
310 - Medicine with Morality	334 - Civil Liberties Australia	360 - Peter Howard
311 - Kim Wheeler	335 - ACT Liberal Democrats	361 - Honor Lee
312 - Andrew Copp	336 - Liza Quinn	362 - Johan Smit
313 - Bob Stirling	337 - Elringtons Lawyers	363 - Carolyn Wightman
314 - Lives Worth Living	338 - Canberra Declaration	364 - Amanda Landers
315 - Wendy Altamore	339 - Exit International (ACT Chapte	365 - Community Options
316 - Sally Curlewis	340 - Ethical Rights	366 - Capital Health Network
317 - Chris & Maree Rule	341 - Susan Wood	367 - Peter McCullagh
318 - Confidential	342 - COTA	368 - Michael Quinlan
319 - Jeremy Couper & David Kissar	343 - Kristin Stirling	369 - David Bignell
320 - Geoffrey Millar	344 - John Paynter	370 - Dom Fiocco
321 - Moya Gunn	345 - Elvis Seman	371 - Name Withheld
	346 - Kathleen Holtzapffel	372 - Joyce Lam

Submission No / Submitters	Submission No / Submitters	Submission No / Submitters
373 - Peter McDonald	396 - Anna Molan	420 - Palliative Care ACT
374 - Ian Hughes	397 - Jonathon Savy	421 - Women's Bioethics Alliance
375 - Julie Connolly	398 - Perry Healey	422 - Name Withheld
376 - Confidential	399 - Rhonda Swan	423 - Timothy Coleman
377 - Gary Presneill	400 - Lois Wishart Lindsay	424 - Mary-Anne Brownlie
378 - Gill Belcher	401 - Clare Cordiner	425 - Chong Wei Ong
379 - Australian and New Zealand Society of Palliative Medicine	402 - Judy Bell	426 - Marion Harris
380 - Edwina Barton	403 - Agnes Walker	427 - Dementia Australia
381 - Thomas Bielenberg	404 - Eric James	428 - Catherine Mannering
382 - Confidential	405 - Robert & Susan Unger	429 - Jennifer Roberts
383 - RM Edwards	406 - Australian Medical Association (ACT)	430 - Lindy Willmott, Ben White & Penny Neller
384 - Karin Hagel	407 - ACT Right to Life Association	431 - HOPE
385 - Edith Parnwell	408 - Malcolm Prior	432 - Mary Aerts
386 - Paula Handreck	409 - Sue Ingram	433 - Damien Haas
387 - Ken Barker	410 - David Coleman	434 - Timothy & Elizabeth Roberts
388 - Australian Catholic Disability Council, Bishops Comission for Pastoral Life	411 - Catholic Health Australia	435 - Catholic Archdiocese of Canberra and Goulburn
389 - Julie Rogers	412 - Susan Brough	436 - Joy Harmer
390 - Siobhan Gibbons	413 - Robin Watt	437 - John Buchanan
391 - Phil Gibbons	414 - Colleen McBride	438 - Warwick Grigg
392 - Ron Gane	415 - Mandy Scott	439 - Linda Foster-James
393 - Anthony Ringrose-Voase	416 - Australian College of Nursing	440 - Australian Psychological Society
394 - Portia Asuako	417 - Shannon Smith	441 - Confidential
395 - Jayan Parry	418 - Gemma O'Sullivan	442 - Australian Catholic Bishops Conference
	419 - Hugh & Fenelle McLaurin	

Submission No / Submitters	Submission No / Submitters
443 - Eric Frith	466 - Marietta Le Grand
444 - Patrick Hartwell	467 - Sarah Carden
445 - Daniel Hartwell	468 - Stephanie Claessens
446 - Canberra Multicultural Community Forum	469 - Gary Walkington
447 - Beverley Cains	470 - Angela Plant
448 - Patrick McArdle	471 - Michael Chapman
449 - Anne Hartwell	472 - Adele Stevens
450 - Helen Crain-Welsby	473 - Anna Walsh
451 - Cancer Council ACT	474 - Matt Bray
452 - Calvary Health Care	475 - Victor Stevens
453 - Phil Murada	476 - John Szilard
454 - Dying with Dignity Tasmania	477 - ACT Human Rights Commission
455 - Health Care Consumers Association	478 - Confidential
456 - Kyle Heine	479 - Leonore Hardy
457 - Australian Christian Lobby	480 - Ken McLean
458 - Stephen Cains	481 - MJ Le Brun
459 - Dione Smith	482 - Australian Nursing and Midwifery Federation
460 - John Gillies	483 - Royal Australasian College of Surgeons
461 - Brendan Long	484 - Lyle Dunne
462 - Josh Manuatu	485 - Public Health Association of Australia
463 - Cathy Carden	486 - Michael Moore
464 - Christine Carden	487 - Beata Dal Piva
465 - Institute for Civil Society	488 - Janise Farrell

APPENDIX B – WITNESSES

THURSDAY, 17 MAY 2018

- BROWN, MS FRANCES, Director of Mission, Calvary John James Hospital
- CORRADINI, MS CLAUDIA, Member, Australian Nursing and Midwifery Federation (ACT)
- DANIEL, MR MATTHEW, Secretary, Australian Nursing and Midwifery Federation (ACT)
- EASTWOOD, MS SUZANNE, Community Development Manager, Canberra Multicultural Community Forum Inc
- FELDMAN, MR PAUL, Chair, Policy Committee, Council on the Ageing (COTA) ACT
- GREEN, MR MARK, National Director of Mission, Little Company of Mary Health Care
- GRIDLEY, MS HEATHER, Manager, Public Interest, Australian Psychological Society
- HUNG, MS YELIN, Secretary, Canberra Multicultural Community Forum Inc
- KANATHIGODA, DR SUHARSHA, Medical Director of Palliative Care ACT, Calvary Public Hospital
- MOBBS, MS JENNIFER, Chief Executive Officer, Council on the Ageing (COTA) ACT
- PELL, MS TRACEY, Member, Australian Nursing and Midwifery Federation (ACT)
- PHILLIPS, MAJOR GENERAL (Rtd) PETER
- STEVENS, MS GLENDA, Chief Executive Officer, Palliative Care ACT
- TAYLOR, MR ANDREW, Public Trustee and Guardian
- THOMPSON, MS CHRISTINA, Director, Guardianship Unit, Public Trustee and Guardian
- WONG, MRS CHIN, Chair, Canberra Multicultural Community Forum Inc

FRIDAY, 18 MAY 2018

- BOERSIG, DR JOHN, Chief Executive Officer, Legal Aid ACT
- CAINS, MRS BEVERLEY, President, ACT Right to Life Association Inc
- CORNWELL, MR GREGORY
- GILLESPIE, ASSOCIATE PROFESSOR ARNOLD, National Convenor, Doctors for Assisted Dying Choice
- HOMAN, MRS MOYA, Council Member, ACT Right to Life Association Inc
- KIRK, MRS LARA, Coordinator, Marriage and Family Relationships, Catholic Archdiocese of Canberra and Goulburn
- LEAF, DR DAVID, State Convenor, Doctors for Assisted Dying Choice
- LUGG, ADJUNCT PROFESSOR RICHARD, State Convenor, Doctors for Assisted Dying Choice
- MCKINNON, MS GABRIELLE, Human Rights Law and Policy, ACT Human Rights Commission

- PROWSE, ARCHBISHOP CHRISTOPHER, Catholic Archbishop of Canberra and Goulburn
- STRANGMAN, MR DENIS, Council Member, ACT Right to Life Association Inc
- STUPARICH, MR JEREMY, Public Policy Officer, Australian Catholic Bishops Conference
- SWANTON, DR DAVID, Chapter Coordinator, Exit ACT
- WATCHIRS, DR HELEN OAM, Human Rights Commissioner and President, ACT Human Rights Commission
- WHELAN, MR TONY, Member, Exit ACT
- WONG, MS RACHAEL, Managing Director, Women's Forum Australia

THURSDAY, 24 MAY 2018

- ARTHUR, MS JEANNE, President, Dying With Dignity ACT
- DODD, MS JUDITH
- DWYER, DR TERENCE, Principal, Dwyer Lawyers
- JONES, MS MAGGIE, Consumer representative, Dementia Australia
- MESSENT, MS PETREA, Regional Director and General Manager, Client Services, Dementia Australia
- PAVKOVIC, MS KATARINA

FRIDAY, 25 MAY 2018

- CONNOLLY, MS HELEN, Projects Coordinator, ACT Disability Aged and Carer Advocacy Service
- KHAMBATA, MR GEV, Member, Health Care Consumers Association
- LONG, DR BRENDAN, Senior Research Fellow, Charles Sturt University
- MAY, MS FIONA, Chief Executive Officer, ACT Disability Aged and Carer Advocacy Service
- QUINLAN, PROFESSOR MICHAEL
- SPILLER, DR SARAH, Policy Officer, Health Care Consumers Association
- STEVENS, DR ADELE, Consumer Representative, Health Care Consumers Association
  WALLACE, MR CRAIG, National Convenor, Lives Worth Living

THURSDAY, 31 MAY 2018

- BIKSHANDI, DR BALAJI, Board Member, Australian Medical Association (ACT) BOESEN, MR MICHAEL
- BURT, DR PAUL
- COLE, ASSOCIATE PROFESSOR ANDREW, Chief Medical Officer, HammondCare
- DONNELLY, MR GREGORY JOHN, Member, New South Wales Legislative Council DOUMIT, MS MONICA, Spokesperson, HOPE
- GARFIT, MS JUNE

- GIBBONS, DR SIOBHAN
- HEINE, MR KEVIN
- HEINE, MRS MICHELLE
- HIGGS, MRS MARIE
- HIGGS, MS PHILIPPA
- HORNE, MS DIRA
- ILES, MR MARTYN, Managing Director, Australian Christian Lobby
- MORTON, MR TIMOTHY
- SOMERVILLE, MR PETER, Chief Executive Officer, Australian Medical Association (ACT) TAYLOR, DR ELISABETH, Director, Research, Australian Christian Lobby
- VAN DER LINDEN, MS BRANKA, Spokesperson, HOP

FRIDAY 1 JUNE 2018

- AGAR, PROFESSOR MEERA, President, Australian and New Zealand Society of Palliative Medicine
- BONE, MR CHRIS, Deputy Director-General, Canberra Hospital and Health Services, ACT Health
- CHAPMAN, DR MICHAEL, Director of Palliative Care, Division of Cancer, Ambulatory and Community Health Support, Canberra Hospital and Health Services
- DE'ATH, MR MICHAEL, Interim Director-General, ACT Health
- FITZHARRIS, MS MEEGAN, Minister for Health and Wellbeing, Minister for Transport and City Services and Minister for Higher Education, Training and Research
- LAMB, MS DENISE, Executive Director, Cancer, Ambulatory and Community Health Support, Canberra Hospital and Health Services, ACT Health

THURSDAY, 12 JULY 2018

- CHAPMAN, DR MICHAEL
- CORLEY, MR BRIAN, Chief Executive Officer, Community Options Inc
- ETCHELLS, MS JANE, Manager, Clare Holland House
- GARRISSON, MR PETER, Solicitor-General for the ACT
- GREENWOOD, MS SUZANNE, Chief Executive Officer, Catholic Health Australia HARVEY, MS TAMSYN, Executive Director, Legislation, Policy and Programs, JACS
- MOORE, MR MICHAEL AM
- PHILLIPS, PROFESSOR JANE, President, Palliative Care Nurses Australia
- RAMSAY, MR GORDON, Attorney-General, Minister for Regulatory Services, Minister for the Arts and Community Events and Minister for Veterans and Seniors
- SVINTRADZE, MS IA, Executive Director, Quality Management, Community Options Inc

THURSDAY, 26 JULY 2018

- HOGAN, ADJUNCT PROFESSOR ANTHONY
- PERRON, MR MARSHALL
- WHITE, PROFESSOR BEN
- WILLMOTT, PROFESSOR LINDY

THURSDAY, 9 AUGUST 2018

- OTLOWSKI, PROFESSOR MARGARET

WEDNESDAY, 26 SEPTEMBER 2018

- de RAADT-ABMA, MS HILDE, Social Welfare Officer, Illawarra Retirement Trust Kangawa Waters
- MABALO, MS ANDREA, Facilities Care Manager, Illawarra Retirement Trust

APPENDIX C – COMMITTEE VISIT PROGRAM

Geelong and Melbourne, Victoria

Wednesday, 4 April and Thursday, 5 April 2018

Wednesday, 4 April 2018

Time	Discussion with
Morning	**Visit to – Barwon Regional Health Care, Geelong** **Discussions with –** Dr Toni Hogg – Clinical Director, Community Health, Rehabilitation and Palliative Care Services David Meade – Co Director, Community Health, Rehabilitation and Palliative Care Services Dr Ian Grant – Joint Head of Department, Palliative Care Services Dr Peter Eastman - Joint Head of Department, Palliative Care Services Jacqui White – Manager, Palliative Care Services Jill Mann – Program Coordinator, Advance Care Planning **Deakin University** Dr Charlie Corke – Clinical Associate Professor, Faculty of Health, School of Medicine
Afternoon	**Visit to – St Vincent's Palliative Care Centre, East Melbourne** **Discussions with –** **Andrew Crettenden** – Executive Director Strategy & Planning **Peter Hudson** – Director Centre for Palliative Care **Jennifer Philip** – VCCC Chair Palliative Medicine

Thursday, 5 April 2018

Time	Discussion with
	Venue – Parliament House, Melbourne
Morning	**Discussions –** **Mr Daniel Mulino MLC** , A member of the Victorian Legislative Council Legal and Social Issues Committee **Dr Karen Detering –** Advanced Care Planning Australia **Ms Inga Peulich MLC –** A member of the Legislative Council Legal and Social Issues Committee
Afternoon	**Discussions with –** **Ms Jackie Kearney** Assistant Director, Person Directed Care and Worker Wellbeing, Health and Wellbeing Division, Victorian Department of Health and Human Services **Mr Julian Gardner AM**, Chair, Voluntary Assisted Dying Implementation Taskforce **Mr James Cameron** Policy Officer, End of Life Care team, Person Directed Care and Worker Wellbeing

APPENDIX D – COMMITTEE LETTER TO THE ROYAL COMMISSION INTO AGED CARE QUALITY AND SAFETY

LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON END OF LIFE CHOICES IN THE ACT
Ms Bec Cody MLA (Chair), Mrs Vicki Dunne MLA (Deputy Chair)
Ms Tara Cheyne MLA, Mrs Elizabeth Kikkert MLA, Ms Caroline Le Couteur MLA

The Honourable Richard Tracey AM RFD QC, and Ms Lynelle Briggs AO
Commissioners
Royal Commission into Aged Care Quality and Safety
ACRCenquiries@royalcommission.gov.au

Dear Commissioners,

This Select Committee of the ACT Legislative Assembly is currently completing its report to the Legislative Assembly on its inquiry into end of life choices in the ACT. A copy of the Committee's terms of reference are attached for your information.

The Committee received submissions and evidence on issues relating to matters which are before the Royal Commission for inquiry and report. These included aspects of the current Australian approach to palliative care; particularly where palliative care is provided to persons under various forms of care including residential care, both in residential aged care facilities (RACFs), at home and in other settings.

Matters of concern raised during the committee's inquiry were also raised by the Productivity Commission in that part of its report on human services reform which deals with End of Life Care

https://www.pc.gov.au/inquiries/completed/human-services/reforms/report/01-human-services-reforms-life.pdf

Submissions to the Committee reflected views put to other parliamentary inquiries into end- of-life choices conducted in Victoria and Western Australia in the last two years

The Committee notes that the Productivity Commission highlighted the following which - reflecting a national picture - also reflect the Committee's knowledge of experience in the ACT:

- Most of the 160 000 people who die in Australia each year would benefit from end-of-life care but many do not receive care that fully reflects their choices or meets their needs. Demand for care will grow rapidly in coming years as more people enter the older age groups in which most deaths occur.

- Where it is available, the quality of end-of-life care services in Australia is often excellent. But services are not available everywhere and to everyone who would benefit. Delivery of more effective end-of-life care will require investment and coordinated action across the Australian, State and Territory Governments. (Chapter 3, PC Report, page 61)

Difficulties now confronting RACFs in providing palliative care at end-of-life are increasing, and include situations where a person requiring palliative care may have complex symptoms and needs, such as Alzheimer's, dementia, Parkinson's and terminal illness. The increasing incidence of these situations presents often considerable difficulties as to how RCAFs can - under current funding arrangements - provide palliative care as needed.

The arrangement which places responsibility for funding residential care on the Commonwealth, and for funding palliative care on State and Territory health agencies appears to be a central and key problem.

The Committee believes it is appropriate and important for the Royal Commission to address several issues to do with these current arrangements.

The Committee also agrees with a view put forward by the Productivity Commission, that:

> ... reforms are needed to ensure that people residing in residential aged care receive end-of- life care that aligns with the quality of care available to other Australians.

The Select Committee particularly wishes to submit that your inquiries address this important issue during your deliberations and in due course make recommendations to government for its consideration.

The Select Committee has included a final copy of the tabled report for your consideration and wishes you well in your endeavours.

Yours sincerely,

Bec Cody MLA
Chair
20 March 2019