

# Victorian Government Voluntary Assisted Dying Bill: Discussion Paper

Australian Psychological Society Response

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## **Executive Summary**

The Australian Psychological Society (APS) welcomes the opportunity to respond to the Victorian Government Voluntary Assisted Dying Bill Discussion Paper, and to provide our profession's perspective on the access, safeguards and practical considerations in creating a compassionate and safe assisted dying framework.

The focus of the Discussion Paper is recommendation 49 of the Parliamentary Committee – that the government introduces a legislative framework to allow voluntary assisted dying based on the framework recommended by the Parliamentary Committee.

The APS endorses a best practice approach to end-of-life care, wherein the person fully understands the alternatives and the main ramifications of his/her decisions. Ultimately, the APS emphasises the importance of a process that is characterised by care, compassion and considered decision-making over time. The APS envisages such a process to include access to the full range of care options, from the highest quality palliative care, the most competent psychological assessment and psychosocial support, and the fully-informed choice to request assistance to die when 'enough is enough'. Palliative care is not a substitute for assisted dying, but an integral part of a person-centred approach to end-of-life care.

Mental health issues that accompany many end-of-life illnesses and their effects on individuals, carers and families are the professional domain of psychologists. The APS thus 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 and carers as well as the person (including decisions about assisted dying should it become legal), the assessment of psychological disorders and mental competence, and the treatment and management of psychological disorders at the end-of-life.

This submission provides a response to questions posed in the Discussion Paper that are relevant to the APS and to psychologists' areas of expertise.

### ***Summary of Recommendations***

In summary, the APS commends the Ministerial Advisory Panel for highlighting a comprehensive and thoughtful list of key issues for consideration in relation to Recommendation 49. However, the APS draws attention to the other 48 recommendations and urges the Government to continue to resource and improve palliative and advance care planning services which will likely reduce demand for assisted dying.

The APS identifies the following issues as fundamental for the Panel's consideration in response to the key issues:

- Having a disability (e.g. cognitive impairment), disease (e.g. Alzheimers) or a mental illness (e.g. depression) does not automatically negate a person's

right to assisted dying or render them incapable of making a decision. The APS believes there should be the presumption of rationality on the part of any person.

- People living in institutional care may be the most vulnerable in relation to equity of access to voluntary assisted dying. Particular attention should be given to ensuring residents have appropriate access to relevant and independent information and services.
- The APS acknowledges that decisions are influenced by a range of factors, including the opinions of others, notably family members and health professionals. As such, strategies to minimise the risk of coercion, e.g. making decisions in private, may be appropriate.

## **1. Introduction**

The Australian Psychological Society (APS) recognises the psychological burden imminent death represents to many people in the community. The APS commends the Victorian Government for its political leadership around end-of-life care and for facilitating a conversation that enables those who are experiencing these issues to feel normalised. This is a crucially important first step for growing community capacity for conversations related to end-of-life care decisions.

The focus of this Discussion Paper is Recommendation 49 of the Parliamentary Committee – that the government introduces a legislative framework to allow voluntary assisted dying based on the framework recommended by the Parliamentary Committee. The framework would allow adults with decision-making capacity, who are suffering from a serious and incurable condition and at the end of their life, to be provided with assistance to die in certain circumstances. While the Parliamentary Committee's framework provides broad parameters, further considerations are required to determine the details of how this framework could work in practice. We understand that this Discussion Paper is not about repeating the moral and social arguments for and against assisted dying.

The APS is the national professional organisation for psychologists, with more than 22,000 members across Australia. Psychologists are experts in human behaviour and understand crucial components necessary to support vulnerable people to optimise their function in the community. APS members are required to abide by principles of professional conduct, responsibilities and confidentiality. These are set and monitored by the APS in its Code of Ethics (<http://www.psychology.org.au/Assets/Files/APS-Code-of-Ethics.pdf>), which has been adopted and endorsed by the Psychology Board of Australia. The Code of Ethics is built on three general ethical principles: Respect for the rights and dignity of people and peoples; Propriety; and Integrity. Each of these principles is pertinent to end-of-life care.

This APS response to the Discussion Paper builds on our work in this area over the last two decades, which includes:

- [APS Submission to the Victorian Parliamentary Inquiry into End-of-life Choices](#) (July 2015)
- [APS Submission to the Senate Inquiry into the exposure draft of the Medical Services \(Dying with Dignity\) Bill](#) (August 2014) and associated attendance at the hearing on 15 October 2014.
- [APS Discussion Paper Psychological Perspectives on Euthanasia and the Terminally Ill](#), updated in 2008.

The APS endorses a best practice approach to end-of-life care, requiring that the person fully understands his/her alternatives and the main ramifications of his/her decision. 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, the most competent psychological assessment and psychosocial support, and the fully-informed choice to request assistance to die when 'enough is enough'. Palliative care is not a substitute for assisted dying, but an integral part of a person-centred approach to end-of-life care.

Mental health issues that accompany many end-of-life illnesses and their effects on individuals, carers and families are the professional domain of psychologists. The APS thus believes that 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 and carers as well as the person (including decisions about assisted dying should it become legal), the assessment of psychological disorders and mental competence, and the treatment and management of psychological disorders at the end-of-life.

For this reason, the APS is disappointed that there is no representation by a psychologist on the Ministerial Advisory Panel responsible for developing voluntary assisted dying legislation.

### ***Context for Assisted Dying Legislation***

People with a life-limiting illness have the right to receive the highest quality care. The adequacy of care is likely to play an important role in the 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. Inadequate medical, palliative or psychiatric care or support may significantly influence a request for premature death (Komesaroff, Lickiss, Parker & Ashby, 1995). The APS is concerned about the adequacy of physical, medical, psychiatric and psychological care provided to the person, carers and family by the current health system, particularly within the palliative care system. This is particularly the case in rural and remote parts of Australia, many people from non-English speaking backgrounds as well as those experiencing clinical mental health issues.

Where services meet our obligations under human rights legislation, the need for control over end-of-life choices may not be so pressing. It is generally agreed

that when end-of-life care is adequate (e.g., pain management, communication, having a choice to remain at home, feeling comfortable), requests for end-of-life options are likely to be less frequent, although they will still arise. This highlights the need to start with and focus on better quality care and support. Adequately addressing social and environmental factors, such as ageism, discrimination, inappropriate and inadequate palliative care services and residential aged care amongst others, is likely to assist in improving quality care and support.

In the Western world in particular, death is becoming increasingly invisible (e.g. people die in hospitals away from view) and this is having implications for society at large (e.g. increasing fear and stigma about death and dying, and reduced 'death literacy'; Noonan et al., 2016). There is a growing movement to challenge this silence and start to facilitate conversations and communication about death and dying (publicly and privately) (Bartel, 2016).

Death and dying have become increasingly medicalised and assumed to be the sole domain of medical professionals. We have lost our 'death literacy' where once we were naturally engaged in the care of the dying and bereavement (Horsfall et al, 2015; Noonan et al, 2016). End-of-life is more than deteriorating physical health. It is about individual perceptions of what a life worth living looks like, and enabling people to create their own possibilities, hope and choices.

This submission provides a response to questions posed in the Discussion Paper that are relevant to the APS and to psychologists' areas of expertise.

## **2. Response to the Discussion Paper Questions**

### **2.1 The person**

- *Is the existing decision-making capacity test in legislation such as the Medical Treatment Planning and Decisions Act 2016 sufficient?*

The decision-making capacity test is sufficient. The APS advocates best practice in terms of psychosocial support, requiring that the person fully understands his/her alternatives and the main ramifications of his/her decision, and this requirement is encapsulated in the test.

The test is particularly commendable in that its stated purpose "is not to determine whether the decision 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.

As intimated in the test, 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. 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.

- *In what circumstances should a psychiatric assessment be required? Are there any other specialist referrals that would be appropriate for assessing decision-making capacity?*

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 decision-making capacity. In many cases (e.g. early stages of Alzheimer's), people are competent to make decisions. 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, 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 (e.g., organic brain conditions, delirium, anxiety disorders and chronic alcoholism).

One difficulty here is that some doctors and mental health practitioners may regard the presence of a decision to end life as proof that the person is mentally incompetent. Some training of doctors and mental health practitioners regarding indicators of mental competence and incompetence may be required.

## **2.2 Access & Eligibility**

- *Is greater specificity required to identify what constitutes a person being at the end-of-life and, if so, how should that specificity be worded?*

Given that the 'final weeks or months of life' are difficult to pinpoint, eligibility should be widened, particularly to allow people in the early stages of dementia to

be involved in the decision-making. Consideration needs to be given to people who are not moribund but are in a position of incurable suffering.

Palliative Care does not always prevent/alleviate suffering – up to 20% of people in palliative care experience moderate to severe suffering (Connolly et al, 2005 - See table 28, p.34). In addition to physical pain, other factors that contribute to suffering include symptoms like breathlessness, itching, nausea, loss of autonomy, loss of control over bodily functions, etc.

Anecdotal evidence (such as that unearthed by Andrew Denton in his Wheeler Centre Podcast series 'Better off dead') indicates that a major fear about end-of-life is not so much death, but the prospect of suffering and not being in control. Having access to assisted dying services can alleviate these fears and associated distress.

- *How should a 'serious and incurable condition' be defined?*

The APS considers the following statement to be problematic: "There is a range of conditions that may fall within this definition that some may feel should not qualify a person for voluntary assisted dying" (p.14). The 'feelings' of 'some' are insufficient reason to exclude any particular condition.

## **2.3 Making a request**

- *What safeguards are necessary to ensure that a request is voluntary? How should this be assessed?*

Notably absent from this section is information about who is receiving the request and what training they have had.

The process of making a request – verbally, then in writing, then verbally again – is a structure used elsewhere overseas. Obviously, if a person is unable to write (e.g. has a neurological illness), an alternative form of communication should be acceptable.

There is no provision for ensuring that individuals residing in nursing homes or palliative care facilities have equal access to this opportunity. These institutions are often run by religious organisations that frequently have strong objections to the provision of voluntary assisted dying. There could also be a conflict of interest where patients are contributing a significant stream of income to those institutions. When considering the influence of external parties, the possibility that nursing homes/palliative care facilities may try to exert their influence in the opposite direction should also be considered.

The Discussion Paper refers to excluding family members as witnesses to the person's official request for assisted dying, presumably reflecting concerns that family members may try to hasten the death of relatives for personal gain. This is a reasonable safeguard to ensure that the request is totally voluntary, and not unduly influenced by family members. Family members are not excluded from any



other decision-making processes.

Families often provide invaluable support to individuals with a life-limiting illness. The APS is pleased that the Discussion Paper acknowledges the strain on family members, and the associated needs of family members for appropriate support.

What is not addressed in the Discussion Paper is the role of families in relation to end-of-life choices. Families can be a strong influence, both in support and against the use of medical treatment to assist dying. For this reason, there is a need to work with the terminally ill person to ensure that their wishes are being respected - a role which could be met by a psychologist, and is referred to in the APS Ethical Guidelines for working with older adults

<https://www.psychology.org.au/Assets/Files/EG-Older-adults.pdf>.

The aim of this proposed framework is to ensure that the person's decision is entirely their own, and not subject to undue influence by anyone, 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.

- *Should there be a prescribed time period that must pass between the first and final request and, if so, what period?*

While the APS supports a process characterised by comprehensive and considered decision-making, the process needs to be balanced and streamlined in acknowledgement that the individual may be experiencing significant pain and suffering. For this reason, the APS does not consider a prescribed number of days is needed to pass between the first and last request. Consideration should be given to the person's stage of disease. Where a person has only one or two weeks to live, imposing a mandatory time period between requests would be impractical.

- *Should there be specific offences for those who fail to comply with the requirements in the Act or are the offences of homicide or aiding or abetting suicide appropriate and sufficient?*

While the APS does not have the expertise to comment on the legal aspects related to assisted dying, we highlight that there is no mention of an offence for failing to pass on the request of a person who wishes to access his/her rights under the Act.

## 2.4 Properly informed

- *Should the legislation include prescribed information that a medical practitioner must provide to a person requesting voluntary assisted dying and, if so, is the list recommended by the Parliamentary Committee in the box above sufficient?*

The APS believes that the legislation should include prescribed information and the list recommended by the Committee appears to be sufficient.

- *What resources should be developed to support legislative obligations to provide information that would be useful in practice?*

Printed brochures describing information related to voluntary assisted dying should be available in GP and health clinics, nursing homes and palliative care facilities. Information should also be available online on State Government websites. Efforts should be made to reach people in institutions whose ethos opposes voluntary assisted dying, and these persons should be actively approached to advise them of their rights in relation to this issue. It will also be important to ensure that this information is available in languages other than English. Likewise, people who may have limited English proficiency or literacy should also be provided with the appropriate supports, such as an interpreter trained in the prescribed information process.

- *Who should undertake the assessments and provide information?*

A wide range of professions other than doctors could undertake the assessments and provide information, including but not limited to: psychologists, social workers and nurses. In all cases, training should be provided on the topics of consent, values in this area and obtaining agreement without undue influence.

## 2.5 Confirming a request

- *Should the legislation prescribe specialist expertise required for medical practitioners to participate in voluntary assisted dying?*

This expertise could be acquired by most GPs and indeed members of the other relevant professions such as psychologists, social workers and nurses (although only medical practitioners could actually issue the appropriate prescription. Some training in relation to key issues in the legislation may be appropriate.

- *Should there be a requirement for a palliative care specialist referral or consultation?*

Requirement for a palliative care specialist referral or consultation is not necessary, but rather makes the process more difficult and cumbersome.

## 2.6 Conscientious objections

- *How should conscientious objection to voluntary assisted dying operate?*
- *Should health practitioners who conscientiously object be required to refer patients to other health practitioners?*

As highlighted, in Victoria, if a medical practitioner is a conscientious objector to abortion, they are required to refer patients to another practitioner who does not hold such an objection. In the same way, in the event that assisted dying is legalised in Victoria, health practitioners who object to participating in facilitating the process should be required to refer patients to other health practitioners.

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 nursing homes 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.

- *Should health practitioners who conscientiously object be required to declare their objection? If yes, when should this occur?*

Conscientious objection should be declared as soon as reasonably possible after health practitioners are aware that their patient suffers from one of the conditions listed as likely to come under the Act. Alternatively, a register of medical practitioners who conscientiously object could be created and made available particularly at nursing homes and palliative care facilities.

## 2.7 Administering a lethal dose of medication

- *Are additional safeguards required when a medical practitioner administers the lethal dose of medication and, if so, what safeguards would be appropriate?*
- *Where should a medical practitioner administer the lethal dose of medication, and what practical and other challenges would this create?*

There is evidence that a substantial proportion of medical practitioners at times help their terminally ill patients to end their lives (Douglas et al., 2001; Kuhse et al., 1997; Neil et al, 2007). This occurs both covertly (illegally), and under the guise of the principle of “double effect” (where the stated aim is to relieve suffering, but death is an ‘unintended consequence’). Doctors rely on the principle of “double effect” to avoid prosecution, but the legality of their actions is unclear.

The lethal dose should be prescribed by the medical practitioner when all eligibility criteria have been met by the person. The person can then self-administer the medication at a time and place of their choosing. This may occur at home, or in a

facility. Where patients are not able to self-administer due to limitations of their illness, assistance from nursing staff may be arranged, in collaboration with the patient's request. Choice about where to be cared for and to die will always be constrained. Some conditions and some pain management may need hospital care. This should be acknowledged.

## **2.8 Monitoring the use of a lethal dose of medication**

- *How can a prescribed lethal dose of medication be effectively monitored without placing undue burdens or pressure on people accessing or using the medication?*

Effective monitoring processes could be informed by the legislation about safe storage of guns - describe what would constitute safety in the Act and require that the person store it in that way. Make it clear that the person has an obligation to treat the substance, whatever it is, with respect – primarily to prevent anyone else gaining access to it. There would be no need to keep asking the person about the medication.

## **2.9 Attendance**

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

A health practitioner should be allowed to be present if this is requested by the person, but it should not be mandatory.

## **2.10 Lethal dose of medication not effective**

- *What should the obligations of a health practitioner be to treat a person who has chosen to ingest a lethal dose of medication?*
- *What is the best way to indicate that a person has chosen to take a lethal dose of medication?*

The medical practitioner definitely should not embark on life sustaining treatment. The Californian approach is a good model.

## **2.11 After a person has died**

- *What should be recorded as the cause of death for a person who has ingested the lethal dose of medication?*

The recorded cause of death should be the patient's illness that was bringing the

person's life to an end. This is the practice in nearly all countries that allow voluntary assisted dying. Many individuals do not want euthanasia or voluntary assisted dying on their death certificate, as they were going to die anyway.

- *Should death as a result of voluntary assisted dying be a reportable death?*

A register providing the details of the person's illness/es, and the manner and timing of their death should be kept for all individuals who access voluntary assisted dying. This allows for data collection and monitoring of the system, as well as possible scrutiny should questions arise in the future.

## **2.12 Oversight**

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

The diagnosis of key terminal illness, the lethal substance prescribed, and date and time of death.

- *At what stage should medical practitioners or pharmacists be required to report to the Assisted Dying Review Board?*

When the patient has died.

- *When should an oversight body be required to refer a matter to another agency?*

If there is any suggestion that a person has either been coerced or has been prevented from acting on their own wishes.

## **2.13 Additional safeguards**

- *Does the Parliamentary Committee's framework provide sufficient protection to vulnerable people?*

The Parliamentary Committee's framework appears to provide adequate protection for vulnerable people. The exception may be for residents of institutional care (nursing homes and palliative care facilities) whose access to assisted dying may be thwarted by opposition from within those institutions.

- *What other additional safeguards could be considered?*

As noted in a previous submission to the Dying with Dignity Bill, the APS would like to highlight the following issues and encourage the Panel to acknowledge them in their amendments to the framework:

*Cultural and gendered perspectives*

For many people from Aboriginal and Torres Strait Islander and culturally and linguistically diverse backgrounds, the person wishing to die may not be regarded as an individual unit, but rather a part of a larger unit; the family. Very little is currently known about the views of people from this background, and the APS recommends that perspectives of people from collectivist cultures need to be acknowledged in the framework. As with pregnancy termination in the context of a collective history of forced sterilisation and child removal, Indigenous peoples may be as wary of any limitation to their right to choose life as of the opposite.

There are also gender differences in access to legal voluntary assisted dying services which have largely been neglected by researchers (Allen, 2002). Women are most affected by this debate, because they typically live longer, with greater likelihood of suffering chronic disease at a later age. Further, there is some evidence to suggest that men are more likely than women to request assisted dying services, and medical practitioners are likely to react differently to requests based on gender (Allen, 2002).

#### *Educational, psychological and support needs of decision-makers*

The APS is also concerned about the educational, psychological and support needs of medical, legal and health practitioners in decision-making positions. For example, nurses may be left to administer treatment to end life, or doctors may believe that people who request such treatment are always depressed and thus consider that there is never the possibility of mentally competent decision-making or that depression in itself equates to mental incompetence.

#### *Family perspectives*

It is important to consider the impact of end-of-life decisions on family/carers who may need professional support to deal with them.

The APS supports a communication framework which encourages all medical and support professionals to openly discuss end-of-life issues and to be available for consultation to provide necessary information about a range of related issues. Normalising these discussions and promoting their benefits with carers and families will help ensure the patient's wishes are understood and honoured.

## **2.14 Liability and Insurance**

- *What protections would be necessary for health practitioners who act in accordance with the new legislation in good faith and without negligence?*
- *How should insurance and other annuities of people who access voluntary assisted dying be protected?*

Protections would need to be in place to ensure that practitioners who act in accordance with the new legislation in good faith are protected under the law. However, the APS does not have the specific expertise to identify the details.

The APS Code of Ethics is built on three general ethical principles: Respect for the rights and dignity of people and peoples; Propriety; and Integrity. Each of these

principles is pertinent to end-of-life issues, and together they capture the complexity of the debate around legalisation of assisted dying, in that each can be interpreted in very different ways. For example, respect for a person's rights and dignity could be seen to support their inalienable right to life, or 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 deemed intolerable to the patient.

The current interpretation of APS Code A.5.2.(c) means that a psychologist needs to report 'an immediate and specified risk of harm' as in the case of a client expressing a rational desire to die, and having a plan to do so. Until the law is changed a psychologist would put themselves at risk of an AHPRA notification for not reporting it.

In Oregon, where physician assisted suicide (PAS) is legal but the American Psychological Association has no position on PAS, the ethical responsibilities of psychologists remain open to interpretation (Johnson et al, 2014).

## **2.15 Conclusion**

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

The adequacy of 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 Suicide). 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. We can improve how people die by improving training to create a better workforce, creating better infrastructure, and having more appropriate policies and protocols in place to maximise the real choices available to the seriously and terminally ill.

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