



LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON END OF LIFE CHOICES IN THE ACT

Ms Bec Cody MLA (Chair), Mrs Vicki Dunne MLA (Deputy Chair), Ms Tara Cheyne MLA,
Mrs Elizabeth Kikkert MLA, Ms Caroline Le Couteur MLA.

Submission Cover Sheet

End of Life Choices in the ACT

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1. Executive Summary and Recommendations

The APS endorses a best practice approach to end of life care, requiring that patients fully understand their alternatives and the main ramifications of their decision to access voluntary assisted dying services should they become legal outside Victoria. Ultimately, the APS emphasises the importance of a process that is characterised by care, compassion and considered decision-making over time. The APS envisages that such a process would include access to the full range of care options, from the highest quality palliative care and the most competent psychological assessment and psychosocial support.

Key strategies to improve how people die include education and training to create a better health workforce, creating better infrastructure, and having more appropriate policies and protocols in place to maximise the real choices (and sense of control) available to the seriously and terminally ill.

The APS recommends that:

Recommendation 1

The Government considers the limitations of the existing, and very medicalised, service system to manage people's preferences and sense of control as they approach end of life.

Recommendation 2

The Government draws on robust, transparent and neutral research to examine ACT community views about voluntary assisted dying, and uses this evidence base to drive future decision-making about end of life choices.

Recommendation 3

In the event VAD is legislated in the ACT, the APS strongly advocates for increased access to psychological services to assist in:

- 1. Capacity assessment*
- 2. Therapeutic interventions for patients and their families*
- 3. Clinical supervision for the service/s delivering assisted dying services.*

Recommendation 4

Future legislation should include an equity impact assessment (a process to ensure that a policy, project or scheme does not discriminate against any disadvantaged or vulnerable people).

Recommendation 5

Implementation of any VAD scheme needs to consider the existing and future capacity of the workforce to meet the needs of people approaching the end of their lives.

2. Introduction

The Australian Psychological Society (APS) thanks the Committee for the invitation to make a submission to this Inquiry about end of life choices in the ACT.

Psychologists have important knowledge and skills to contribute towards addressing some of the interpersonal and ethical challenges surrounding end of life trajectories. This contribution relates not only to the debate about legalising voluntary assisted dying (VAD), but also to broader issues such as comprehensive palliative care service systems and advance care planning protocols.

The APS believes psychologists can and should be involved in end of life issues in a variety of ways including: facilitating conversations and addressing the stigma around death and dying, contributing to policy development and best practice for the care of the terminally ill, involvement in the process of support and decision-making for family as well as the patient (including decisions about VAD should it be legal), the assessment of psychological disorders and mental competence, and the treatment and management of distress associated with end of life.

This submission focuses on the context around end of life care and choices from a psychological perspective, and highlights the importance of ensuring people approaching the end of their lives are supported by practitioners and broader support systems to access appropriate information and care.

3. Responding to the Terms of Reference

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

If asked, most people have clear preferences regarding their end of life care. Seventy per cent of people want to die at home, yet only about 14% do so (Swerissen & Duckett, 2014). Although hospitals and residential aged care facilities (RACFs) are usually the least preferred places to die, 54% of people die in hospital and 32% in residential aged care (Broad et al., 2013).

The major fear about end of life is not so much death itself, but the prospect of suffering and not being in control. Palliative care is the most established end of life model of care. However its capacity to prevent/alleviate severe suffering (including pain control and refractory symptoms) is not absolute.

Furthermore, palliative care is not always available to all people who might benefit, or equally accessible to diverse community groups (such as residents of aged care facilities, people who have terminal illnesses other than cancer, people living in rural and remote communities, and people from Indigenous and culturally and linguistically diverse backgrounds). Not only are there currently serious shortages of palliative care practitioners, palliative care is not acceptable to a sizeable minority of dying people.

Death and dying has become increasingly medicalised and thus the domain of medical professionals. We have lost our 'death literacy', where once people were naturally engaged in the care of the dying and bereavement (Horsfall et al, 2015; Noonan et al, 2016). In addition to physical health, end of life concerns encompass individual and shared community perceptions of what a life worth living looks like, and how to enable people to create their own possibilities, hope and choices. In the developed world, people are living longer and death, now typically occurring in hospital settings, is becoming less visible and more medicalised. There is a growing movement to challenge the silence around these concerns, and to facilitate conversations and communication about death and dying and promote this as everyone's responsibility (Bartel, 2016). In service provision, this whole person approach to care is known as 'health promoting palliative care' (Kellehear & O'Connor, 2008).

It is pertinent to point out that the APS has not made a distinction between 'palliative care' and 'specialist palliative care'. 'Specialist palliative care' refers to those clinicians with advanced training (e.g. a certificate in palliative care) and they often work out of hospice settings. Whereas 'palliative care' refers to an approach which should/could be adopted by clinicians from all sorts of backgrounds (e.g. GPs, assistants in nursing, cardiologists, radiation oncologists, geriatricians). 'Palliative care' in this sense is also sometimes called 'palliative approach' or 'primary palliative care'.

In summary there is a significant discrepancy between people's preferences for end of life care and choices and what actually happens. There is great potential to enhance how people die by improving training to create a better health workforce, creating better infrastructure, and having more appropriate policies and protocols in place to maximise the real choices (and sense of control) available to the seriously and terminally ill.

Recommendation 1

That the Government considers the limitations of the existing, and very medicalised, service system to manage people's preferences and sense of control as they approach end of life.

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

Numerous polls have been conducted in Australia in the last decade, and all indicate that the majority (66 – 85%) of the community supports terminally ill patients to legally end their own lives with medical assistance (e.g. ABC Vote Compass 2013 and 2016, Newspoll 2012, Australia Institute 2012). Most surveys, while self-selected, have been weighted to be representative of the Australian population, indicating that the ACT community is likely to have similar views.

It is important to take into consideration that the ACT is the only jurisdiction to our knowledge where the specialist palliative care service is only provided by a Catholic hospital. Consequently, the need for robust, transparent and neutral research into community views is critical – particularly in the context of potentially strong arguments against VAD legislation from a religious perspective. The APS supports the application of this evidence to drive user-informed decision-making.

Recommendation 2

That the Government draws on robust, transparent and neutral research to examine ACT community views about voluntary assisted dying, and uses this evidence base to drive future decision-making about end of life choices.

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

The APS acknowledges that dealing with issues surrounding the choice of a terminally ill person to request assistance from a medically qualified practitioner to terminate their life voluntarily and humanely is complex and challenging. This issue needs to be examined from a number of perspectives that encompass psychological, ethical/moral, medical, legal, religious/spiritual, sociological and political considerations.

The APS neither endorses nor opposes VAD. Rather, the APS endorses a best practice approach to end of life care, requiring that patients fully understand their alternatives and the main ramifications of their decision to access assisted dying services should they become legal outside Victoria. Ultimately,

the APS emphasises the importance of a process that is characterised by care, compassion and considered decision-making over time (Maddocks, 2014). The APS envisages that such a process would include access to the full range of care options, from the highest quality palliative care and the most competent psychological assessment and psychosocial support.

The APS is concerned about the potentially detrimental impact of legislative change on the health and wellbeing of people approaching the end of life, their friends and family, their carers and the broader community, as well as the health professionals involved in implementing the legislative changes. Of most concern to the APS is the need to support and ensure that vulnerable people have an informed voice, particularly in legal decision-making around whether assisted dying should be permitted (Forbat, 2017).

Many potential risks of VAD have been identified and discussed at length (e.g. Parliament of Victoria, 2016), both nationally and internationally. The main risks from a psychological perspective will be outlined and addressed below.

Competence and decision-making capacity

One commonly identified risk is that an individual may not have the capacity, or be 'competent', to make a decision to die.

The APS advocates best practice in terms of psychosocial support, requiring that the person fully understands their alternatives and the main ramifications of their decision. Importantly, the focus of capacity assessment is not on whether the decision to die is right or wrong, but to determine whether the person is able to apply the relevant information to make a decision that is in line with their preferences and values. It is also important to acknowledge and account for the fact that decisions can change, and that variations over time are not to be confused with ambivalence, and should not be used to undermine decision-making capacity.

People with a disability should be provided with appropriate support to make decisions, and having a disability does not negate their right to assisted dying or any other service that is legal for non-disabled persons. Patients with 'locked-in' syndrome, Lou Gehrig's disease or other conditions which impair communication will need special attention to ensure that they can express their views.

Some doctors and mental health practitioners may regard the presence of a decision to end life as proof that the person is mentally incompetent.

Training of doctors and mental health practitioners regarding indicators of mental competence and incompetence in this context may be required.

Mental illness and competence

Another risk is that it is often assumed that mental illness and/or dementia automatically deems a person incompetent to make decisions.

The APS believes there should be a presumption of rationality on the part of any person. Therefore, psychiatric assessment should not be considered an automatic corollary when a person has untreated mental conditions such as depression or anxiety. Likewise, people in the early stages of dementia should be assumed to have capacity.

When the person's GP or other treating medical practitioner suspects that the person is confused, or if other indications of psychiatric/neurological disturbances are present which may be affecting their decision making capacity, a referral for assessment by a psychiatrist or psychologist may be warranted. The US legal statutes recommend that a psychologist become involved in 'physician assisted suicide' when there are concerns regarding the person's decisional capacity due to the presence of psychopathology, such as depression (Johnson et al., 2014).

It is important to understand how mental illness (e.g., severe depression) affects competence and advance care planning, although it is equally important to avoid the suggestion that considering ending one's life is a sign of depression in itself. In many cases (e.g. early stages of Alzheimer's), people are competent to participate in advance care planning and decision-making. While psychiatrists and psychologists can play a key part in diagnosis of mental disorders and assessment of competence, a diagnosis of clinical depression or cognitive impairment should not automatically negate a person's right to access care choices available to other patients. It is important to acknowledge, for example, that a person's depression may be a response to a loss of control over the situation, which could be alleviated by the perception of choice over terminating one's life.

Furthermore, in the debate about VAD legislation, assessment of mental competence is often limited to that of clinical depression. However, there are other psychological or neurological disorders that may influence a patient's decision-making capacity (e.g., organic brain conditions, delirium, anxiety disorders and chronic alcoholism).

Coercion

There is also a risk that a person's decision to end their life is not entirely their own, and may be subject to undue influence by other parties, including carers or family members. The APS acknowledges that decisions are influenced by a range of factors, including the opinions of others, notably family members and health professionals. For this reason, the APS recommends that the person should be allowed to make a request in private - i.e. away from the influence of carers/family/nursing homes/palliative care specialists who may disagree with their decision - or in any way that ensures that they do not feel unduly pressured by the opinions of others.

Relationships are lenses through which to examine decision-making around assisted dying (Forbat, 2017). Psychologists and others trained in this modality (e.g. family therapists) have the specialist expertise and tools to support families, clinicians and community systems, to help manage the suffering and distress that arises.

Also of relevance is the indirect coercion potentially experienced as a result of living in a society that regards many vulnerable people (e.g. older people and people with a disability) as a burden. This highlights the need for community education which challenges our attitudes and beliefs about whether some lives are more worthy than others.

Conscientious objectors

There is a risk that an individual who would like assistance to die may not be able to access a practitioner who supports their decision. In the event that VAD is legalised in the ACT, health practitioners who object to participating in facilitating the process should be required to refer patients to other health practitioners who do not hold such a position.

Dying people may be at the limit of their mental, physical and economic resources and find it very difficult to locate another health practitioner who does support assisted dying. This is particularly true for individuals in residential aged care or palliative care facilities, where patients are entirely dependent on visiting medical practitioners who attend to them. Finding an alternative medical practitioner oneself in these circumstances may be excessively onerous or impossible. This may be even more challenging in the ACT, where specialist palliative care is only provided via a Catholic institution.

Impact on practitioners working with people approaching end of life

The impact of legislation on the wellbeing of practitioners is also of concern - particularly those working in locations where assisted dying has been newly

legislated and administrative supports and professional education are in their infancy. Evidence from Canada since assisted dying became legal in 2016 indicates that some medical practitioners are choosing not to participate in the scheme not only due to moral issues, but due to a lack of training in the area and a lack of administrative efficiency and support (Upshur, 2016).

Clinical supervision and support could be important to assist doctors and nurses to manage their potential responses to assisted dying requests and to reflect on their own conflicting personal values, concerns over their own psychological wellbeing and understanding their role (Forbat, 2017).

Adequacy and access to health care

There is a risk that the most vulnerable people in society are less likely to be able to access adequate health care, and therefore more likely to make requests for assisted dying services.

While Australians are increasingly wealthy on average, there is also rising inequality. Inequality leads to poorer health outcomes and higher levels of suicide, particularly amongst people within disadvantaged groups. The adequacy of access to affordable and timely health care is likely to play an important role in a person's decision-making, such that a request for assisted dying may follow a failure of one or more parts of the health system to provide adequate care. Such requests may be made in the context of serious social inequities in access to resources such as basic medical care (APA Resolution on Assisted Dying and Justification, 2017). Inadequate medical, palliative or psychiatric care or support may significantly influence a request for premature death (Komesaroff, Lickiss, Parker & Ashby, 1995).

For this reason, the APS recommends that any future legislation include an equity impact assessment (a decision support tool designed to ensure that a policy, project or scheme does not discriminate against any disadvantaged or vulnerable people).

Palliative care workforce

With the potential introduction of VAD legislation, the lack of appropriately trained health professionals is a significant risk to the effective implementation of the scheme.

Using psychologists as an example, the APS convened a roundtable in October 2017 to identify the implications of any legislative changes as well as assist the APS to develop resources to better equip psychologists to work in this space. Changes to legislation are likely to affect the work of psychologists, particularly if there is provision for psychologists to undertake

mental health and/or decision making capacity assessments. A key finding of the roundtable was that psychologists are likely to require more training and education about end of life issues to work more effectively in this space. This is likely to be the case for many other health professionals working with people approaching the end of their lives.

Not only is the lack of training a risk, but so too is the lack of numbers of health professional working in end of life care. It is not known how many psychologists work with people with life-limiting and life-threatening diagnoses in the ACT nor in Australia more widely. However, from our APS membership data we know that one per cent of members (254 practitioners and academics) self-report as having expertise in palliative care, 6 of whom are based in ACT. There are no psychologists working clinically within the specialist palliative care service in ACT. There are some psychologists working in hospital-based oncology, and there are likely to be some in the community, but the numbers are sparse.

In Europe, the European Association of Palliative Care collates data on the number of psychologists working in palliative care, something that could be very useful in the Australian context to inform and guide future workforce issues. It is likely that more investment will be required to increase the numbers of psychologists working in palliative care in order to maintain and promote psychological wellbeing, and particularly if VAD is introduced.

Recommendation 3

In the event VAD is legislated in the ACT, the APS strongly advocates for increased access to psychological services to assist in:

- 1. Capacity assessment*
- 2. Therapeutic interventions for patients and their families*
- 3. Clinical supervision for the service/s delivering assisted dying services.*

Recommendation 4

Future legislation should include an equity impact assessment (a process designed to ensure that a policy, project or scheme does not discriminate against any disadvantaged or vulnerable people).

Recommendation 5

Implementation of any VAD scheme needs to consider the existing and future capacity of the workforce to meet the needs of people approaching the end of their lives.

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

The APS is not aware of any reasons why a voluntary assisted dying scheme, such as that introduced in Victoria, would not be applicable to the ACT.

With the Victorian legislation not coming into effect until June 2019 unfortunately it is too early to take lessons from the implementation of the Victorian scheme and apply them to the ACT.

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

This is a political issue and beyond the expertise of the APS to comment.

(f) any other relevant matter.

The APS has made several relevant submissions to State and Federal Government Inquiries over the last few years:

- [Inquiry into the need for laws in Western Australia to allow citizens to make informed decisions regarding their own end of life choices](#) - October 2017
- [Victorian Government Voluntary Assisted Dying Bill Discussion Paper](#) - April 2017
- [Victorian Parliamentary Inquiry into End of Life Choices](#) - July 2015
- [Senate Inquiry into the exposure draft of the Medical Services \(Dying with Dignity\) Bill](#) - August 2014

The APS presented evidence at the associated hearing of the Senate Inquiry into the Medical Services (Dying with Dignity) Bill in October 2014. We invite the Committee to read the Hansard transcript as well as the [submission](#) itself, as these documents explain the key concerns of the APS. In summary, the APS noted that the model proposed under the Bill was very medically oriented and did not consider the broader psychological and psychiatric dimensions of introducing this option into the death trajectory. The critical element of “mental competence” being a threshold for access to dying with dignity services was noted as problematic, and thus the APS submission highlighted the need for a holistic assessment (not just medical assessment). The APS was also concerned about the need to acknowledge and incorporate family, cultural and gendered perspectives into the debate.

The APS would be pleased to assist the Committee, and provide further information as required. Please contact Heather Gridley on 03 8662 3327.

About the Australian Psychological Society

The Australian Psychological Society (APS) is the national professional organisation for psychologists with more than 23,000 members across Australia. Psychologists are experts in human behaviour and bring experience in understanding crucial components necessary to support people to optimise their function in the community.

A key goal of the APS is to actively contribute psychological knowledge for the promotion and enhancement of community wellbeing. Psychology in the Public Interest is the section of the APS dedicated to the communication and application of psychological knowledge to enhance community wellbeing and promote equitable and just treatment of all segments of society.

Related APS work on end of life choices

In addition, the APS Discussion Paper [*Psychological Perspectives on Euthanasia and the Terminally Ill*](#), updated in 2008, addresses a number of issues relevant to this Inquiry. The Paper noted that there exists:

an inherent tension between respecting individual autonomy and relieving people from unbearable suffering while still protecting the principle of valuing human life. Any liberalising of laws in relation to euthanasia needs to achieve a satisfactory mechanism which balances this tension, achieves respect for individual rights (of patients, carers and professional health workers), and prevents abuse, without becoming too unwieldy, bureaucratic and time consuming to be practical (p. 21).

The APS takes a similar position to that of the [*American Psychological Association*](#) (APA), which neither endorses nor opposes assisted dying given the complex multitude of issues involved. In their recent [*Resolution on Palliative Care and End-of-life Issues*](#), the APA also advocates for quality end of life care for all individuals; promotes research on assisted dying; promotes policies that reduce suffering; and supports research on ethical dilemmas faced by clinicians and researchers. Both the APS and APA foreground the need to protect first and foremost the wellbeing of the individual concerned. Consideration should also be given to the needs of family members and professionals involved.

APS members are required to abide by the ethical standards set out in its [*Code of Ethics*](#), which has been adopted and endorsed by the Psychologists Registration Board of Australia. The *Code* is built on three general ethical principles: Respect for the rights and dignity of people and peoples; Propriety; and Integrity, all of which are relevant to this Inquiry as well as for psychologists involved in end of life care. For example, respect for a person's

rights and dignity could be seen to support their inalienable right to life, or conversely their right to request a dignified end to that life. Similarly the general principle, Propriety, incorporates the principle of non-maleficence ('do no harm'), which can be interpreted to forbid the hastening of death, or to support active intervention in a situation intolerable to the patient.

We also draw the Inquiry's attention to the most recent issue of the Australian Psychologist, [Vol. 52, No. 5 Special issue: Psychology and End of Life](#), edited by Lauren J. Breen and Anna Ugalde.

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