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The Royal Australasian College of Physicians

## **Statement on Voluntary Assisted Dying**

November 2018

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## The RACP Statement

The RACP respects and supports all its members and does not believe it is appropriate or possible to enforce a single view on a matter where individual conscience is important. The RACP recognises that legalisation of voluntary assisted dying is for governments to decide, having regard to the will of the community, to research, and to the views of medical and health practitioners.

Legislative change related to voluntary assisted dying will affect individual members in different ways. Different clinical settings require ethical and clinical considerations to be made carefully, deliberately and systematically. Our members are not unanimous in their support or opposition for legislative change. The existence of divergent views constrains the RACP from developing a single position on the legalisation of voluntary assisted dying.

The RACP takes the following unified positions *if and where voluntary assisted dying is legalised*:

- Every patient should have access to **timely, equitable, good quality end-of-life care**, with access to specialist palliative care where appropriate. These services must not be devalued.
- On the specific issue of a competent adult in the last stages of incurable illness requesting voluntary assistance to die, the RACP supports a clinical approach of critical neutrality to encourage reflective dialogue.
- Although physicians should **not be forced to act outside their values and beliefs**, they also should not disengage from patients holding different values and beliefs, without ensuring that arrangements for ongoing care are in place.
- Patients seeking voluntary assisted dying should be made **aware of the benefits of palliative care**. Referral to specialist palliative care should be strongly recommended but cannot be made mandatory. Voluntary assisted dying **must not be seen as part of palliative care**.
- Legitimate concerns exist around **protection of vulnerable individuals or groups**. Government, society and physicians must ensure that specific groups have equitable access to palliative and end-of-life care, and that relationships of trust are not jeopardised. Specific regard must be given to cultural and Indigenous experience.
- All physicians must affirm the value of all patients' lives, exploring reasons for requests for voluntary assisted dying, while remaining alert to any signs of coercion and reduced capacity.
- Assessments **must not follow a 'tick box' approach**. They must be underpinned by adequate physician-patient relationships, including appropriate training, skill and experience.
- **Support, counselling and conflict mediation services** must be available for individuals, families and health professionals involved.
- There must be **rigorous documentation and data collection** to enable review of any scheme and to assess changes in practice and the impacts on health professionals, patients and families.

This statement should not be taken as support for legislative change. The RACP will continue to highlight concerns about legislative proposals, drawing on both clinical experience and the ethical perspectives of our members. The RACP will continue to advocate for patient and physician well-being in order to support our members and contribute our expertise as medical specialists who care for dying patients.

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# Definitions

## Terms used in this document

Recognising that the overlap of terminologies is inexact and different formulations exist in the literature, this statement uses the following terms and definitions:

**Voluntary assisted dying** includes:

1. prescription or supply of a lethal drug which a competent patient self-administers without further assistance (sometimes called 'physician-assisted suicide'); or
2. administration of a lethal drug to a competent patient requesting assistance to die (sometimes called 'voluntary euthanasia').

Children, those lacking competence and those not approaching the end of life are out of scope of this definition and statement.

In each case the drug is made accessible at the request of a competent adult patient at the end of life by a medical practitioner or other independent prescriber. The term is used descriptively and without a *priori* judgement as to its ethical or legal standing.

The following are not considered to be voluntary assisted dying and are well established end-of-life practices:

1. patient refusal of life-sustaining treatments: patients with capacity have the right to refuse treatment including the provision of medically assisted nutrition and/or hydration
2. physician withholding or withdrawal of 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
3. provision of appropriate palliative sedation to manage refractory symptoms and
4. titration of medical treatment to relieve symptoms.

The RACP recognises that voluntary assisted dying, as defined above is distinct from and not part of the practice of palliative care. It should be noted that the Australian and New Zealand Society of Palliative Medicine (ANZSPM) has stated that 'in accordance with best practice guidelines internationally, the discipline of Palliative Medicine does not include the practices of [voluntary assisted dying].'(1) This reflects statements from the International Association for Hospice and Palliative Care, and the European Association for Palliative Care, that the provision of voluntary assisted dying should not be included into the practice of palliative care.(2, 3) Likewise this position of the ANZSPM position has been affirmed by the Australian and New Zealand Society of Geriatric Medicine.(4)

**End of life:** patients are approaching the end of life when an experienced clinician would anticipate death occurring within the next 6-12 months, even if the trajectory is uncertain. This includes those living with:

1. advanced, progressive, incurable conditions, e.g. neurological or malignant disease
2. general frailty and co-existing conditions that mean that they are expected to die within 12 months and
3. life-threatening acute conditions caused by an irreversible sudden catastrophic event.

**Dying:** the terminal phase of life, where death is imminent and likely to occur within hours or days, or occasionally weeks. This is sometimes referred to as ‘actively dying’.(5)

**Palliative and supportive care:** care provided by health professionals for people with a terminal or serious physical illness that aims to:

1. optimise a patient’s quality of life until death by addressing their physical, psychosocial, spiritual and cultural needs and
2. support the patient’s family, whānau, and other caregivers where needed, through the illness and after death.(6)

**Specialist palliative care:** care provided by medical practitioners and other healthcare professionals who are accredited by their training in palliative medicine and who work in the context of an expert multidisciplinary team of palliative care professionals.

**Double effect:** the principle that there is a morally relevant difference between actions with consequences that are both foreseen and intended, in contrast to actions with consequences that are foreseen but not intended. Although philosophically disputed by some, the principle gives an important legal and moral justification to provide treatment intended to relieve symptoms but that could foreseeably but unintentionally hasten death.(7-11) Of particular note, the appropriate titration of opioid medication for pain control does not hasten death,(12-16) and current evidence, although limited, suggests that the use of sedation at the end of life does not have a significant impact on the timing of death.(17)

## Terms not used in this document

Debate on this topic has often become polarised. Much of the language has been loaded by association with negative or disputed values. The following frequently used terms are therefore avoided in this document:

1. euthanasia: disputed definition; sometimes associated with actions performed contrary to the patient’s wishes
2. assisted suicide: negative connotations with the use of the word ‘suicide’; sometimes associated with a more fundamentally independent action on the part of the patient, in which providing support is overtly eschewed
3. death with dignity: disputed, as it can be used in a way that pre-supposes the validity of arguments both for and against voluntary assisted dying
4. mercy killing: disputed as it is ambiguous as to the patient’s wishes
5. good death: disputed, as it can be used in a way that presupposes the validity of arguments both for and against voluntary assisted dying.

## Terms that are difficult to define

The following terms are important when discussing voluntary assisted dying but are complex and difficult to define clearly or are used in a variety of ways which may be substantively relevant:

1. suffering: often conflated with physical pain, but considered to span categories including physical, psychological, social, and spiritual or existential; Cicely Saunders’ ‘total pain’ concept is a parallel.(18) Suffering is also difficult to measure in an externally consistent way.
2. terminal illness: identifies incurability but is often used in a way that is unclear as to expected length and quality of life; the terms ‘end of life’ and ‘dying’ are considered to be more generally useful here.

## Introduction

In recent years, a number of proposals to legalise voluntary assisted dying have been considered by Parliaments in Australia and New Zealand. As evidenced by recent public inquiries and sustained reform attempts, there is significant community interest in having voluntary assisted dying as an option at the end of life. Community sentiment has been informed by the impacts of illness on family life, examples of distressing deaths, even suicide, and an appeal for greater control at the end of life.

The RACP acknowledges this is a complex and controversial topic and that while some physicians will welcome contemporary discussion of the issues, other physicians may disapprove of the College engaging in this space. The College's work on this topic is grounded in the professional and civic responsibility that all physicians have towards advancing the understanding of death and dying, and promoting the best possible care for all people. This involves enhancing public discussion about all aspects of end-of-life care and advocating for the delivery of good end-of-life care in physician practice, hospitals, the health system and the community.

This statement is offered as guidance to physicians and policymakers, whilst acknowledging the diversity of opinion of our membership and the complexities associated with end-of-life care.

# **Part 1: The RACP Statement**



## 1.1 Background

### How did the RACP develop this Statement?

End-of-life care is an area in which current practice and service delivery too often falls short and has been an area of focus for the RACP for a number of years. Following the launch of the RACP position statement [\*'Improving Care at the End of Life: Our Roles and Responsibilities \(May 2016\)'\*](#), the RACP formed a working party in 2016 to develop a College statement on voluntary assisted dying with the intention of offering a meaningful and contemporary contribution to policy debate. The working party comprised physicians with a broad range of clinical and cultural expertise and encompassed those with differing moral and ethical perspectives.

In developing this document, the working party followed an extensive consultation process, including face-to-face and online consultation with Fellows, Trainees, College bodies, and Specialty Societies. Conversations amongst Fellows and Trainees were focussed by external developments throughout 2017, including the introduction of bills and inquiries in the New Zealand, Victorian, New South Wales and West Australian Parliaments, and the passage of the Victorian Voluntary Assisted Dying Bill in November 2017 for commencement of the scheme in 2019.

The thoughts and perspectives shared by members have been extremely informative in developing this statement. Face-to-face deliberations have involved deep thinking on the part of Fellows and Trainees in working collaboratively through the complexities. Written submissions and online dialogue have also enabled all interested members to express their view in a private and unstructured way. In all cases, the views expressed have reminded working party members of the fact that physicians wear many hats – as patient advocates, medical leaders in the community, educators, colleagues, members of religious and cultural communities, and as patients and family members themselves.

### Why has the term 'voluntary assisted dying' been chosen?

The Working Party that developed this Statement was established in 2016 under the rubric of "Euthanasia and Physician-Assisted Dying". As noted above in the discussion of definitions, the Working Party considered this language to be loaded, and to lead to polarised thinking and a stalemate.

Accordingly, the Working Party proposed a change of the title to 'medical assistance in dying', as used in Canada. The reception of the new language during the consultation phase was mixed. Some Fellows and Trainees preferred to stay with 'assisted suicide' and 'euthanasia', viewing these as more accurate descriptors. Other Fellows and Trainees supported 'medical assistance in dying' or preferred the umbrella terms of 'assisted dying' and 'physician-assisted death'.

During the consultation, legislation to enable "voluntary assisted dying" was enacted in Victoria and considered in New South Wales and Western Australia. In the end it seemed most practical to use the prevalent legal language, accepting that all the terminology is to some extent disputed.

Voluntary assisted dying is currently illegal in New Zealand and in all Australian states and territories, except Victoria where the *Voluntary Assisted Dying Act 2017* is due to commence operation in June 2019. Medical organisations have historically been opposed to voluntary assisted dying (19, 20) and while some physicians believe that this is the appropriate stance to take, others do not.

There is diverse opinion across the College about the professional involvement of physicians in voluntary assisted dying. The College's consultation process has highlighted this is a contentious topic which goes to the heart of many physicians' professional identity and beliefs.

During consultation, RACP members were asked for their view on a number of possible RACP positions (we reproduce here the language used in consultation):

1. in opposition to any form of medical assistance in dying
2. of 'studied neutrality' to any form of medical assistance in dying, acknowledging that it is the prerogative of society to decide whether laws should be changed and that there are diverse views both within the College and society and
3. supporting medical assistance in dying; such support might be restricted to defined cases and circumstances.

Separate from the above options, two possibilities were also set out as to how the RACP might engage on the issue:

1. decline to take part in further public discussions around proposed legislation or
2. continue to take part in discussions around proposed legislation in order to exert its influence on issues such as safeguards, conscientious objection and protection for our members.

Throughout consultation, Fellows and Trainees expressed views ranging from strong opposition to strong support, with concerns about the implications for vulnerable people, impact upon families and practitioners where different individuals express different preferences for care, and professionals' (dis)comfort in these settings.

This range of views led the Working Party to recommend the College focus its Statement away from political advocacy and towards practical guidance for physicians dealing with this challenging topic. 'Critical neutrality' was proposed as a clinical approach to encourage respectful and reflective dialogue with patients, families and colleagues who might have differing views. Critical neutrality is a term with its origins in educational practice.<sup>(21)</sup> It is an approach that avoids imposing one's own values on another person in favour of helping them find their way to a conclusion consistent with their own set of values.

## 1.2 Common ground

The RACP has striven to foster collegiality and respect throughout dialogue with members. Common ground arises regarding the following values that unite all physicians when considering care at the end of life:

1. Patients and families are at the centre of clinical practice.
2. Death and dying are a natural and inevitable part of life.
3. It is the shared aim of all physicians to provide good medical care throughout the lifespan, including at the end of life.
4. High quality end-of-life care, including specialist palliative care, and high quality aged care should be readily accessible to all.
5. There are many ways to consider human dignity.
6. Most people near the end of life value their life in many ways and their life is valued by those who love, care for and treat them, including their medical teams.

7. People should be entitled to make autonomous decisions about their care, recognising that end-of-life decisions are best made with involvement of individuals, families/carers and health professionals.
8. Some individuals may find value in their suffering through their own cultural, spiritual and religious beliefs while other individuals may find no value in suffering.
9. Palliative and supportive care can alleviate much pain, related symptoms and loss of function, but cannot relieve all suffering for all people in all circumstances.
10. Where voluntary assisted dying is legalised in Australia or New Zealand, it would be a steep change in how end-of-life care is practised and perceived.
11. Both proponents and opponents of voluntary assisted dying say they are motivated to ease suffering and provide high-quality care at the end of life.

## 1.3 The RACP Statement

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## **Part 2: Discussion of the Issues**

## 2.1 Historic framing of the issues

Researchers and commentators in the academic, legal and medical literature have explored and debated voluntary assisted dying, under its various guises, for many years.(22-29) Although a complete history of this work is beyond this paper's scope, a brief review is pertinent.

Historical claims in favour of legalisation (these have been contested):

1. **Individual autonomy.** Individuals have the right to make their own decisions about health care, are best placed to make quality-of-life assessments for themselves, and want control and choice at the end of life.(30-32)
2. **Avoidance of suffering.** Physical, psychological, social, spiritual and existential suffering that occurs in dying can be avoided or minimised where voluntary assisted dying is available.(33-35)
3. **Harm minimisation.** International studies have shown that these practices are happening even when illegal.(36-40) Legalisation will serve to regulate this activity, in turn allowing for it to be monitored and for appropriate safeguards against abuse to be set up.
4. **The ethical continuum of end-of-life decision-making.** Voluntary assisted dying lies on a continuum of end-of-life decision-making where hastened death is the "intention"; because no categorical distinction is seen to exist in such a continuum, it is ethically justified in the same way.(41-44)

Claims in opposition to legalisation (these have also been contested):

1. **The value of life and community interest in not taking life are paramount.** In the past, communities were prepared to sacrifice life only where it was justified on a community level, for example in conflict or penal settings. (45)
2. **The meaning of autonomy may be more elusive than it at first appears** in light of issues such as the change in preferences over time (e.g. regret), concern about decision making capacity in different settings, and the intersection of biopsychosocial, spiritual, and cultural dimensions with free will.
3. **Risk of damage to the doctor's role as healer and erosion of trust in the doctor patient relationship.**(46) Formulations include:
  - a) "doctors are not authorised morally to take life";
  - b) incredulity that doctors would be asked to take on this role, suggesting that it could be handed to some other technical profession with appropriate legal support;
  - c) traditional medical paradigms hold the supposed primacy of doing no harm to patients and the preservation of life as paramount and deliberate action to cause death runs counter to the purpose of medicine; and
  - d) legalising and endorsing doctors' capacity to take life may erode trust in the doctor patient relationship, in that the patient relies on the doctor's assumed obligation to do no harm; this is particularly acute for groups in society who already distrust doctors.(47)
4. **Risk to vulnerable groups and individuals, and so-called 'slippery slope' arguments.**(48-50) This slippery slope argument has many forms, but essentially it states that if voluntary assisted dying is legalised, the potential exists for:

- a) pressure on vulnerable persons to seek voluntary assisted dying when it is actually in someone else's interest that they do so;
- b) widening of the clinical criteria to include other groups in society, for example those who are 'tired of life'; voluntary assisted dying then supplants other remedies that people have for their non-end-of-life problems;
- c) an increase in instances of non-voluntary and involuntary medicalised ending of life;
- d) progressive devaluation of life culturally; and
- e) financial toxicity, for example through people being quantified in terms of their assets (e.g. housing value) and this being weighed up against expenditure on care.

**5. Moral loss that comes with avoidance of suffering or by controlling time and method of death.** Some moral traditions including those described as Stoic have perceived value in some types of suffering and do not necessarily see patient or doctor control of death as a good.(51)

## 2.2 Data from other jurisdictions

Jurisdictions with established legal mechanisms to support voluntary assisted dying (under various names) include the Netherlands, Belgium, Luxembourg, Switzerland, and the American states of Oregon, Washington State, Vermont and Montana. More recently, legalisation has occurred in Canada and in the American states of California, Colorado and Washington D.C.

In this section, data coming out of US regions and Europe are presented. This may inform thinking in the Australasian context. Generalisations and extrapolations around such a complex issue cannot be easily made (52) and readers should note that there may be other sources of information available which shed new light on the information below. Emerging data from recently legalised jurisdictions, whilst not covered here, may also be valuable in understanding new implementation experiences – for example, anecdotal reports from Canada of doctors who have provided medical assistance in dying once and who do not wish to be involved again.(53)

### Oregon and Washington State

In Oregon and Washington State, eligible adults may be prescribed the lethal medication by a doctor. Patients who choose to take the medication must take it without assistance. The term used is 'physician-assisted suicide'.

Rates are increasing although remain low proportionally to all deaths.(54-56) In Oregon in 2017, the rate of reported deaths was 39.9 per 10,000 deaths.(57, 58) In 2016, (58) reported physician-assisted suicide accounted for 0.37% of all deaths in Oregon. The majority of patients were 65 years of age or older (80.4%), with median age 74 years. Decedents were almost all white (94.4%), often well educated (48.9% university level), and had cancer as a primary illness (76.9%), followed by amyotrophic lateral sclerosis (7.0%) and heart/circulatory disease (6.3%).(57, 58)

Of the minority of people who access this option, not all patients take the prescribed lethal medication. However, the majority do, and for some the data are missing - in 2017, 218 prescriptions were written, and 144 (66.05%) are known to have died from ingesting the prescribed medication. Ingestion status for 44 patients is unknown for 2017.(57, 58) Most patients died at home (90.2%).(57, 58)

The most frequently cited end-of-life concerns were loss of autonomy (87.4%), decreasing ability to

participate in activities that made life enjoyable (88.1%) and loss of dignity, though dignity is undefined (67.1%).(57-59) Studies have investigated the patient drivers and uncontrolled physical symptoms, including pain, are not the primary issue. (60, 61) Of note, only a small proportion of patients accessed the law based on fear of uncontrolled symptoms such as pain.

Reported complication rates are low but data in 50% of cases are missing. Between 1998-2017 in Oregon, 1275 patients took the lethal medications; data are missing in 638 cases. Seven patients regained consciousness after ingesting the medication, and 25 reported difficulty ingesting or reported regurgitating. (57, 58)

In 2017 a total of 92 physicians wrote 218 prescriptions (1-29 prescriptions per physician). There has been some evidence collated from the state-wide statistics that a small number of participating physicians are responsible for a significant concentration of the fatal prescriptions in Oregon, with 61% of the fatal barbiturate prescriptions in 2001 to 2007 written by 18% of the participating physicians, and 23% written by only 3 of the 109 participating physicians.(62, 63) No referrals to the medical board were made for failure to comply.(57, 58)

Undiagnosed depression may be an issue. In Oregon 5% of patients received psychiatric evaluation. In Washington State 4% were referred for psychiatric evaluation.(64, 65) A retrospective review found that some patients prescribed lethal medications had signs and symptoms of depression and remained undiagnosed.(66)

## **Europe (Benelux Countries and Switzerland)**

Eligible persons may be prescribed the lethal medication by a doctor. The prevalent term is 'assisted suicide'. Patients who choose to take the medication may self-administer it or, more commonly, request that a doctor administer it. In Switzerland, only self-administration is legal.

The incidence of assisted suicide is rising. Data (including unreported cases) show it accounted for about 4.6% of all deaths in Belgium in 2013 (67) and 4% of all deaths in the Netherlands in 2016.(68, 69) Of all deaths by assisted suicide in the Netherlands in 2016, 48.6% of persons were female, 36.9% occurred in persons under 70 years old and 33 occurred in persons over 80 years old.(68, 69) While this indicates a younger group than in the US states, data indicate increasing access among those 80 or older.(70)

In Belgium and the Netherlands, almost all assisted suicide occurs at home and by injection of lethal medication rather than by a self-administered oral medication.

There is evidence from the Netherlands that notwithstanding strict legal guidelines, the scheme may have been open to abuse.(71-74) In the Netherlands and Belgium, patient concerns/reasons are not officially recorded in a consistent way. However there is evidence in Belgium that reasons such as 'tired of life' are increasing.(75, 76) There have been some qualitative studies of families and patients (77, 78), but most data come from physicians retrospectively reporting the motivations of their patients.

In the Netherlands, complications such as inability to insert an intravenous cannula, vomiting up of oral medications, and the patient either not dying or taking a very long time to die are reported to have occurred.(29, 79)



In February 2014, Belgium extended its euthanasia laws to also apply to children of any age with a terminal illness.(80) Attention has turned toward the extensions of the legislation to consider enabling other groups who may want access to assisted suicide(e.g. people with refractory mental illness, minors and patients with cognitive impairment).(81-84)

While the evaluation of palliative care servicing is contested, underdevelopment of services has not as yet been linked empirically to uptake of assisted suicide.(85)

## **Vulnerable groups**

Vulnerable groups measured in the data groupings do not appear to be overrepresented based on the reported numbers accessing voluntary assisted dying in both regions. The available data do not show evidence of increased relative risk to vulnerable groups, and no sustained increase in the incidence of life-ending medical interventions without the explicit request or consent of the individual patient.(86) The exception to this is the HIV positive population.

The caveat is that not all vulnerable groups are necessarily identified. Vulnerable groups reported in the overseas studies include low socioeconomic status, females, the elderly and nursing home patients.(86, 87)

## **2.3 Socio-cultural context**

Advances in medical treatment and public health have meant that many people are living longer and healthier lives, with the burden of illness shifting to the last stages of life. This has led to a shift from acute treatable conditions to chronic degenerative diseases and cancers as the main cause of death in adults.

This in turn has changed the way in which many of us die, with many deaths occurring in hospital or intensive care settings. These deaths more frequently involve human intervention,(88) creating a sense that dying can be negotiated. Death and dying may therefore be seen as something to fear or as a 'failure' of care at the end of life both by healthcare professionals and by some parts of society.

Many surveys on attitudes towards voluntary assisted dying in the peer-reviewed academic literature in English-speaking countries have identified public and professional support.(36, 89-96) Peer-review notwithstanding, survey results have been criticised based on how the issue is framed and questions formulated.(29, 97) Survey results also often lack detail on the definition of exactly what form of assisted dying is being discussed, the way responses are interpreted, the population surveyed, and the quantification of the results. Similarly, opinion polls undertaken by media and researchers in Australia and New Zealand find majority public support for voluntary assisted dying for competent adults who are terminally ill and suffering.(98-102) It is likely that such surveys and polls have contributed to a political perception of wide public support for legalisation to enable voluntary assisted dying and it is conceivable that public views would be more ambivalent if more sophisticated cases and scenarios were considered.

Various ideas have been examined in the literature as to the socio-cultural reasons for community interest in voluntary assisted dying. These include increased reliance on science and technologies, the routinisation of life-extending practices, and the medicalisation of dying.(103) It has also been argued that Western societal value placed on individualism and efficiency affects attitudes towards

death and the conditions that dying people and their carers face. (104) This may provide some link to realities in the United States where the common demographic profile of persons who have received voluntary assisted dying (see above) is white and well-educated.(29)

In multicultural countries such as Australia and New Zealand, it should be recognised that many cultures believe an individual is a person in relationship to others, reflecting a culture-specific approach to autonomy and a preference towards more communal end-of-life decision making and planning.

## Indigenous perspectives

There are a range of Indigenous community views and what follows is just a limited sample.

The RACP Aboriginal and Torres Strait Islander Health Committee has highlighted the nuance needed around Indigenous understandings of death and dying. Whilst much remains to be described about the Indigenous Australian setting, these understandings include connection to country and dying on country, particularly outside metropolitan areas, as well as different concepts of family and quality of life. There is an unmet need for access to culturally appropriate end-of-life care amongst this group, with geographical and other access issues compounding the gap. This would appear to be the utmost priority in improving end-of-life care for Indigenous Australians.

Across the Tasman, the New Zealand Parliament has been considering the End of Life Choice Bill which proposes to give those with a terminal illness or a grievous and irremediable medical condition the option of requesting voluntary assisted dying. The RACP was provided the following Māori perspective on the Bill which describes some of the discomfort that may arise in this area:

“The End of Life Choice Bill does not acknowledge the existence of a mātauranga Māori [Māori worldview] approach to death and dying, which can vary within whānau, hapū, and iwi [extended family, subtribe, and tribe]. Some of the assumptions underpinning the Bill, including ideas of ‘choice’ and ‘dignity’ as used in the Bill, are not in fact universal but are based on cultural assumptions.

Dying and sickness from a mātauranga Māori perspective do not happen solely to the individual. This is reflected for example in the practice of kīrimate and whānau pani (bereaved whānau). In these practices (which vary from rohe to rohe [area to area]) the close family of the deceased effectively enter into the world of the dead during the tangihanga [wake and funeral] and become highly tapu [sacred], and are returned to the world of the living through their participation in the hakari [feasting] and other rituals.(105)

The body is important in the traditional Māori funeral custom. The wairua (spirit) of the deceased is considered to stay by its body at first and needs encouragement to start on the journey to the next world. This underscores the importance of the body as a focus for Māori funeral custom (tangihanga). When a Māori patient dies it is critical that the whānau has prompt access to the tūpapaku [corpse]. If a post-mortem is required this must be done as soon as feasible.(106)”

The New Zealand Committee of the RACP upholds a Māori perspective on death and dying:

“An important cultural consideration in Te Ao Māori is that the mauri [life force] of a person is independent from their brain; in this context spiritual presence is still respected during physical and psychological deterioration. Furthermore, the mana of an iwi and whānau is often relative to the number of kaumātua (elders) present. As such, independent of whether Māori elderly are in poor health their continuing presence is seen as enhancing the mana of their Marae and people”.

The assumption that death is purely about individual choice is a faulty one. This also makes problematic the processes as outlined in the End of Life Choice Bill, especially the lack of whānau involvement in key decision making points.

The Bill also fails to acknowledge the problematic relationship between Māori and social policy and legislation. While it makes claims as to the efficacy of the legislative safeguards for the vulnerable in other jurisdictions, it does not allow for the historical and social context that is unique to New Zealand. In this context, seemingly universal legislation often has a disproportionately negative impact on Māori. This is noticeable in many spheres of New Zealand life including education, justice and health. Factors such as ‘unconscious bias’ can influence how policy is implemented in such areas, are not accounted for in legislation and end with outcome disparities in many areas for Māori.

## 2.4 Issues raised from clinical experience

Individual patient situations at the end of life involve multiple factors which are often complex. Based on professional experience, many patients do not fit neatly into particular rules or situations. The codification of medical practice by law can create reassurance in some situations but can also work against the careful deliberative negotiation of complexity favoured in physician practice. In this way, even a well-drafted law can be defeated by clinical complexities. Factors that increase complexity include:

1. defining what is a terminal illness;
2. estimating life expectancy and the imminence of dying;
3. exploring the reasons for a request;
4. judging whether an individual’s mental state is affecting their ability to decide;
5. assessing a person’s capacity to make a request for voluntary assisted dying, especially in those who are debilitated, have reduced mental capacity or have other diseases and problems that affect decision-making; and
6. defining ‘enduring and unbearable suffering’ that cannot be relieved in a manner the patient deems tolerable.

Here we provide examples of the complexity inherent in everyday clinical situations. The following are by no means the only issues that could arise in this area.

### Defining end of life and estimating life expectancy

Many illnesses will eventually cause the person’s death. Even so, the time frames can be uncertain. Cancer is the main disease which many people think of in the context of requests for voluntary assisted dying. In many situations cancer is a predictable cause of death but different types of cancer have different trajectories. Some cancers (for example adenocarcinoma of pancreas or small cell carcinoma of lung) often have an aggressive course and poor survival, whereas others (such as adenocarcinoma of prostate) may have an indolent course where the person may be expected to die

with the cancer but of other causes. Even with specific cancers there is variation in how they behave, with some lung cancers (e.g. EGFR-mutated adenocarcinomas of lung treated with tyrosine kinase inhibitors) in some patients taking many years to cause death. Uncertainty is an inescapable part of medicine, especially when it comes to estimating prognosis.

Other diseases such as heart failure or severe respiratory disease such as chronic obstructive pulmonary disease will also prove fatal for many people. However, trajectories for these illnesses are typically characterised by exacerbations followed by periods of stability. Even when these illnesses are severe and at their end stage, it is difficult to predict life expectancy in an individual person. All physicians will recall experiences of treating patients with severe organ failure who they believed were going to die very soon but then improved to survive beyond expectation.

The situation is even more difficult where one or other form of dementia or slow neurodegenerative condition (e.g. Parkinson's disease) is present, where disease trajectory may be highly variable and the occurrence of other illnesses, such as infections, as a cause of acute deterioration leading to end of life is quite unpredictable.

Being confident of a 12-month lifespan on an individual basis is therefore very difficult. As expressed in a recent systematic review,(107) accurate forecasting is (nearly) impossible for a number of reasons explained below.

Prognostication is not only affected by patient factors but also by the level of clinician experience, duration of relationship with the patient and whether it is done by an individual or a multidisciplinary team. It is based on statistical data which will only apply on average. Therefore, if a certain group of patients have a median 12-month expectation of life, half will die before this time and half afterwards. Studies are also heterogeneous. Most studies have been in the cancer population and there are studies in non-cancer populations that show forecasting is even more inaccurate in those settings.

As described in the review, there are also varying types of estimates (continuous, categorical and probabilistic) and of the three estimates, probabilistic estimates "may be slightly more accurate than categorical or continuous".(107)

Studies show that clinicians are more likely to overestimate than underestimate survival.

## **Exploring the reasons for a request**

Careful examination of the psychodynamic issues that may be involved in making and receiving requests for assisted dying is critical. Questions should be asked about what is going on in the patient's mind, the practitioner's mind, and the interactions between the two (not to mention family members, other health care professionals and societal and institutional mores).

People approaching death may experience intense periods of existential reflection and physical challenge. The motivations behind expressing a desire to die or requesting hastened death may be complex.(108) For example, such requests may be a vehicle to express other concerns, such as a fear of being a burden on others, fear of loss of control or fear of loss of a sense of self and dignity.(109) Other motivations may be more immediate, such as poor symptom control and suffering. It is however important to note that only a small proportion of patients in Oregon access assisted

suicide based on fear of uncontrolled symptoms such as pain: rather, loss of autonomy is most frequently cited.(57)

People's wishes and preferences for death in certain conditions may change during their illnesses. For example, there is a study from Belgium of patients with locked-in syndrome who at first sought assisted suicide but changed their perspective over time.(110)

Reduced food and fluid intake, with poor appetite, switching to catabolic metabolism and significant weight loss, is very common as the end of a person's life approaches. In this setting, many family members feel very conflicted if food brought to a patient as a symbol of love and care is refused.

More generally, misguided and poorly-informed public comment may centre around dying people :”starving to death”, where images of starvation in younger people are incorrectly transposed onto perceptions of end-of-life care in these patients and used to justify voluntary assisted dying.

This is regarded by many specialists as a normal part of the body's shut-down process at the end of life and can be well-managed, like other end-of-life symptoms, with palliative care. Exploring each of the issues of concern is critical in providing good end-of-life care.

People with concerns about end-of-life care may request voluntary assisted dying for themselves or a family member even though symptom relief and a peaceful death may be available by other palliative means. Individuals may need to be reassured of the following:

1. Palliative care is not exclusively for people in the last weeks to days of life. Supportive and palliative care can be delivered alongside disease modifying treatment at any time. Palliative care aims to improve the quality of life of patients and their families facing life-threatening illness through the prevention and relief of suffering.
2. Intolerable suffering at the end of life is not inevitable. The vast majority of symptoms that may cause suffering in the terminal phase can be anticipated and treated.
3. Withholding or withdrawing life sustaining treatment in a dying person allows natural death from the underlying disease processes. This is already a normal part of end-of-life care and can be explored through advance care planning discussions.
4. Administering treatment for the express purpose of ending life is not the same as palliative sedation and the use of opioids for pain relief and symptoms resistant to other treatments. (111-114)
5. The appropriate titration of opioid medication for pain control does not hasten death(96-100) and current evidence, although limited, suggests that use of sedation at the end of life does not have a significant impact on the timing of death.(17)

Although studies have shown that people have many non-medical concerns at the end of life, it is freedom from pain that is generally the most wished for outcome by patients, families and health professionals.(115) Although significant numbers of :”clandestine” end-of-life practices have been reported in the literature, there are no reports of such practices in the context of palliative care in Australasia.(36, 116)

Access to social and community support and financial concerns are factors that may also play a role in motivating requests. These include social isolation and the cost/availability of suitable nursing home placements, long-term care for young patients and respite for carers.

## **Assessment of mental state in the context of end-of-life care**

People approaching the end of life often report emotions such as anger, grief, hopelessness, guilt, regret and existential emptiness. These may manifest in ways that resemble depressive symptoms, such as poor appetite, hopelessness, nihilistic thinking, low self-esteem and anhedonia. Clinicians often face a challenge in differentiating such symptoms, which may lead to a request for voluntary assisted dying, from treatable clinical depressive illness, which left alone or treated inappropriately, may itself lead to suicide.

Other mental and cognitive disorders may need to be taken into consideration, particularly in the elderly, and like the symptoms mentioned above, may vary at different points in a person's illness. All these things can complicate the medico-legal assessment of competence.

Attributes of decision-making capacity include the ability to understand the facts involved, understand the main choices, weigh up the consequences of the choices, understand how the consequences affect them, and communicate their decision.(117) Such capacity can exist even where the option selected is not what other people might choose. Consistency with previously held beliefs and values may also be taken into account.(117) Capacity is assessed for a specific decision and is not a global requirement. A person might not have the capacity to make complex decisions but nonetheless be able to make more basic ones. People who are unwell may temporarily lose capacity to make decisions but regain it when they become well again.

Assessment of capacity is commonly undertaken in clinical practice. Examples include decisions about whether to have a surgical procedure or medical treatment, the ability to manage one's own finances, appoint a power of attorney, and whether to live at home or move into residential aged care. Under normal circumstances capacity is assumed to be present unless sufficient reason exists to question it. Physicians in Australia and New Zealand are familiar with assessing capacity in relation to decisions around specific procedures or treatments or in ordering personal affairs, but are much less familiar with how to do this in the complex context of a request for voluntary assisted dying. Several cases from the common law have highlighted the need for greater certainty about criminal liability and about how competence should be tested in such cases.(118)

## **Defining 'enduring and unbearable suffering' that cannot be relieved in a manner the patient deems tolerable**

Many people assume that requests for voluntary assisted dying are made predominantly because of unrelieved pain. Suffering is a far broader concept than physical pain.(119) It is not for health professionals to judge whether symptoms are unbearable for the patient. The main drivers of requests for voluntary assisted dying are not unrelieved physical pain.(29) Significant topics in relation to the nature of suffering at the end of life include existential distress and feelings of lack of physical and temporal control.

## **Potential impact on already complex care**

The care of the dying is a complex intersection of immediate and anticipated needs. As well as symptom management, physicians must think ahead on such things as the options for withdrawal of treatment, and what to do when decision making capacity is lost. They must negotiate these topics with reference to the person's wishes as expressed to them directly and mediated via their families.

They must communicate their own knowledge and experience in a way that supports the learnings of both patient and family. Community health literacy around death and dying is generally estimated to be poor, at least in the time before people find themselves in these situations.(120)

Legislation to enable voluntary assisted dying could further complicate this aspect of physician care. Some patients and families may experience concern that decisions may be made without a person's consent, regardless of the wording of the law. Physician involvement in voluntary assisted dying, were it to become legally available, is likely to have consequences for all people, not only the ones who want to access this choice, but for all families - both of those who seek this choice, and in other circumstances, those who do not seek this choice, not to mention those families where there is no unity about a given choice by an individual patient. There could also be unintended effects on the end-of-life care of patients excluded from legislation.

## **Part 3: Guidance and Recommendations**



## 3.1 Guidance for physicians

The depth of feedback from Fellows and Trainees highlights that the issues are complex and should not be viewed in binary terms. Voluntary assisted dying is not a single concept but is used to refer to a variety of different practices with differing implications. The relevant values and how to prioritise them for each case may be different for individual physicians. The RACP encourages physicians to consider their own stance on the issues.

Regardless of physicians' personal views or intentions in this regard, physician practice is likely to be affected in Victoria and other jurisdictions where medical assistance might in future be legalised. Some guiding principles are therefore needed. Common ground is shared by all physicians by focusing on patients and their clinical care. This includes principles that can be inferred from the usual attributes of physician practice.

### 1. End-of-life care

- a. All physicians have a duty to provide high quality end-of-life care to patients, families and carers. This involves:
  - open and honest communication with patients and their families and carers about impending death;
  - a doctor-patient relationship based on openness, trust and good communication;
  - recognising 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.

### 2. Care that is centred on the patient and the family

- a. Patient and family expectations may differ from a physician's values and conception of good medical care.
- b. The challenge will be for physicians to approach this issue from patients' and families' frames of reference.
- c. The ultimate aim is to help patients and families find their way to decisions that reflect their own goals and values in the context of end-of-life care.

### 3. Professionalism

- a. Physicians are encouraged to consider their own values and beliefs on voluntary assisted dying, how they may handle a patient request and, if legalised, to what degree they may feel able to participate. This may be informed by a range of considerations such as their moral and ethical perspectives, patient need, individual beliefs and clinical experiences.
- b. It is important that physicians respect colleagues who may have differing opinions.
- c. No physician should feel that they have to act outside their values and beliefs and the RACP will continue to advocate in this regard.
- d. Physicians should have regard for the wellbeing of both themselves and their colleagues.
- e. See also the 'Domains of expertise' on **Page 28**.

### 4. Communication skills:

- a. Requests for voluntary assisted dying are also requests for communication.

- b. Communication skills are essential to fully explore patient requests for voluntary assisted dying and any underlying reasons for these requests that can be managed in other ways.
- c. A person's will to live may fluctuate in the last phase of their life, even as death seems imminent. By communication the physician can identify sources of anxiety, fear and suffering and effective ways of treating or managing these.
- d. The professional empowerment of physicians will depend on continuing to develop and refine their skills and knowledge to engage in end-of-life conversations, especially where these may move into areas of conflict with physicians' own values and beliefs.

## 3.2 Recommendations for policymakers

The RACP has concerns about the potential for legalised voluntary assisted dying to jeopardise vulnerable populations, be abused, expose health practitioners to professional risk, harm patients and families and erode trust in the medical profession. If parliaments in Australia or New Zealand decide that laws should be changed, the development of laws, regulations and guidelines must be undertaken in consultation with medical and health experts, the RACP and other medical and health organisations.

Some key recommendations for policymakers are set out below. These have been developed in consultation with our members as the RACP responded to legislative proposals during 2017. The issues are connected with the accessibility of good end-of-life care.

The recommendations stated in the RACP's position statement ['Improving Care at the End of Life: Our Roles and Responsibilities \(May 2016\)'](#) should also be referred to in this context, including:

- supporting system changes including enabling health professionals to take the time they need to discuss end-of-life care with patients, and to conduct and document family/whānau conferences including goals-of-care discussions, appropriate social work support and bereavement care;
- providing adequate resources in the community to support patients wishing to die at home, in a hospice or in a residential aged care facility;
- ensuring patients can access specialist palliative care support as needed, at any time of day or night;
- streamlining patient information to ensure health professionals have access to key patient information and documents; and
- funding systems to measure and benchmark outcomes of end-of-life care.

Inequitable access to good quality end-of-life care persists for many Australian citizens. This includes Aboriginal and Torres Strait Islander people and people from culturally and linguistically diverse backgrounds. Other groups that experience inequitable access to care include 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 one or more chronic diseases. Inconsistent care is more prevalent in rural and remote communities in Australia.(121) Similar issues apply in New Zealand, especially for Māori.(122-124)

Governments must remain vigilant in the areas of palliative care and aged care and commit adequate resourcing to ensure that good end-of-life care is being delivered to all citizens. Every patient should

receive timely, equitable, good quality end-of-life care, including access to specialist palliative care where appropriate.

## If and where voluntary assisted dying is legalised

### 1. End-of-life care and palliative care

#### Recommendations regarding end-of-life care and palliative care:

- The need for palliative care services must not be devalued; indeed, palliative care must be given even greater priority and resourcing than it is now.
- Governments must ensure that all patients have access to good end-of-life care and palliative care as needed. This includes equitable access for populations that currently experience poor access, such as people from rural, regional and remote areas, Culturally and Linguistically Diverse backgrounds, Indigenous backgrounds, people with intellectual disability, patients dying from diseases other than cancers, and people living in residential aged care facilities.
- Governments and oversight bodies must dedicate resources to closely examine voluntary assisted dying requests that arise where the patient actually has poor options for good end-of-life care, for example in circumstances where symptom relief and a peaceful death cannot be provided to the patient because of limited access to palliative and supportive care.
- Patients seeking voluntary assisted dying must be made aware of the benefits that palliative care can offer at the end of life and referral to specialist palliative care should be strongly recommended.
- However, palliative care referral or consultation after a request for voluntary assisted dying has been made cannot be mandatory given:
  - consultation or referral to palliative care services, like any medical referral, is not mandated and is a care option that a patient may or may not choose to accept;
  - legalisation of voluntary assisted dying in any form will create significant challenges for palliative medicine specialists and palliative care organisations;
  - voluntary assisted dying must not be seen as part of palliative care - these are distinct practices; and
  - 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.
- Consideration of a more formal legal clarification of the principle of double effect is an important, but separate, issue from the legalisation of voluntary assisted dying.
- The Victorian scheme due to commence in June 2019 requires a number of complex end of life conversations with individuals and assessments to be undertaken. Physicians must be able to take the time required for these consultations.

## 2. Conscientious objection

In general, where objections of conscience have arisen in medical practice in Australia and New Zealand, clinicians have accepted they should refer patients to another practitioner. However, for some physicians the moral impact of referring a request for voluntary assisted 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.

Conscientious objection affects not only the medical practitioner but the multidisciplinary team treating the patient. Conscientious objection may also occur for other non-medical individuals within multidisciplinary teams or at an institutional level.

Conscientious objection may present issues in certain settings, for example amongst inpatients of an objecting hospital or hospice, those who are unable to go to another clinic, practitioners who would perform voluntary assisted dying but are not accredited at a given site, and patients living in rural areas serviced only by an objecting practitioner(s).

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 relating to the perception by patients, families, colleagues and the broader community, if a public register of practitioners were to be mandated. A practitioner may not want to be identified because they are concerned that patients will not come to see them if they are known to be participating in voluntary assisted dying. Conversely, a patient may refuse to see a doctor if they choose not to participate. This could compromise timely assessment and care in a geographical area where there are limited doctors to see.

It should also be recognised that some practitioners may be willing to participate in voluntary assisted dying for eligible patients in restricted ways, e.g. in a limited range of cases, or in only providing a second opinion.

### Recommendations regarding conscientious objection:

- Physicians should not be forced to refer, but neither should they hinder patients from accessing such services.
- A central information source on the scheme should be available to assist patient access.
- Should a register of practitioners be developed, protections should be available for both participating and objecting practitioners who do not wish to be identified for reasons of harassment and stigma.
- Provision could be made for practitioners who are willing to participate in restricted ways, e.g. in a limited range of cases, or in only providing a second opinion.

### 3. Consent and potential coercion

Coercion of patients will be difficult to safeguard against completely. A significant proportion of the terminally ill and elderly are estimated to experience some form of self-perceived burden. (125) Coercion may also arise where individuals with poor access to good end-of-life care may choose voluntary assisted dying even though symptom relief and a peaceful death could have been provided if they had had appropriate access to end-of-life care.

#### Recommendations regarding consent and coercion:

- Consideration must be given to enabling the exchange of information in formats accessible to the patient such as in the patient's preferred language, via sign language, interpreters, or orally.
- Legislative and regulatory measures must reflect the legitimate concerns that exist around protection of vulnerable individuals or groups, especially where discussions may not be perceived to have been fully transparent.
- Data must be collected, monitored and reported in a manner that can pinpoint abuse at an individual and population level.
- Avenues to report and investigate suspected coercion must be built into any scheme including via coronial review.

### 4. Conflict and bereavement support

Adequate family support, counselling and conflict mediation services will be required in the event of legalisation. Frameworks for voluntary assisted dying are based on the culture-specific concept of individual autonomy and do not generally acknowledge that end-of-life decisions are not made in a vacuum.

The role, and the effect on family, carers and other loved ones are important considerations. What support systems will be provided for individuals, families and health professionals who may be involved, and who may suffer personal trauma or other harm as a result of this involvement, regardless of whether or not the patient ultimately proceeds with a medically assisted death?

This must be dealt with in any proposed framework. 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.

Voluntary assisted dying 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 wishes this but family members or other health professionals disagree with their decision, and the family may blame the physician if it goes ahead. Evidence shows that many doctors who have participated in voluntary assisted dying experience emotional distress.(29, 126) If a proposal is legalised, there is a clear need for education, support and guidance for bereaved family members and health professionals.

Recommendations regarding conflict and bereavement support:

- Time for family/carer conferencing must be available to patients and health professionals to acknowledge the impact on families and to enable family/carer participation and response.
- Support systems must be provided for individuals, families and health professionals who may be involved and who may suffer emotional distress, personal trauma or other harm as a result of this involvement, regardless of whether or not the patient ultimately proceeds with a medically assisted death.
- Adequate funding will be required for such family support, counselling and conflict mediation services.

## 5. Domains of expertise and training required of participating practitioners

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(s) presenting in each person requesting assistance in dying. Proposals could consider setting out the domains of expertise required to provide voluntary assisted dying, rather than restricting it to a particular profession or qualification level, which could create barriers to access or lead to an inexperienced medical practitioner confirming a request.

For example, a neurologist who specialises in stroke care, and holds 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 artificial ventilation. This would need to be balanced against the access issues that arise in regional and remote areas when patients are too sick to travel. These situations would require detailed consideration around how assessment could be done by someone suitably skilled.

Genuine engagement with the person must be a feature of any proposal to reduce the risk of “doctor-shopping” and multiple cursory assessments being undertaken by a small number of practitioners. There is a need for assessment to be underpinned by a genuine and enduring relationship with the person. This is an important safeguard to avoid reliance on potentially simplistic assessments/reviews of paper documentation. Whilst the RACP has been made aware of recommendations for a specifically trained occupational group/practitioners as an alternative approach, this concept has not been further developed during preparation of this Statement.

Recommendations regarding expertise and training in the event of change to current law:

- Upholding the trust society places in the medical profession is of key importance.
- Participants must practise with the appropriate level of training, skill and experience, within systems of collegial accountability.
- Assessment of the requesting person must be underpinned by:
  - a genuine and enduring relationship with the participating practitioner;
  - a sufficient understanding of the patient’s preferences and values; and
  - an informed understanding of the diagnosis and prognosis of the person’s medical condition. (127)

- Policymakers must safeguard against simplistic assessments/reviews of paper documentation, “doctor shopping”, inexperienced practitioners confirming requests and cursory assessments being undertaken by a small number of practitioners.
- Training, including clinical supervision where appropriate, must be adequately funded and available for those practitioners interested and/or willing to participate, particularly in relation to:
  - the law and its implementation;
  - communicating options at the end of life;
  - the psychodynamic issues that may be involved in making and receiving requests;
  - defining end-of-life and estimating life expectancy;
  - exploring the reasons for a request;
  - assessment of mental state and capacity in the context of end-of-life care;
  - defining ‘suffering to the person that cannot be relieved in a manner that the person considers tolerable’; and
  - potential impact on already complex care.

This training must be available to all physicians, including Trainees who may be asked to explore patient requests, even though legislation in Victoria does not permit them to provide voluntary assisted dying.

- The requirement for assessment to be done by someone suitably skilled would need to be balanced against the equitable access issues that arise in regional and remote areas when patients are too sick to travel.
- To ensure legal clarity, clear and consistent guidance will need to be developed by relevant authorities in consultation with the medical profession and other relevant health professions on a range of practical issues, for example around attendance by a treating practitioner and their obligations in the event the lethal dose is not effective.
- Prudent prescribing and storage principles apply as much as ever; participating practitioners must understand and communicate the possible outcomes and harms for medications. In the case of intentionally lethal doses of medicines, this would include the possibility that they are used otherwise than as intended, do not work and may cause unwanted symptoms.

## 6. Reporting and evidence-based practice

A major practical role for involved physicians will be the capture of information around the quality, performance and outcome of activities that result from legalisation. It is imperative that robust and accurate records are kept both at the micro and macro levels and as part of the medical record. Reporting must be undertaken directly to a monitoring body to track trends, patient motivations etc. For example, there could be a specific reportable form filled out and sent to a monitoring body for review.

Instances of voluntary assisted dying must be reported to enable audit of the scheme. It is acknowledged there may be stigma felt by individuals in knowing that voluntary assisted dying may be listed as the cause of death on the death certificate. Even so, there is overriding public interest in having this information available in a de-identified manner. Enabling both the immediate and underlying causes of death to be listed and reported should be considered. Cause of death data must remain completely accurate for future planning of medical care. The cause of death must not only

include the terminal illness that made the patient eligible, but also that a substance was taken to provide active assistance to the patient in dying.

All records in connection with a voluntary 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 all requests, 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 voluntary assisted 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 voluntary assisted dying should be maintained. Patient-level reporting processes for pharmacovigilance must also be built into any proposed scheme.

Monitoring should cover a range of areas including reasons for requests, conscientious objection, disposal of unused lethal medication and impact on suicide rates more generally.

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 voluntary assisted dying is found to have negative or unintended effects, there must be a mechanism to review or even withdraw legislation and to examine and manage problems arising in practice, unforeseen or otherwise.

Recommendations regarding reporting and evidence-based practice:

- A central database of all who have requested and been declined or approved to access voluntary assisted dying and a research programme that transparently reports the uptake and outcomes of the new legislation over time will be necessary. Areas of key interest include the reasons for requests, patient demographics, requests amongst vulnerable groups, impact on suicide rates, the disposal of unused lethal medication and patient -level reporting processes for pharmacovigilance purposes.
- Review of each individual case by a competent judicial officer (e.g. coroner) may be required to ensure that the legislation has been complied with (parallel to the current system of checks regarding deaths in medical care).
- A parliamentary committee must scrutinise the data collected and the operation of the legislation with the potential for its review, amendment, further public consultation or withdrawal.
- For future planning of medical care, cause of death data must remain completely accurate by specifying the terminal illness that made the patient eligible and that a substance was taken to provide voluntary assisted dying.



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