

# RACP Submission: Victorian Government Discussion Paper on a Voluntary Assisted Dying Bill

April 2017

#### Introduction

The Royal Australasian College of Physicians (RACP) wishes to provide its feedback in relation to the questions raised in the Victorian Government Discussion Paper on a proposed Voluntary Assisted Dying Bill. **However, our submission must not be viewed as support for medical assistance in dying.** 

There is a wide range of opinion within the RACP Fellowship regarding the implementation of medical assistance in dying and the more fundamental question of whether it should be legalised.

The RACP is currently developing a position on the issues in consultation with the membership. The purpose of our submission is to 1) highlight the impact that the introduction of a scheme for medical assistance in dying would have on physician practice in Victoria, particularly for palliative medicine specialists, 2) highlight the impact on patients, bereaved families and carers and other health professionals; and 3) provide advice on issues that should be considered if the Victorian Government proceeds with legislation on this issue.

A key issue observed by the RACP is that the proposed framework is heavily based on individual autonomy and does not adequately address the context in which end of life decisions are made, and the significant role of family and carers.

### Terminology used in this submission

In this submission, the term *medical assistance in dying* refers to the following treatment provided at the request of a patient by a medical practitioner or those with appropriate prescribing rights, and includes:

- i. The prescription or supply of a lethal drug which a competent patient self-administers without further assistance; or
- ii. The administration of a lethal drug to a competent patient requesting assistance to die.

The following are not considered to be medical assistance in dying and are well established end of life practices:

- a. Refusing life-sustaining treatments: Patients with capacity have the right to refuse treatment including the provision of medically assisted nutrition and/or hydration
- b. Withholding or withdrawing treatments that are not benefiting the patient: physicians have a duty to consider the benefits and harms of any treatments including the provision of medically assisted nutrition and/or hydration before instituting them. The benefits and harms of ongoing treatment should also be regularly reviewed
- c. Providing appropriate palliative sedation to manage refractory symptoms
- d. Titrating medical treatment to relieve symptoms even if it may have the perceived potential to hasten death.

## **Background**

Legalisation of medical assistance in dying is a highly contentious and divisive issue, raising a number of ethical, social, legal and religious concerns. Arguments for and against legalisation are well-articulated in the medical literature and public discourse.

Individual patient situations at the end of life are often not straightforward. Assessment of quality of life, capacity and prognosis can be contested. If the law were changed to allow medical assistance in dying in certain circumstances, physicians would be required to assess many complex issues. Our experience tells us that there would be many patients who would not fit neatly into particular rules or situations and working through these issues would push any boundaries that are set.

## **RACP** position on medical assistance in dying

The RACP is in the process of establishing a position paper on medical assistance in dying, in consultation with its membership.

While this policy work is underway, the RACP has drawn on consultations with key College bodies as well as our broader membership to inform this submission. These include the College's Euthanasia and Physician

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Assisted Death Working Party, Ethics Committee, the Australasian Chapter of Palliative Medicine Committee, and the RACP Victorian State Committee.

Regardless of the many issues raised by legalising access to medical assistance in dying, the RACP holds that physicians and society have a duty to provide high quality end of life care to patients and their families and carers. This is set out in the RACP's position statement <u>'Improving Care at the End of Life: Our Roles and Responsibilities'</u> (May 2016), the RACP advocates for:

- High quality end of life care for patients and the duty of all physicians to provide this;
- Open and honest communication with patients about impending death;
- A doctor-patient relationship based on openness, trust and good communication;
- The positive contribution a physician can make to end of life care; and
- Acknowledging and respecting different cultural preferences and approaches to death and dying and providing culturally sensitive end of life care.

The RACP recognises that medical assistance in dying as defined above is distinct from the practice of palliative care. It should be noted that the Australian and New Zealand Society of Palliative Medicine has strongly stated that the practices of euthanasia or assisted suicide are not part of the Palliative Medicine discipline.<sup>1</sup>

## **RACP** response to Discussion Paper questions

This submission focuses on selected questions in the Discussion Paper. These have been numbered based on the order they appear in the Discussion Paper for easier reference.

#### Page 14 - Confirming a request

# 11. Should the legislation prescribe specialist expertise required for medical practitioners to participate in voluntary assisted dying?

If medical assistance in dying is legalised, the RACP would support the safeguards proposed by <u>AMA Victoria</u> that relate to participating medical practitioners having:

- developed an adequate (preferably long-term) professional relationship with the patient
- a sufficient understanding of the patient's preferences and values in relation to end of life care:
- an informed understanding of the patient's medical condition.<sup>2</sup>

Participating practitioners would also have to be properly skilled in a number of domains, and would have to be qualified in the diagnosis and prognosis of the specific medical condition. The Victorian Government could consider setting out the domains of expertise required to provide medical assistance in dying, rather than circumscribing it to a particular profession or qualification level, which could create restrictions to access, or lead to an inexperienced medical practitioner confirming a request. For example, a neurologist who specialises in stroke care, and holding qualifications in neurology, may still not have sufficient experience of motor neurone disease management to be able to discuss prognosis in detail, or answer questions about the role of artificial ventilation.

#### 12. Should there be a requirement for a palliative care specialist referral or consultation?

Specialist physicians trained in palliative care are commonly part of the multidisciplinary team caring for and monitoring patients at the end of their lives. This involvement is often essential to ensure that patients are well managed. Every patient should receive timely, equitable, good quality end-of-life care, including access to specialist palliative care where appropriate.

Referral to specialist palliative care should be strongly recommended for patients considering medical assistance in dying. However, the RACP would not recommend mandatory palliative care referral or consultation after a request has been made, for a number of reasons:

<sup>&</sup>lt;sup>1</sup> Australian and New Zealand Society of Palliative Medicine (2013). Position Statement - <u>The Practice of Euthanasia and Assisted Suicide</u>

<sup>&</sup>lt;sup>2</sup> AMA Victoria (Dec 2016) Physician Assisted Dying Position Statement

- The provision of assisted dying must not be seen as part of palliative care as already stated, these
  are distinct practices
- Referral or consultation is not mandated for any patients under existing arrangements
- Legalisation of medical assistance in dying in any form will create significant challenges for palliative medicine specialists and palliative care organisations
- The risk that involvement of palliative care referral and/or consultation is simply seen as, and becomes, a procedural step or 'tick the box' exercise.

At the very least, patients must be made aware of the benefits that palliative care can offer at the end of life.

To this end, the Victorian Government should make information on palliative care available for patients and their carers through a neutral and centralised information service. Such a service could assist with informed consent and offer additional support by (amongst other methods):

- providing patients with consistent information
- providing information in accessible formats, and
- supporting practitioners and healthcare institutions in answering questions from patients, families, carers and other members of the health care team.

#### Page 15 - Conscientious objection

- 13. How should conscientious objection to voluntary assisted dying operate?
- 14. Should health practitioners who conscientiously object be required to refer patients to other health practitioners?
- 15. Should health practitioners who conscientiously object be required to declare their objection? If yes, when should this occur?

Many physicians consider that providing medical assistance in dying is not within the professional boundaries, or authority of physicians.<sup>3</sup>

In general where objections of conscience have arisen in medical practice in Australia, clinicians have accepted they should refer patients to another practitioner. However, for some physicians the moral impact of referring a request for medical assistance in dying to a willing practitioner may be felt deeply. The RACP holds that physicians should not be forced to refer, but neither should they hinder patients from accessing such services.

It must also be acknowledged that this affects not only the medical practitioner but the multi-disciplinary team treating the patient. Conscientious objection may also occur for individuals within multidisciplinary teams or at an institutional level.

The matter of conscientious objection may present issues in certain settings, for example inpatients who may be within an objecting hospital or hospice, who are unable to go to another clinic; practitioners who would perform medical assistance in dying but are not accredited at that site; and patients living in rural areas serviced by an objecting practitioner(s).

The Victorian Government should consider establishing in legislation a neutral intermediary body to maintain an opt-in confidential list of participating practitioners and to create links with providers where appropriate. As part of this arrangement the Government could consider involving others such as patients themselves, family members and other health professionals in linking patients with an intermediary body.

Requirements for participating practitioners should still apply, in that they must have:

- developed an adequate (preferably long-term) professional relationship with the patient
- a sufficient understanding of the patient's preferences and values in relation to end of life care;
- an informed understanding of the patient's medical condition.<sup>4</sup>

<sup>&</sup>lt;sup>3</sup> The RACP notes the World Medical Association Declaration on Euthanasia which states that deliberately ending the life of a patient is unethical:

<sup>&</sup>quot;Euthanasia, that is the act of deliberately ending the life of a patient, even at the patient's own request or at the request of close relatives, is unethical. This does not prevent the physician from respecting the desire of a patient to allow the natural process of death to follow its course in the terminal phase of sickness."

World Medical Association (1987) <u>WMA Declaration on Euthanasia</u> - Adopted by the 39th World Medical Assembly, Madrid, Spain.

Having a centralised body such as this managing conscientious objection may also go some way to alleviate very difficult conversations between patients and treating physicians. However, this must be on a voluntary basis.

Protections should be available for participating or objecting practitioners who do not wish to be identified. Some practitioners might encounter stigma, victimisation, harassment and other issues if a public register of practitioners is mandated. It should also be recognised that some practitioners may be potentially willing to participate in medical assistance in dying for eligible patients in limited ways e.g. in a limited range of cases, or in only providing a second opinion.

#### Page 18 - Attendance

## 19. Should a health practitioner be allowed to be present at the time the person self-administers the lethal dose of medication? If so, what should their role and obligations be?

If medical assistance in dying is legalised, attendance may put treating physicians in a difficult situation – opening up the risk of a physician refusing care to a patient at a time of significant vulnerability and of major physical and existential need.

The RACP suggests that there be no statutory prohibition to attendance by a health practitioner, and that the patient and the health practitioner should both be freely able to request or decline the health practitioner being present.

However, the role and obligations of an attending practitioner are important considerations that require close examination. If a health practitioner is present, comprehensive guidance should be available covering what to do in a range of scenarios e.g. management of side effects, if the patient does not die in the expected time period, failure of self-administration or if the lethal dose of medication is not effective.

#### Page 19 - Lethal dose of medication not effective

## 20. What should the obligations of a health practitioner be to treat a person who has chosen to ingest a lethal dose of medication?

This question raises different issues depending on the "health practitioner". Documentation indicating that a person has chosen to take a lethal dose of medication would have to be readily available to ensure any treatment provided accords with the patient's wishes. Possible scenarios include:

- A medical practitioner in attendance when the patient ingests and the lethal dose of medication has not been effective
- A medical practitioner in the Emergency Department receiving a patient who has ingested the medication but it has not resulted in the death of the patient
- A medical practitioner in the Emergency Department receiving a patient who has ingested the medication and the family request treatment because they do not agree with their decision to end their life
- A paramedic called to a patient who has ingested the medication but it has not been effective
- A paramedic called by the family to a patient who has ingested the medication because the family do not agree with their decision to end their life.

Clear guidelines would have to be developed to assist and protect all individuals involved in the above scenarios before, during and afterwards. These must be developed by the Victorian Government in consultation with the medical profession and other relevant health professions.

#### 21. What is the best way to indicate that a person has chosen to take a lethal dose of medication?

It is important that individuals draw the right conclusions when faced with an unexpected death. A number of issues may arise here, for example, if the patient's family is not aware of their decision. The Californian process, whereby a person must lodge a form when they plan to ingest the drug within the next 48 hours, could be a reasonable way of being able to identify a person who has chosen to take a lethal drug via medical assistance. However, it is unclear whether this would create unwanted administrative burdens, for example,

<sup>&</sup>lt;sup>4</sup> AMA Victoria (Dec 2016) Physician Assisted Dying Position Statement

for paramedics needing to check whether a form had been lodged for every unconscious person they attended

#### Page 20 - After a person has died

#### 24. Should death as a result of voluntary assisted dying be a reportable death?

Death brought about via medical assistance in dying must be reported in some form to enable audit of the scheme. It is acknowledged there may be some stigma felt by individuals in knowing that medical assistance in dying may be listed as the cause of death on the death certificate; however there is significant public interest in having this information available in a de-identified manner. The Victorian Government could consider enabling both the immediate and underlying causes of death to be listed.

#### Page 22 - Oversight

# 25. What information should a medical practitioner be required to report to an oversight body such as the Assisted Dying Review Board?

All records in connection with a medically assisted death should be provided to a central body for transparent monitoring, and to enable important research on areas such as uptake, the reasons for requests, and requests amongst vulnerable groups. There should be a two stage process, which includes recording the request, requests which are declined, and patients who change their mind following a request.

At a minimum, a central database of all who have requested and been approved to access medical assistance in dying and a research programme that reports the outcomes of the new legislation over time will be necessary to track uptake and outcomes. Accurate and explainable records of all deaths that occur due to medical assistance in dying should be maintained.

Safeguards are needed to prevent the diversion of the lethal drug by, for example, a bereaved family member. Patient level reporting processes for pharmacovigilance must also be built into any proposed scheme.

#### Page 23 - Additional safeguards

#### 30. Does the Parliamentary Committee's framework provide sufficient protection to vulnerable people?

No – the RACP has the following concerns with regard to the many groups with poor access to good end of life care, and risks to individuals who do not fit the criteria or who do not want a medically assisted death. There is also the risk of coercion of vulnerable patients, which will be difficult to completely safeguard against,

#### Groups with poor access to good end of life care and palliative care

Individuals with poor access to good end of life care may choose medical assistance in dying even though symptom relief and a peaceful death could have been provided if they had had appropriate access to end of life care.

It is important to highlight the evidence that inequitable access to consistent, good quality end-of-life care persists for many groups of our citizens. This includes people from Culturally and Linguistically Diverse backgrounds, Aboriginal and Torres Strait Islander people, people with intellectual disability - acquired or congenital , patients dying from diseases other than cancers, and people living in residential aged care facilities, some of whom are under 65 years of age, living with a chronic disease. Inconsistent care is more prevalent in rural and remote communities in Australia.<sup>5</sup>

The quality of healthcare that patients receive towards and at the end of life also significantly affects the patient, and their family, friends and carers.

#### Individuals who do not fit the criteria or who do not want a medically assisted death

There is a risk that such legislation would compromise the treatment or palliation options available for people who do not fit the criteria or who do fit the criteria but do not want a medically assisted death. If medical

<sup>&</sup>lt;sup>5</sup> Queensland Health: Statewide strategy for end-of-life care 2015

assistance in dying is legalised, a contemporaneous legal provision clarifying double effect<sup>6</sup> must be introduced to avoid any implicit assumption that those experiencing severe suffering who do not fit the criteria or who do not want a medically assisted death cannot receive treatments which might, as an unintended secondary consequence hasten their deaths. Of particular note, the appropriate titration of opioid medication for pain control toward the end of life does not hasten death, despite commonly held misconceptions.<sup>7</sup>

#### 31. What other additional safeguards could be considered

#### Improving end of life care

If medical assistance in dying is legalised, the Victorian Government must remain vigilant in the areas of palliative care and aged care, and adequate resourcing to ensure that good end of life care is being delivered to people in Victoria. This should be seen as a safeguard to ensure medical assistance in dying is a genuine 'choice' and to protect vulnerable people.

The RACP's position statement 'Improving Care at the End of Life: Our Roles and Responsibilities' (May 2016) makes a number of recommendations in this regard.

#### Evidence-based review period

It is recommended that a five-year review period be included in legislation. As a minimum a parliamentary committee should scrutinise the data collected and the operation of the legislation. This might lead to amendment or further public consultation. If the introduction of medical assistance in dying is found to have negative or unintended effects, there must be a mechanism to review or withdraw the legislation and to examine and manage problems arising in practice, unforeseen or otherwise.

#### Data collection

A system for the careful and thorough collection of data is essential for monitoring the effects of legalisation. This system must be part of any proposed legislation. Monitoring should cover a range of areas including reasons for requests, conscientious objection, disposal of unused lethal medication, and impact on suicide rates.

#### Page 25 - Further issues

# 34. Are there any further issues related to the Parliamentary Committee's recommended framework that require the Ministerial Advisory Panel's consideration?

#### Complexities of practical scenarios

The range of complexities potentially involved should the Bill be legislated have not been considered fully in the Discussion Paper – for example in the following scenarios relating to administration of a lethal drug:

- The patient is too frail to take the medication so a family member, who is at the patient's bedside, holds it for the patient and in effect gives it to them;
- Scenario as above, but the family member holds the cup containing the lethal drug in liquid form as well as a straw to the patient's mouth;
- The patient ingests the medication by self-administering it into a feeding tube;
- The patient is physically unable to take the medication but is able to independently direct a machine to administer the medicine.

#### Support services for conflict, bereavement and distress

The RACP recommends that the Victorian Government should provide adequate family support, counselling and conflict mediation services as part of this process. The proposed model for medical assistance in dying is based on individual autonomy and does not acknowledge that end of life decisions are not made in a vacuum.

<sup>&</sup>lt;sup>6</sup> Where the administration of treatment or other action intended to relieve symptoms of suffering may have a secondary consequence of hastening death

<sup>&</sup>lt;sup>7</sup> Sykes N, Thorns A. Sedative use in the last week of life and the implications for end-of-life decision making. Arch Intern Med. 2003 Feb 10;163(3):341-4.

It does not acknowledge the role, or the effect on family, carers and other loved ones. There is no mention in the proposal about what support systems will be provided for individuals, families and health professionals who may be involved, regardless of whether or not the patient ultimately proceeds with a medically assisted death.

This must be dealt with in any proposed framework, perhaps as an extended role of an Assisted Dying Review Board. The impact of conflict and bereavement can be considerable, as can the stress on individual doctors receiving requests on a regular basis, and at varying levels of involvement. Doctors may, for example, face pressure from patients who are deemed not to meet the criteria for access. Patients may also face pressure or coercion from family members or carers.

Medically assisted deaths may also lead to enduring conflict and complex grief for remaining family members, carers and health professionals. Physicians may be placed in very difficult situations when an individual wants medical assistance in dying but family members disagree with their decision, and the family may blame the physician if it goes ahead. Evidence shows that many doctors who have participated in medical assistance in dying experience emotional distress. <sup>8,9</sup> If a proposal is legalised in Victoria, there is a clear need for education, support and guidance for bereaved family members and health professionals.

#### **About The Royal Australasian College of Physicians**

The RACP trains, educates and advocates on behalf of more than 13,500 physicians – often referred to as medical specialists – and 5,000 trainees, across Australia and New Zealand. The College represents more than 32 medical specialties including palliative medicine, paediatrics & child health, cardiology, respiratory medicine, neurology, oncology and public health medicine, occupational & environmental medicine, sexual health medicine, rehabilitation medicine and addiction medicine. Beyond the drive for medical excellence, the RACP is committed to developing health and social policies which bring vital improvements to the wellbeing of patients. <a href="https://www.racp.edu.au">www.racp.edu.au</a>

<sup>&</sup>lt;sup>8</sup> Emanuel EJ, Onwuteaka-Philipsen BD, Urwin JW, Cohen J. Attitudes and Practices of Euthanasia and Physician-Assisted Suicide in the United States, Canada, and Europe. <u>JAMA.</u> 2016 Jul 5;316(1):79-90. doi: 10.1001/jama.2016.8499.

<sup>&</sup>lt;sup>9</sup> Stevens KR Jr. Emotional and psychological effects of physician-assisted suicide and euthanasia on participating physicians. Issues Law Med. 2006 Spring;21(3):187-200.