



Reflections and Learnings

Assisted dying in Canada and the United States

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PalliativeCare
AUSTRALIA

Acknowledgements

This report has been developed based on information received or obtained, on the basis that such information is accurate and complete. The views expressed in this report are not necessarily the views of Palliative Care Australia.

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Introduction

This is a report of meetings conducted between 1 October – 13 October 2018 by Palliative Care Australia (PCA) Board members and PCA CEO with various associations, health services and individuals, as well as information obtained through attendance at selected sessions at the Montreal International Palliative Care Conference that related to the implementation of Medical Assistance in Dying (MAID) in Canada.

Delegation

Andrew Allsop

PCA Board Director, Vice President PCA

Liz Callaghan

CEO Palliative Care Australia

Helen Walker

PCA Board Director

Professor Lindy Willmott

PCA Board Director

Aim of visit to Canada and United States

To identify the impact on palliative care services, policy and funding and patients at the end of life of Medical Assistance in Dying (MAID) in Canada and physician assisted dying in Quebec, as well as the *Death with Dignity Act (1997)* in Oregon.

The delegation were primarily seeking to understand the lessons Australia can learn from the implementation of assisted dying in these two countries regarding the impact on palliative care, and on patients at the end of their life.

Legislative context

Assistance to die is now lawful in limited circumstances in Canada and some jurisdictions in the United States. In Canada, legislation was enacted following a decision of the Supreme Court of Canada in *Carter v Canada (Attorney General)*¹ which held that the Criminal Code provisions prohibiting physician-assisted death in all cases breached the Canadian Charter of Rights and Freedoms. Following the decision, the Canadian

Parliament passed legislation which came into force on 17 June 2016.² Under the Canadian legislation, to receive assistance to die, the person must be an adult, be capable of making health decisions, have made a voluntary request, have given informed consent, and have a grievous and irremediable condition. The legislation provides that to have such a condition:

- » the person must have a serious and incurable illness, disease or disability;
- » the person must be in an advanced state of irreversible decline of capability;
- » the person must have enduring physical or psychological suffering that is intolerable to them which cannot be relieved under conditions that are acceptable to them; and
- » the person's natural death must be reasonably foreseeable.

In addition, Quebec enacted *An Act Respecting End-of-Life Care*³ which commenced operation in December 2015. The stated objective of the Act is 'to ensure that end-of-life patients are provided care that is respectful of their dignity and their autonomy'.⁴ The Act regulates end-of-life care more broadly and includes both palliative care and medical aid in dying.⁵

Physician-assisted dying is legal in eight jurisdictions in the United States: Oregon,⁶ Washington,⁷ Vermont,⁸ California,⁹ Colorado,¹⁰ the District of Columbia¹¹ and Hawaii¹² through legislation, and in Montana by way

1 *Carter v Canada (Attorney General)* [2015] 1 SCR 331. For commentary on this case, see Downie, 'Permitting Voluntary Euthanasia and Assisted Suicide: Law Reform Pathways for Common Law Jurisdictions', <https://lr.law.qut.edu.au/article/view/613>

2 *An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)* S.C. 2016.

3 *An Act Respecting End-of-Life Care*, R.S.Q. c. S-32.0001.

4 *An Act Respecting End-of-Life Care*, R.S.Q. c. S-32.0001, s 1.

5 *An Act Respecting End-of-Life Care*, R.S.Q. c. S-32.0001, s 3.

6 *Death with Dignity Act*, Or Rev Stat §§ 127.800–127.995 (1994).

7 *Death with Dignity Act*, Wash Rev Code §§ 70.245.010–70.245.904 (2008).

8 *Patient Choice and Control at End of Life Act*, Vt Stat Ann §§ 5281–93 (2013).

9 *End of Life Option Act*, Cal Health and Safety Code §§ 443–443.22 (2015).

10 *End-of-Life Options Act*, Colo Rev Stat §§ 25-48-101 – 25-48-123 (2016).

11 *Death with Dignity Act*, Law 21-577 D.C (2016).

12 *Our Care Our Choice Act 2018* (Hawaii).

of court decision.¹³ Most States model their legislation on the Oregon model. Under Oregon law, residents of Oregon can receive prescriptions for self-administered lethal medication from their doctors provided the patient is 'capable' (able to make and communicate decisions about their health care), and has an illness expected to lead to death within six months.¹⁴ The legislation contains other safeguards.

There are significant differences between the legislative models in Canada and the United States. One important difference is relevant to how assistance to die occurs. In the United States, a prescription is given to the patient who then self-administers. There is no requirement for a doctor to be present at the time of self-administration.

Under the Canadian model (leaving aside Quebec which is also regulated by its own legislation), death can occur through the medical practitioner administering the lethal drug or through self-administration. In practice, death almost always occurs through intravenous delivery of the lethal substance by medical practitioners.

Method

Sixteen separate interviews were scheduled over the course of eight working days. In addition to this schedule, four additional interviews were held and two follow up interviews also held making a total of 22 separate interviews over eight days.

Whilst the PCA delegation were in Montreal the opportunity was taken to attend ethics stream sessions that related to the introduction of MAID or physician assisted dying offered at the Montreal International Palliative Care Conference. A total of 3 sessions were attended by the PCA delegation.

During each interview, a range of issues were explored. Following the interviews, notes were typed by Professor Willmott and Helen Walker and checked against hand written notes of Liz Callaghan. These summary documents were then checked for accuracy by Helen Walker and Andrew Allsop.

Limitations

This report has been fact checked where possible but, to a large extent, it reports on people's perceptions of how MAID and Physician Assisted Dying has operated in Canada and the United States respectively. Where participants have referred to a source, we have attempted to verify that the information is correct. The authors also do not claim that the views expressed are representative of health practitioners or the broader community or of the services or organisations that the person is employed by or represents.

The report also contains quotes from individuals. The interviews were not recorded, and the quotes are obtained from the hand-written notes of the members of the delegation. Each quote has been checked with others present at the meeting.

Overview of interview approach

Each interview explored at a macro level the following:

1. Understanding of organisation/individual perspective (baseline, introductory comments/biases)
2. How did MAID or assisted dying impact organisation/individual? Where, how, why?
3. What was the response to the impact? How did the system adapt?
4. What lessons did they learn and what does good practice look like?

The below were the topics explored during the interviews. There was some variation of the topics explored depending on the interviewee.

Preliminary observations

- 1. We are interested in your general impressions of how MAID has been working and what challenges have you faced since legalisation?**
 - a. What have been the early challenges and how have they been dealt with?
 - i. What has been unexpected?
 - b. What has been done well, and what should Australia seek to emulate?
 - c. What have been the implications for the palliative care workforce? Who is involved? What support is there? What are the credentialing processes to provide MAID?
 - d. Where [clinical setting] is MAID occurring and who is providing it?

.....
¹³ *Baxter v Montana* 224 P 3d 1211 (2009).

¹⁴ *Death with Dignity Act*, Or Rev Stat §§ 127.800-127.995 (1994), s 2.01.

Conscientious objections

2. We are interested to learn how you have handled conscientious objection from both a service and health professional perspective?

- a. Has there been respectful treatment of health professionals who are prepared to assist while others don't want to be involved?
- b. Has there been sufficient focus on conscientious objection for all health professionals involved with end-of-life care, not only doctors and nurses?
 - i. How do these differences affect teamwork and staff morale? E.g. what happens when a doctor is ok to be involved but other members of the care team may not be?
- c. Are some institutions not providing MAID, and what are their policies around referral for patients requesting MAID? What is happening in practice?
- d. How does care continue to be managed for the patient requesting MAID?
 - ii. How do the duties to refer on work in practice? How has the principle of non-abandonment been included in the referral process?

Patient outcomes

3. What are your impressions about the outcomes for patients – is the MAID process working for them?

- a. What has been done well?
- b. What could be improved?
- c. What are the implications of conscientious objections from health professionals on the care of a patient requesting MAID?

Implications for palliative care funding

4. What have been the implications of MAID on palliative care funding?

- a. Has there been any opportunities for increased funding from the increased focus on good end-of-life care?
- b. Quebec – What has been the effect of the legislative duty to make palliative care available
 - i. How is that going in practice?
 - ii. Has it made any difference to funding?
- c. Do you have suggestions for how this issue can be used to leverage additional funding for palliative care service delivery?

Position Statements

5. How have your position statements changed since the legalisation of MAID?

- a. Does your organisation have a position statement about MAID?
- b. What content would be useful for our palliative care workforce?
- c. How have the views of your palliative care workforce changed since the legalisation of MAID?

General

6. For peak health organisations – if you had your time over, what is something you, as a peak body, would do differently to support to your health workforce?

- a. What is your advice for PCA in terms of advocacy around this debate?
- b. What were the implications of your members being divided on this issue?

7. What's your advice for maintaining cohesion in the palliative care community on this topic given the mixed views of clinicians and organisations?

Input was received from the following:

Organisations

- | | |
|--|--|
| » College of Family Physicians of Canada | » Oregon Health Authority |
| » Royal College of Physicians and Surgeons | » Oregon Hospice and Palliative Care Association |
| » Canadian Society of Palliative Care Physicians | » End of Life Choices Oregon |
| » Canadian Hospice Palliative Care Association | » Canadian Association of MAiD Assessors and Providers |
| » Health Canada | » Canadian Nurses Association |
| » Canadian Medical Association | » College of Pharmacists |
| » Health Ethics Centre, Alberta | » College of Nurses Alberta |

Services

- | | |
|---|--------------------------------|
| » Centre Hospitalier de l'Université de Montréal (CHUM) | » Bay Area End of Life Options |
| » Mt Sinai | » Alberta Health Service |
| » Ontario Health Service | |
| » McGill | |
| » SickKids | |
| » Covenant Health | |

After completing interviews and consideration of ethics stream presentations at the Montreal International Conference the authors identified nine broad themes:

1. Competency and capability of sector
2. Implications of MAID on funding of and access to palliative care
3. Research and data
4. Respect and dialogue
5. Impact of MAID on palliative care sector
6. Governance
7. Patient-centered care
8. Ethical frameworks
9. Legal certainty

Patient view

Whilst the delegation did not have an opportunity to speak with people wanting to access MAID or speak to families who have participated in MAID with a family member, there was a significant discussion in different interviews regarding personal stories.

Anecdotally, interviewees report that there appears to be a key cohort of MAID requestors who are well educated, from higher socioeconomic groups and valued autonomy and control over their lives.

There was also mention of people with progressive neurological disease as being a cohort that was seeking access to assisted dying. Our understanding is that the Indigenous population is under represented in the MAID recipient cohort.

Limited qualitative data about how MAID is operating and the implications for those involved and the broader palliative care sector is not yet available in Canada. However, the need for such research has been identified and this is currently occurring.

Models of care

The key learning from our visit was the requirement to continue access and provision of palliative care, regardless of whether the patient is considering and /or seeking MAID.

In Catholic services which do not provide MAID, we were informed of the distress caused to staff when there was no communication between the MAID team and care givers in the hospice or long-term care facility. The lesson from this was to ensure shared communication between providers of care in the facility in which the patient lives or is an inpatient, and the MAID provider team.

The principle of abandonment was mentioned frequently. Unfortunately, there were some reports of the palliative care team withdrawing services once MAID was raised by patients, and some families feeling judged by their association with MAID. These issues are not in the patient's best interest and models of care that continue until the MAID process is implemented is preferred.

The delegation heard frequently that MAID is but one legal option for end-of-life care in Canada and the USA and the focus for palliative care needed to be on the delivery of evidenced based services which continue to support patients and families.

The remainder of this report discusses the themes identified opposite.

THEME 1

Competency and capability of sector

The delegation sought to explore the issues of service delivery and quality control measures that might be in place for palliative care and end-of-life services.

We were interested in exploring the safety and quality standards that might be in place in order to ensure the public is kept from harm and to improve the quality of end-of-life care. The health care system is complex in Canada. Much of the health service delivery and accreditation of health practitioners occurs at a provincial and territorial level. There did not appear to be safety and quality standards at a national level. It is possible that work is occurring at a provincial or territory level in this regard, but this was perceived to be relatively ad hoc and inconsistent across the country.

We were interested to know if health service organisations had put in place any credentialing processes in order to verify qualifications and experience of MAID providers and their ability to provide safe, high-quality services. We were of the view that a robust credentialing or competency framework would help safeguard patients.

What was explored with interviewees were issues such as quality assurance; training of health workforce; support provided to team delivering MAID and; understanding and assessment of suffering.



Findings

1. There is no national accreditation framework for MAID providers.

- » Health professionals have no additional competencies required to provide MAID.
- » Tools to assist in measuring quality may be provided at some provincial level, but are not publicly reported.

"Would have been good if provider was credentialed to carry out an assessment"

MAID provider

"There is no system of certification – every assessor should be accredited"

MAID provider

"Who is watching to see if safeguards are being followed?"

Peak body

"Quality is determined at the level of the health facility"

Peak body

2. Physicians, nurse practitioners and other health professionals directly involved must follow the rules set out in the criminal code and applicable provincial and territorial health related laws, rules and policies.^{15,16}

3. Provincial and territory governments have responsibility for determining how and where health services are provided and make rules about where MAID can take place.

- » Health regulatory colleges at a provincial and territory level may establish policies and standards regarding MAID that the providers must comply with.

4. There is no publicly available register of MAID providers.

"There is a lot of complexity in having a MAID provider list"

MAID provider

"Don't list my name, my father does not know I do this"

MAID provider

"I have not volunteered my name – ever"

MAID provider

15 Bill C-14, *An Act to amend the Criminal Code and to make related amendments to other acts (medical assistance in dying)* [Bill C-14], 1st. Sess. 42nd Parl. 2016 (first reading 14 April 2016), online: www.parl.ca/DocumentViewer/en/42-1/bill/C-14/first-reading.

16 Jocelyn Downie and Jennifer A. Chandler, *Interpreting Canada's Medical Assistance in Dying Legislation*, IRPP Report, March 2018 <http://www.camapcanada.ca/JDownie-Interpreting.pdf>.

5. Various organisations have MAID training programs, but initially physicians were self-taught.

- » Canadian Association of MAID Assessors and Providers (CAMAP) – emerged from providers of MAID who were a group of interested people. The formal association emerged because there was perceived to be a void of professional support.
 - CAMAP hold half or full day training exploring interpretation of law, context and case reviews, and have set up an online community. The perception was this support was needed particularly in the early days of MAID implementation, but the organisation is continuing to grow suggesting there is a continued need for support.
 - The association developed resources on legislative information and clinical guidelines to assist medical professionals.
- » Since then various colleges, societies and organisations provide training on MAID and have developed guidance. Training does not appear to be coordinated across organisations or provinces.

"I taught myself how to do it, there were no instructions"

MAID provider

"An online community of providers emerged early on to support each other"

MAID provider

"Training is not uniform."

Peak body

6. There was a strong perception that supports for health professionals involved in delivering MAID were insufficient, and there are also implications for the health workforce who are not involved.

- » Nurses are involved with MAID in the community, in hospices and hospital settings.
- » There are profound implications reported for those involved, both positive and negative.
- » There is much work to be done to develop training to address skill capability.
- » It was recommended that Australia consider increasing health professionals' ethical training.

"I sought support from the Canadian Medical Protection Association for every case, I would send them my notes and they would look over them for me, before I carried out procedure. Other ways of accessing support was missing in the early days"

MAID provider

"Negotiating the boundary between MAID and palliative care is difficult, it is a 'tragic dilemma' and impacts on moral identity"

MAID provider and academic

"Debriefing is not done well yet"

MAID provider

"This becomes very personal. What a practitioner goes through is huge and it is about need for interprofessional care."

MAID provider

"Give yourself a year to train doctors. I trained myself. Doctors are used to doing things they are trained to do."

US Assisted Dying provider

7. There was strong recommendation that a competency framework should be developed for clinicians undertaking MAID assessments, including exploring suffering.

"Competency in exploration of suffering is very important - there is no mandatory education for these professions"

MAID provider

"Requires education beyond entry to practice"

MAID provider and academic

"Need to ensure people have competencies - put in place a framework. Go to the old 'see one, do one, teach one'"

MAID provider

"There is no gold standard for assessing capacity, suffering or determining coercion, have to leverage your existing skill set"

MAID provider

"Need a community of practice and people need to understand definition of intolerable suffering"

MAID provider

"Important to understand how to go about evaluation of psychological suffering...is suffering subjective, objective or inter-objective?"

MAID provider and academic

THEME 2

Implications of MAID on funding of and access to palliative care



The delegation sought to explore how the introduction of MAID had impacted the delivery and funding of palliative care services.

Like Australia, reliable data on who is accessing palliative care is difficult to confirm and quantify. Australia however has more data available such as Palliative Care Outcomes Collaboration, Australian Institute of Health and Welfare, Medical Benefits Scheme, Pharmaceutical Benefits Scheme and Australia Health Safety and Quality Commission, so Australia would be better placed to be able to track access and delivery.

The delegation heard that access to palliative care was patchy across the country, but heard no evidence that people were accessing MAID in lieu of access to palliative care. Health Canada's contribution to increasing funds for palliative care has been to announce the development of a national strategy for palliative care. They were referencing what was occurring in Australia. **Health Canada hopes** there will be investment in better data collection as part of this strategy.

The issue of access to palliative care is intertwined with issues regarding access to MAID.

Findings

1. Access to palliative care in Canada is variable. *The Access to Palliative Care in Canada 2018*¹⁷ report released while PCA delegation were in Canada revealed the following:

- » Many Canadian jurisdictions name community palliative care as a priority, but few Canadians receive formal palliative care outside of hospitals. In provinces where this could be measured (Ontario and Alberta), fewer than 1 in 6 people (15%) who died in 2016–2017 received publicly funded palliative home care.
- » Little comparable information currently exists in Canada about how palliative care is delivered across the country.
- » People who received palliative home care in their last year of life were 2.5 times more likely to die at home than other home care clients.
- » Early access to palliative care is effective in reducing emergency department visits and intensive care unit stays at the end of life.
- » 80% of the time when people in hospital primarily received palliative care, the stay was unplanned or they were admitted through the emergency department. In 10% of those hospitalisations, patients had to wait a median of 9 days to be discharged to a more appropriate setting.
- » Cancer patients were three times more likely to receive palliative care than others, both in hospital and at home. Age was also a factor: adults age 45 to 74 were more likely than younger adults and older seniors to receive palliative care across most settings of care.
- » Few health care providers in Canada specialise or practise primarily in palliative care. Alberta reports that just 1% of doctors practised primarily in palliative care in 2012–2013, while 2% of licensed practical nurses across Canada in 2016 worked most of the time in this area. Data from an international survey of primary care physicians shows that Canadian doctors, on average, feel less prepared to manage care for palliative patients than do their peers in 10 other countries.
- » Variations in provincial and territorial policies, strategies, frameworks and funding models affect the organisation and delivery of palliative care services — and access to them — across the country. There are also variations within jurisdictions, with some health regions or institutions developing their own criteria regarding who qualifies for palliative care. Limitations of this report are similar to limitations in Australia:
 - Information gaps on access to palliative care, notably at the community level, where data is lacking on home care, hospice care and

¹⁷ Canadian Institute for Health Information, *Access to Palliative Care in Canada*, 2018 <https://www.cihi.ca/sites/default/files/document/access-palliative-care-2018-en-web.pdf>.

residential care: Across all sectors of care, there is a lack of data on the suite of palliative services patients receive, and on what patients and their families experience.

- The lack of a single shared definition of palliative care in Canada and common standards for delivering it in practice: Across settings of care, there is no consensus on what receiving palliative care means and what services this should include. This makes comparable measurement a challenge.

"The national government has provided \$1.5million to develop a framework for palliative care.

These are the only additional palliative care dollars we have seen so far"

MAID provider

"Our advocacy goal is universal access to palliative care...people still don't understand what hospice or palliative care is."

Peak body

2. Access to MAID does not appear to be linked to availability of palliative care services.

"We would like for everyone to have had a palliative care assessment before accessing MAID"

Peak body

"In relation to resourcing of palliative care - MAID was not the disaster expected, and palliative care is still in the same mess (financially)"

MAID provider

"People will come at this differently. Most will come saying it's an interesting option in case I can't cope with the experience. [Doctors] should be able to have exploratory conversations"

Health ethicist

"Being a MAID provider is completely consistent with palliative care"

MAID provider

3. Models developed to enable continuation of palliative care service delivery following MAID request e.g. request marked on patient record and electronically flagged so a provider of MAID could step in to provide.

- » In Alberta, the delegation met with the provisional co-ordinating team for MAID where nurses were employed as navigators of the MAID process.

"Navigators can help to ensure equity of access to palliative care and MAID"

Health ethicist

4. The financial resourcing of MAID for both clinicians and services were highlighted as issues still needing to be addressed.

- » Adequate reimbursement is an issue for providers.
- » No report of an increase in palliative care funding, and palliative care doctors in one hospital advised of decrease in funding for palliative care physicians. A palliative care physician in another hospital observed that they had many positions for palliative care trainees that they could not fill.
- » Anecdotal reports of decreasing hospice resources in situation where MAID not provided.
- » Funding varies from province to province, but reports that in one province, if a health service receives more than 50% government funding, it must provide MAID.
- » The government has invested \$25million in monitoring MAID.¹⁸

"The idea that MAID is an advantage for palliative care is wrong - there has not been a single extra clinician, it's all hot air"

Palliative care physician

"Have always had 18 palliative care trainee physicians in our service, last year we only had five. People are turning their back on the field"

Palliative care physician

18 Canadian Institute for Health Information, *Medical assistance in dying: a framework for mapping information needs*, 2017 <https://www.cihi.ca/sites/default/files/document/maid-framework-en.pdf>.

THEME 3

Research and Data

The delegation sought to explore what research and data specific to Canada had been collected and reported in regards to palliative care and MAID. The delegation attended two sessions at the Montreal International Palliative Care Conference in October 2018 that dealt with data collection for MAID. In those sessions researchers reinforced the need to be diligent in interpreting data and their sources. Current empirical data in Canada was limited regarding the experience of the health workforce in participating in MAID, so little is known about the impact MAID has had on the workforce. They recommended a longitudinal approach to qualitative data collection. Similarly, there was limited data on patient and carer experience.

It was recommended to the delegation that research in the Australian context was important, and investment is needed to monitor and evaluate the impact on health workforce, patients and carers. Data collection should include implications for the workforce, patients and carers at the time that voluntary assisted dying occurs.

Findings

1. Data should be captured for those people receiving MAID in relation to their access to palliative care. For example, in Canada between June 17, 2016, and March 31, 2017, 349 records of assisted death in hospital were identified through CIHI's Discharge Abstract Database.¹⁹ Of those patients:

- » 70% were identified as palliative at some point during their final hospitalisation; 35% were hospitalised primarily for palliative care. The proportion hospitalised primarily for palliative care was higher than for other people who died in hospital (25%).
- » 30% of all people who received assistance in dying at a hospital were identified as having palliative needs prior to their hospital admission.
- » 70% had cancer and their average age was 73.
- » 61% of people who died an assisted death in hospital had an unplanned admission (meaning they were admitted to hospital through the emergency department or by ambulance), compared with 89% of all people who died in acute care. The median length of stay for people who had an assisted death in hospital was 12 days (the legislated 10-day waiting period required between the request and receipt of the service may be relevant in interpreting this 12 day period of stay).

¹⁹ Canadian Institute for Health Information, *Access to Palliative Care In Canada*, 2018 <https://www.cihi.ca/sites/default/files/document/access-palliative-care-2018-en-web.pdf>

²⁰ Canadian Hospice and Palliative Care Association, *Online Directory of Services*, accessible at <http://www.chpca.net/family-caregivers/directory-of-services.aspx>

“Be cautious about what you think you know is happening”

Physician and academic

2. Data should be collected about experiences of all health professionals involved with MAID.

- » None of the 670 palliative care programs in the national Directory of Services²⁰ indicate whether they participate in MAID.
- » Research on the effect on physicians will be important.
- » Qualitative research describing experience of patients (those who wanted access and couldn't access, as well as those who wanted to access and did) and health providers' experience is important.

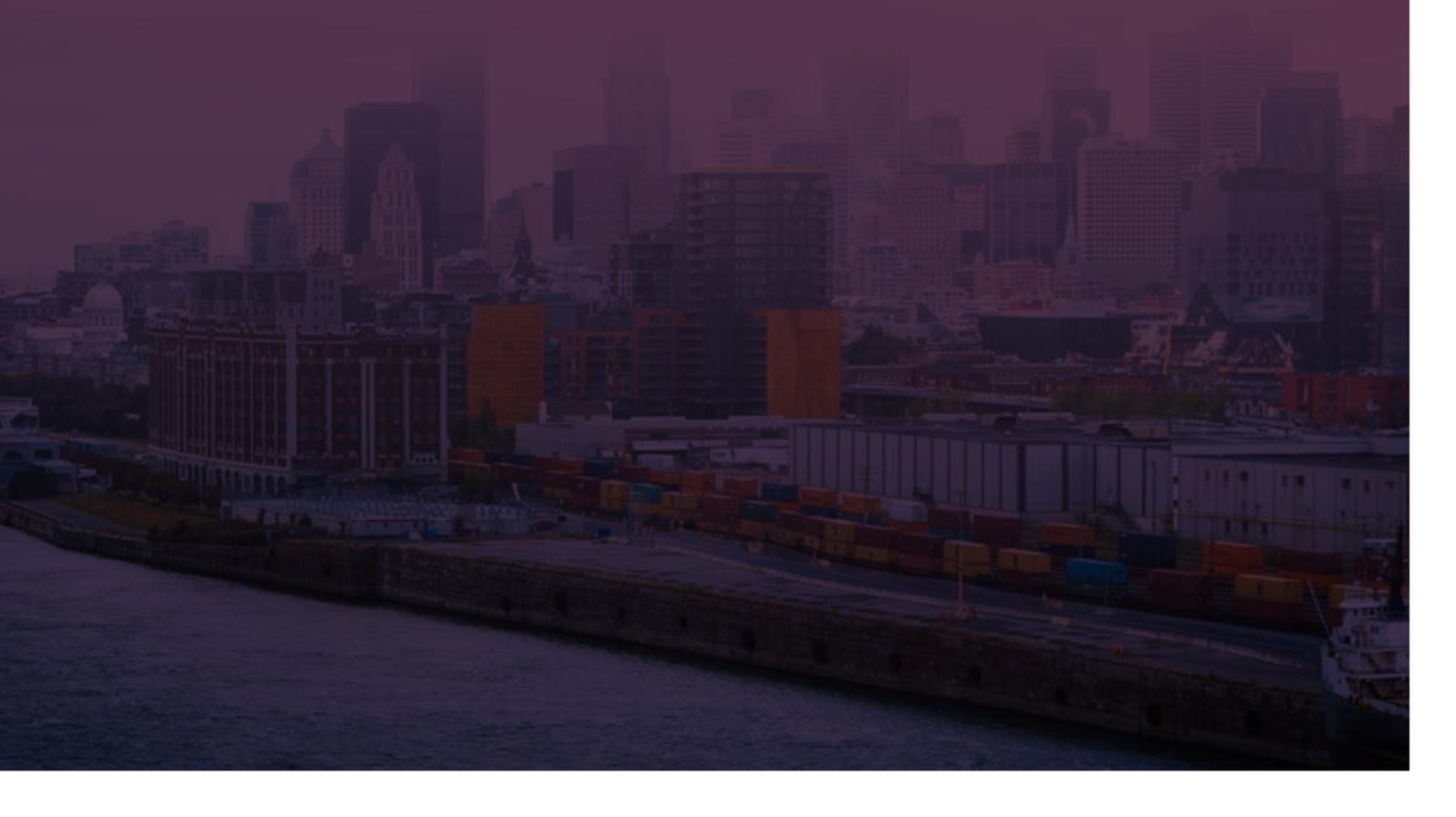
“Formal research is lacking. Don't have the voice of families or health workers”

Health service

“

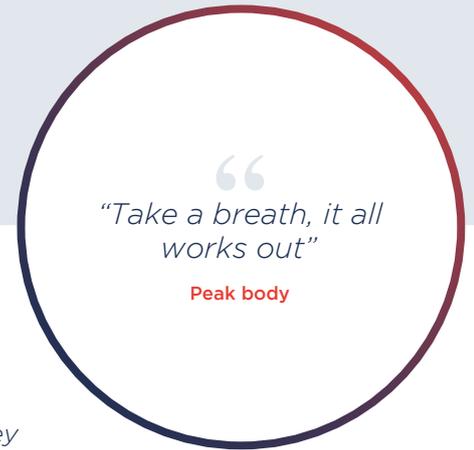
“Formal research is lacking. Don't have the voice of families or health workers”

Health service



THEME 4

Respect and dialogue



The delegation wanted to explore how the relationships between the palliative care sector and health sector more broadly were impacted by MAID. Relationships between team members, organisations and broader community were also explored.

In Canada after the decision of the Supreme Court in *Carter v Canada (Attorney General)*,²¹ the palliative care sector advocated strongly against the legislation. Once legalised, that advocacy continued to the detriment of their involvement in setting regulation and also resulted in fracturing of professional and personal relationships within palliative care. There was also a perception in the community that palliative care was trying to stop patients from accessing their legal right to MAID. Therefore, the palliative care sector’s relationship with the public and their understanding of what palliative care is and what services can provide was damaged.

It was also important to hear how the complex relationships between palliative care health professionals and their patients were affected too and this is explored in detail in theme seven.

Other messages received during the interviews included the importance of respect and maintenance of dialogue between those in the palliative care workforce who have differing opinions; moral challenge of some members of the workforce despite cognitive acceptance of MAID as a legitimate option; not allowing vilification of those with different view; and the importance of not criticising people for participating or for abstaining; as well as the need to explore cooperative models.

Findings

1. There was initially fracturing of relationships within the palliative care community, but this has improved over the last two years. All people interviewed in Canada reported a change to palliative care services since MAID introduction. Some described it as a seismic shift for palliative care. The same was described in the US State of California – “it changed quickly, hospice is a different organisation from day one to now”.

2. We heard multiple reports of fracturing within the palliative care community and consequently the sector was not able to have open discussions about MAID.

“People were yelling at me all the time”

Peak body

relaying a quote from a palliative care physician

“There is a huge fifth column - there are supporters (of MAID) within palliative care but they can’t talk about it openly.”

MAID provider

3. We heard multiple reports that supporters and objectors then realised they had more in common than no, and then started to coalesce around commonalities.

“Palliative care should take a principled approach to this and have respectful dialogue. There can be mutual respect where there is sharp division.”

Palliative care provider

“Start with common, ethical foundation in care.”

Palliative care provider

21 *Carter v Canada (Attorney General)* [2015] 1 SCR 331. For commentary on this case, see Downie, ‘Permitting Voluntary Euthanasia and Assisted Suicide: Law Reform Pathways for Common Law Jurisdictions <<https://lr.law.qut.edu.au/article/view/613>>.’

4. We heard the importance of discussion and respect within teams and organisations.

"Everybody is welcome- what unites us all is that we all care about supporting patients. We need to focus on that."

Peak body

"Need to do a work around for faith-based services."

MAID provider

"Respect for conscientious objection is important - respect both the patient and colleague's autonomy."

MAID provider

5. MAID is difficult to discuss.

"Dealing with MAID is really hard, and it should be hard"

MAID provider

"Look to the literature on the wish to hasten death. It is important to understand that patients are suffering."

MAID provider

6. There are a range of external influences (such as media) which make it difficult to retain respectful relationships within the community, and respectful dialogue is needed to resist fracturing within the community.

"Pay attention to community views."

Peak body

"Not getting public resistance in Oregon anymore but 40% of physicians are opposed still."

Peak body

7. There needs to be strong emotional support for all health professionals engaged in MAID.

"In the early days, I was called a murderer, and was vilified. In the same way objectors shouldn't feel vilified"

MAID provider

"It is wrong to criticise colleagues who are involved in something legal"

MAID provider

"Approach from a place of respect. People have been told they can't work in palliative care if they participate in MAID"

MAID provider

"British Columbia has not been a safe place for palliative care physicians to attend public meetings on this issue"

Peak body

THEME 5

Impact of MAID on Palliative Care Sector



The main purpose of the study tour was to identify the impact of MAID on palliative care – across services, workforce, funding and community. This theme was explored in all interviews to understand both qualitative and quantitative impacts. The delegation was interested to understand the extent to which MAID was integrated as a component of end-of-life care including palliative care; how access to palliative care was affected; what safeguards for palliative care patients were in place; what support for palliative care workforce was provided; safety and quality issues (see theme 1) and participation rates in MAID by palliative care physicians.

Messages received during the interviews included the impact of MAID on the workforce; the public not understanding why the palliative care community are not involved (families being angry and feel judged by palliative care if they wish to discuss MAID); potential for not accessing palliative care in order to maintain capacity for decision making; and difficulty for palliative care workforce to avoid involvement because patients are looking to them for support and advice.

Findings

1. It is difficult for the palliative care workforce to avoid being involved in MAID.

- » The public are looking at palliative care to be involved. The public doesn't understand why palliative care is not involved; families feel angry and they feel judged by palliative care.
- » Palliative care did not want to see the introduction of this practice as they thought the importance of palliative care was being diminished or neglected. But the discourse from the community was stronger.
- » There was a strong impact on palliative care membership (increase) to peak bodies – by both those in support and opposed to MAID.
- » Palliative care should be involved in discussions to ensure people who do not wish to be involved are protected and to educate the public.
- » One person viewed palliative care involvement as a mistake. *“Palliative care ward is a therapeutic environment and need to protect that”.*
- » The spectrum of palliative care involvement is changing, and patients are driving the change.

“Palliative care is only focusing on palliative care, we need to delineate the ‘specialness’ of palliative care”

Peak body (non-palliative care)

“Palliative care has to be there for everyone requesting MAID”

MAID provider

“Being a MAID provider is completely consistent with palliative care”

MAID provider

“Once MAID was in place we shifted focus to support members”

Peak body

“Keep defending palliative care, not oppose MAID”

Peak body

“Don't use ‘end of life’ anymore, only hospice, palliative care or palliative approach”

Peak body

“If I give care to a patient I am comfortable with the decision [to provide MAID] ...if I don't do it [MAID] they might stop palliative care all together”

MAID provider

2. MAID is regarded as a new end-of-life practice.

- » Palliative care and family physicians have had to challenge their own assumptions and listen to what is at stake for the community. In many ways, the issue was seen as a professional issue, with the health workforce, especially physicians needing to catch up with the legislation and community views.
- » There were multiple reports of moral distress being experienced by members of the professional and non-professional health care team where there was an interface with MAID.
- » Support for all staff and volunteers is vital to deal with moral distress.

“In terms of requests for MAID- exploration of the issue does not mean you are complicit”

MAID provider

“Nurses never use their own views to stop people accessing MAID. They can ‘co-exist’ with the right to die the MAID way”

Academic research relating to nurses

“Hospice philosophy to neither hasten or prolong death goes out the window when palliative care are now aggressively managing underlying disease in order to ... keep capacity for patients in preparation for assisted dying”

US Assisted Dying physician.

3. There are many models to facilitate access to MAID (including accommodation of conscientious objection).

- » In Ontario there is a toll free number for referrals because there are doctors who will not refer. For example Toronto supports a parallel access system. A 1800 number gets them into the system straight away. There is a team of 23 physicians who will address the referral.
- » In one hospice in Toronto, they manage conscientious objection by some palliative care physicians by noting a MAID request on the patient's chart. This generates an electronic flag that identifies when a patient expresses a wish to hasten death. The physician who has a conscientious objection can continue to provide palliative care while doctors who do not have a conscientious objection does the MAID assessment.
- » Alberta Health Service has navigators in place to assist with referrals.
- » Palliative care units have changed the way they admit patients. They have specific policies as to whether they admit just for MAID or not.

4. Palliative care services are receiving regular requests for MAID from patients.

- » Latest survey of palliative care physicians shows that most physicians explore the request for MAID and provide information. 21% are involved in undertaking assessments, 11% receive referrals for MAID and 7-8% provide MAID to their patients.²²

"Look after yourself. There are people who started doing it and now stopped"
MAID provider

"Don't do too often, but not rare. Some people change their mind, they want MAID but then decide they want a natural death"
Palliative care physician

"Sometimes patient may be concerned that doctors might not support MAID. Have had to learn how to speak about that without sounding negative towards it"
Palliative care physician

5. There is a feeling of isolation and reluctance to discuss with colleagues for fear of judgement.

- » Survey of palliative care showed that around 80% of people working in palliative care believe in palliative care but don't want to be engaged in the discussions about MAID.²³
- » MAID is seen to impact on an individual's moral identity – how we see ourselves and how others see us.

"Have to manage staff so they don't feel they are being cast aside. Don't make views a secret, be transparent"

Peak body

"Values are in conflict. MAID interrupts the end of life"

Academic research relating to nurses

"I thought if I accepted to do MAID then I am not a doctor anymore, as this is not part of health care"

Physician and academic reporting view of palliative care physician providing MAID

6. Allied health and pharmacy professionals were left out of consultations and policy decisions.

- » Their views were not sought and were not engaged in discussions around implementation, regulation or training. As a result they have had to adapt to the changed environment quickly.

22 Canadian Society of Palliative Care Physicians, *CSPCP Medical Assistance in Dying Results*, October 2017 <https://www.cspcp.ca/wp-content/uploads/2018/02/CSPCP-MAID-survey-report-Feb-2018.pdf>

23 Ibid.

THEME 6

Governance

The delegation sought to hear experiences of how health professionals and organisations were involved in the development of regulation and policies around MAID.

The delegation's impression was that regulation could have benefited from palliative care expertise being involved as early as possible. Failing to consider palliative care and how it sits with the provision of MAID, has resulted in a retrospective management of how these practices can co-exist for the benefit of the patient. MAID is now regarded as one possible option at the end of life, and it is therefore important for the palliative care community to be part of conversation around its regulation.

Findings

1. Medical, nursing and palliative care organisations have taken different approaches to engagement with the development of MAID regulation and practice.

- » Because delivery of health services is regulated at a provincial and territorial level, MAID has been implemented differently across Canada.
- » Palliative care should be asking to track resource implications for MAID, including workforce implications. This data should be part of the collection of broader health care system related information as well as cost data.

"Palliative care community was not involved. They should come to the table - and will need to be involved whether they want to or not."

MAID provider

2. There has been pressure on organisations to have a position either for or against MAID.

- » A variety of positions have been taken including positions that are:
 - agnostic;
 - oppositional to reform; and
 - actively engaged to develop position or policies in advance of a change of law.

3. The palliative care community should be a part of the conversation around regulation.²⁴

- » Being part of the conversation would enable the palliative care community to advocate for access to health services generally including palliative care, and ensuring there is a sufficient workforce to deliver palliative care as well as MAID.
- » If palliative care is not part of these conversations then most likely all regulators hear are 'bad stories' about end of life care.

4. Nurses experienced difficulty having a place at the table (and, under the Canadian model, nurse practitioners can be MAID providers).²⁵

24 Canadian Society of Palliative Care Physicians, *Input on proposed regulations for the monitoring of medical assistance in dying*, February 2018 <https://www.cspcp.ca/wp-content/uploads/2018/02/CSPCP-Input-on-MAiD-Reporting-Requirements.pdf>

25 Canadian Nurses Association, *Ethics in Practice - Respecting choices in end-of-life care: Challenges and Opportunities for RNs*, 2015 <https://canadian-nurse.com/-/media/canadian-nurse/files/pdf%20en/respecting-choices-in-end-of-life-care.pdf>

“

“Palliative care should take a principled approach to this and have respectful dialogue. There can be mutual respect where there is sharp division.”

Palliative care provider



THEME 7

Patient-centered care

“
The barrier that
palliative care puts up
doesn't protect palliative
care from MAID; it protects
palliative care from
patients”

MAID provider

The extent to which the relationship between palliative care and their patients was affected by MAID was explored by the delegation. It became obvious very quickly in Canada two years since legalisation that relationships with patients was paramount and the issue of non-abandonment of patients was predominant in all conversations. In Oregon where the legislation has been in place for nearly two decades, we heard that palliative care works closely with physician assisted dying providers to ensure the patient is at the centre of all care.

The concept of non-abandonment was very important in all of our consultations.

Findings

1. Non-abandonment of the patient is central to all considerations around MAID.

- » The duty of non-abandonment appears in some of the position statements eg Canadian Medical Association²⁶ and College of Family Physicians.²⁷
- » Some faith based services have developed practices to ensure focus on patient centred care first and foremost. This can include developing policies around transfers, and also allowing MAID providers entry in order to undertake assessments.
- » Patient experience was less than ideal in some cases where physicians or the health service had a conscientious objection against providing MAID.
 - Examples include MAID assessments being conducted in parks (as MAID assessors not permitted in the health service), and a physician pretending to be a visitor in order to undertake a MAID assessment.
 - Rapid effective transfer where the health service does not carry out MAID doesn't occur universally.
 - We heard stories of people dying in ambulances in the process of being transferred to access MAID.

“Hospices are opening their doors for families of people who signed up to MAID”

Peak body

“We're in this together, put the patient at the centre”

MAID provider

“How do we deal with the fact that 80% of the community want access to MAID?”

Peak body

“Have started to talk more about person-centred care, for example transferring care at the end of life”

Palliative care peak body

2. The bereavement experience associated with MAID was identified as an issue requiring further exploration.

3. Patients should be allowed to request MAID and health services and health professionals who conscientiously object should ensure an effective referral or transfer to another facility.

4. Some palliative care physicians are prepared to provide palliative care alongside MAID.

- » Palliative care physicians who are involved in MAID or who are working in services where MAID is provided said that in their assessments they firstly explore what problems the person is having 'right now'.
- » Those physicians involved in assessments explore in detail the patient's suffering, what treatments they have had and what ones they could consider.

“MAID is not a failure of palliative care”

MAID provider

26 Canadian Medical Association, *Medical Assistance in Dying Policy Statement*, 2017. https://www.cma.ca/Assets/assets-library/document/en/advocacy/EOL/cma_policy_medical_assistance_in_dying_pd17-03-e.pdf.

27 The College of Family Physicians of Canada, *A Guide for Reflection on Ethical Issues Concerning Assisted Suicide and Voluntary Euthanasia*, September 2015. https://www.cfpc.ca/uploadedFiles/Health_Policy/_PDFs/Guidefor%20Euthanasia_EN_Final.pdf.

5. Patients choosing MAID early because of concern around retaining capacity.

- » Some palliative care physicians expressed concern that some patients are seeking MAID earlier than they would like to ensure they still had capacity to make the final request (as required by the legislation).
- » Some palliative care physicians expressed concern that some patients were not taking medication to relieve their pain out of concern that this may affect their capacity to make the final request (as required by the legislation).

"MAID should be difficult to get. Everyone has a right to eligibility assessment and the right to explore it. But in order to reduce requests for MAID we should introduce palliative care early in the illness"

MAID provider

"I say to patients 'I want to understand why you have refused (x or Y treatment / medication), and when did you start thinking about MAID and what would you do if you did not access MAID'"

MAID provider

"Faith based services have adopted approach to transfer patients home for MAID, but rapid effective transfer doesn't happen"

MAID provider

"Effective transfer home for patients seeking MAID happens"

Faith based palliative care provider

"Palliative care services are faced with moral distress in having to deal with voluntary stopping of eating and drinking of patients so they can get closer to be assessed as suitable for MAID"

Health ethicist

6. Some MAID providers commented that there is no gold standard for assessing capacity, suffering or coercion.

- » Existential suffering is the most difficult to alleviate.
- » MAID providers who were interviewed felt that they were confident in being able to assess capacity and coercion. Different views were expressed about the extent to which patient 'suffering' should be explored.

"There are different types of suffering - existential, physical and psychological. There is nothing that can be offered for existential distress"

MAID provider

"Existential distress often relates to being a burden, it doesn't mean that others are pressuring you"

MAID provider

7. There are inconsistencies of access to both palliative care and MAID services depending on where you lived.

"Not a choice if MAID is your only option"

Peak body

8. In Oregon, the consistent message we received was that it is difficult for the patient to access physician-assisted dying as the process is very much patient driven.

"You have to be assertive about your medical care....You have to really want it in Oregon to get it"

Oregon Health Organisation

THEME 8

Ethical framework



As described in theme seven, the palliative care workforce have come to a point where they remain committed to their relationships with patients and families. There has been deep consideration of the physician/patient relationship and the duty to do no harm as well consideration of patient autonomy and the limitations of medicine. This area of healthcare involves complex issues that deserve careful attention and should involve ethical deliberations.

The onus remains with palliative care to engage in ethical deliberation on what this legal change means for them and the implications for their practice and patients.

Findings

1. There was variation in how physicians saw their participation in MAID. Some saw it as part of social accountability of medicine. Others have very different views.

"To come to the point that this is ethical is a major shift"

MAID provider

"If you are crossing that ethical line, better make sure you get it right"

MAID provider

"In your position statement, you should go one step further and say that it's OK for palliative care to talk about it and it's OK to do it"

MAID provider

"Need to understand your own moral view in order to meet the needs of the patients and providers, and to be as neutral as possible"

Health ethicist

2. Health professionals need space and time to discuss ethical frameworks.

- » The College of Family Physicians drafted a policy to provide guidance about how to consider ethical issues around MAID.²⁸
- » The College's policy provides guidance around non-abandonment of the patient for doctors who conscientiously object to providing MAID.
- » Many recommended ethics education for the health workforce around this issue, and to ensure educators have ethics training.

"To make a decision about whether to provide MAID requires knowledge, time to reflect and a body of literature to draw upon"

MAID provider and academic

"82% of (nurses) believe personal beliefs inform their practice"

MAID provider and academic (small sample)

"What are the moral issues you have to address? You need to try and get people comfortable"

Health ethicist

3. While MAID expands choices at the end of life, there are limits to this autonomy.

- » Everyone has the right to be assessed for MAID but not everyone has the right to access MAID (given the eligibility provisions of the legislation).
- » In some cultures, the emphasis on individual autonomy is not as relevant.

28 The College of Family Physicians of Canada, *A Guide for Reflection on Ethical Issues Concerning Assisted Suicide and Voluntary Euthanasia*, September 2015 https://www.cfpc.ca/uploadedFiles/Health_Policy/_PDFs/Guidefor%20Euthanasia_EN_Final.pdf

THEME 9

Legal certainty

The delegation heard many times that those participating in MAID were concerned about some uncertainties regarding the Canadian legislation. There are also reviews underway regarding whether the legislation should be extended to apply to mature minors, individuals with mental illness, and a request made in an advance directive. There are also some Constitutional challenges relating to the legislation in progress through the legal system.

Findings

1. There is a lack of certainty around some aspects of the legal framework in Canada which causes concern for MAID providers.

- » There have been interpretative problems particularly around what “foreseeable death” means, and how close to death a person must be to satisfy this criterion.

2. When the Canadian legislation was enacted, reviews (to report by the end of 2018) were also established to determine whether the law should be extended in the following three ways:

- » Mature minors,
- » Individuals with a mental illness only,
- » Advanced request for MAID.

3. Administrative burden and red tape may be a barrier to MAID access for some patients and perhaps to a greater extent to individuals in the United States (see further theme 7).

- » There are rigorous safeguards in place including waiting periods which may mean that the person dies after requesting MAID but before MAID is provided.
- » Because there is a requirement to reaffirm the wish for MAID at the time of delivery of MAID, people are choosing to access MAID earlier in case their capacity is lost.
- » Copious paperwork must be completed as part of the process (and reports of more than 12 pages of paper work required for each assessment).

4. There is a lack of legal support for providers.

- » Early on, some MAID providers forwarded documentation to Canadian Medical Protection Association to get advice (before provision) to ensure they were acting in a legally compliant manner.

Conclusion

The delegation came away with a much clearer understanding of how MAID and physician assisted dying systems operate in Canada and the US and its impact on palliative care services, policy and funding as well as on people at the end of life. This report will be used by Palliative Care Australia to inform future policy statements, engagement with the health sector and advice to governments. The delegation would like to thank all interviewees for their generosity in sharing their experiences.

Appendix

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Palliative Care Australia Limited ABN 85 363 187 904

P: 02 6232 0700

Unit 8, 113 Canberra Avenue PO Box 124

E: pca@palliativecare.org.au

Griffith ACT 2603

Fyshwick ACT 2609

www.palliativecare.org.au



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