

Legal & Social Issues Committee Parliament House Spring Street Melbourne VIC 3002

Level 11, 257 Collins Street Melbourne VIC 3000 PO Box 38 Flinders Lane VIC 8009 T: (03) 8662 3300 F: (03) 9663 6177 www.psychology.org.au

By email: lsic@parliament.vic.gov.au

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To Whom It May Concern,

Inquiry into End of Life Choices

The Australian Psychological Society (APS) welcomes the opportunity to make a submission to this Inquiry about the need for laws in Victoria to allow citizens to make informed decisions regarding their own end of life choices.

While the APS neither opposes nor endorses voluntary termination of life, several issues and concerns that warrant attention are highlighted in this submission in the event of any legislative changes.

The APS is the national professional organisation for psychologists, with over 21,000 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. 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 Psychologists Registration 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 the current Inquiry. 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.

The APS acknowledges that dealing with issues surrounding the purported right of a terminally ill person to request assistance from a medically qualified person to voluntarily terminate his or her life in a humane manner is complex and challenging, and needs to be examined from a number of perspectives, including psychological, ethical/moral, medical, legal, religious, sociological and political considerations. Psychologists have the knowledge and skills to allow them to become involved in these issues in a variety of ways: they can enter the debate on dying with dignity, be involved in policy development and in practice for the care of the terminally ill, in the process of support and decision-making, and in the assessment of psychological disorders and mental competence.

In August 2014, the APS made a submission to the Senate Inquiry into the exposure draft of the Medical Services (Dying with Dignity) Bill 2014. The APS also attended the associated hearing on 15 October. We invite the Committee to read the Hansard transcript as well as the submission itself (attached), as these documents explain the key concerns of the APS. In summary, the APS believes 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 that 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.

In addition, the APS Discussion Paper *Psychological Perspectives on Euthanasia and the Terminally Ill*, updated in 2008, addresses a number of issues relevant to the current Inquiry:

http://www.psychology.org.au/Assets/Files/euthanasia position paper.p df. 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 suicide" given the complex multitude of issues involved (http://www.apa.org/about/policy/assisted-suicide.aspx). The APA also advocates for quality end-of-life care for all individuals; promotes research on "assisted suicide"; promotes policies that reduce suffering; and supports research on ethical dilemmas faced by clinicians and researchers. Both the APS and APA statements 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.

We would be pleased to assist you further. For further information please contact me on

Yours sincerely,

Ms Heather Gridley FAPS Manager, Public Interest

Australian Psychological Society



Submission to the Senate Inquiry into the exposure draft of the Medical Services (Dying with Dignity) Bill 2014

Australian Psychological Society

APS contact: Heather Gridley Manager, Public Interest

August 21 2014

Level 11, 257 Collins Street Melbourne VIC 3000 PO Box 38 Flinders Lane VIC 8009 T: (03) 8662 3300 F: (03) 9663 6177 www.psychology.org.au The Australian Psychological Society (APS) welcomes the opportunity to make a submission to the Senate Inquiry into the exposure draft of the Medical Services (Dying with Dignity) Bill 2014. While the APS neither opposes nor endorses voluntary termination of life, several issues and concerns that warrant attention are highlighted in this submission in the event that such a Bill is passed and the current law is changed.

The Australian Psychological Society (APS) is the national professional organisation for psychologists, with over 21,000 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. 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*

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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.

On 24 June 2014, the Senate referred the exposure draft of the Medical Services (Dying with Dignity) Bill 2014 to the Legal and Constitutional Affairs Legislation Committee. The Senate directed the Committee to have regard to the rights of terminally ill people to seek assistance in ending their lives, and an appropriate framework and safeguards with which to do so. The Dying with Dignity Bill (as with the Rights of the Terminally Ill Bill 2008) would enable a medical practitioner to assist to end a patient's life where the patient requests it, has had a terminal illness diagnosed and confirmed by two medical practitioners, is experiencing pain, suffering distress or indignity to an extent unacceptable to him/her, and has been assessed by a psychiatrist to be "mentally competent" and not suffering clinical depression.

The APS acknowledges that dealing with issues surrounding the purported right of a terminally ill person to request assistance from a medically qualified person to voluntarily terminate his or her life in a humane manner is complex and challenging, and needs to be examined from a number of perspectives, including psychological, ethical/moral, medical, legal, religious, sociological and political considerations. Psychologists have the knowledge and skills to allow them to become involved in these issues in a variety of ways: they can enter the debate on dying with dignity, be involved in policy development and in practice for the care of the terminally ill, in the process of support and decision-making, and in the assessment of psychological disorders and mental competence.

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In this submission, the APS highlights concerns with the exposure draft, from a psychological perspective. Some additional issues, not raised in the draft, are also identified that warrant attention in the event that such a Bill is passed and the current law is changed.

Mental Competence (Objects of this Act, Section 3)

As stated in the exposure draft, the objects of the Act are (Section 3a) "to recognise the right of a mentally competent adult who is suffering intolerably from a terminal illness to request a medical practitioner to provide medical

services that allows the person to end his or her life peacefully, humanely and with dignity". The APS is concerned about and would like more details of the proposed definition and assessment of "mentally competent".

The APS advocates best practice in terms of psychosocial support, requiring that the patient fully understands his/her alternatives and the main ramifications of his/her decision. The APS also acknowledges the rights of terminally ill patients to the highest quality care. Ultimately, the APS emphasises the importance of a process that is characterised by care, compassion and considered decision-making over time (Maddocks, 2014).

Dying with dignity may be the outcome preferred by some terminally ill patients, but its consideration as a treatment option requires the careful examination of all possible medical, palliative, psychiatric and psychological factors which may be contributing to the request. Thus a patient's stated desire to die is a necessary but not sufficient justification for acquiescence. In order to determine whether a person is competent to make such a decision, a careful and thorough clinical assessment is required by an appropriately skilled psychologist or psychiatrist, administered on more than one occasion with a reasonable time interval between assessments, where possible. Undertaking assessments on more than one occasion would increase the degree of confidence in the findings of the assessment.

To further protect the interests of the individual and the community, and to minimise the chance of errors of judgment, assessment should ideally include detailed history-taking and listening to the patient's experience of life and of illness, and his/her fears and expectations. Where possible, it should also involve careful mental status testing, including assessment of cognitive state, mood, form and content of thought, and a precise examination of the stated and implied reasons for the request. Taking account of situations of great pain and suffering is also vital, given the likelihood that intolerable suffering can impair mental competence.

While the APS supports an assessment 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, and that there might always not be sufficient time or resources to enable extensive, repeated assessments or second opinions.

People with cognitive impairments may require additional support to make decisions, but their impairment should not negate their right to access dying with dignity medical services, if these become legally available to other community members.

Preconditions to providing dying with dignity medical services (Section 12)

The proposed Bill indicates that "mental competence" is the critical threshold for consideration of access to dying with dignity medical services. To that end, the draft proposes that the person with a terminal illness be examined by three medical practitioners, the third of whom is a qualified psychiatrist, as a precondition for their request to access dying with dignity medical services.

The APS is concerned about the nature and adequacy of the assessment proposed as part of this process. The assessment of cognitive state/ mental competence in an individual with a terminal illness who is likely to be experiencing considerable physical and emotional distress at the time is a complex task and should only be undertaken by a health professional with the appropriate skills and experience. It is therefore critical that the assessment process include a psychiatrist and/or psychologist competent to undertake this complex work. This is not sufficiently clear in the draft Bill. Experienced psychologists should be included as assessors given their skill base and the need to ensure an adequate workforce across Australia.

As indicated, the context for the assessment of "mental competence" in these circumstances is challenging. An additional complexity not adequately addressed in the draft Bill is the situation whereby the nature of an end-stage terminal illness itself impacts on the individual's mental state (for example, renal disease or cerebral carcinoma). The Bill needs to consider a process for managing situations where the request has been made at a time when the individual was competent to do so, for example in a 'living will'.

The assessment process needs to allow for obtaining additional opinions to account for instances where there is disagreement amongst the assessors and/or the patient disagrees with the findings. There should also be flexibility so that the assessment can be repeated in cases of diagnosed mental health conditions (such as clinical depression) that may fluctuate.

The Bill also states that the three medical practitioners are not relatives or employees of or members of the same medical practice. This goes some way to maintaining a degree of independence of the assessment. However, further measures could be implemented such that practitioners do not know whether they are first, second, or third practitioners, nor the outcomes of previous assessments.

Clinical Depression (Section 12, 1e)

Section 12(1e) (Preconditions to providing dying with dignity medical services) states "a further medical practitioner (the third medical practitioner) who is a qualified psychiatrist has examined the person and has confirmed that the person is not suffering from a treatable clinical depression in respect of the illness." This issue closely relates to Section 3 (Object of this Act) which referred to a person being "mentally competent". In the previous section, the APS outlined a number of concerns with the proposed process for the assessment of mental competence.

With regard to a diagnosis of clinical depression, it needs to be recognised that this should not automatically negate a person's right to access legal dying with dignity medical services. Rather, the presence of a depressive illness needs to be carefully assessed and treated in its own right, by a suitably qualified health practitioner. For example, a patient'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.

In relation to section 12 (1e) an emphasis is placed on clinical depression, but no mention is made of other psychological or neurological disorders that may influence a patient's decision (e.g., organic brain conditions, delirium, and anxiety disorders). The APS is concerned that limiting the assessment to only clinical depression is too narrow in scope.

Satisfaction on reasonable grounds (Section 12, 1k)

A further stated precondition (Section 12, 1k) is that "the first medical practitioner is satisfied, on reasonable grounds, that the person is of sound mind and that the person's decision to end his or her life has been made freely, voluntarily and after due consideration."

The APS questions whether a medical practitioner is always qualified to determine that a person is of "sound mind". Medical practitioners are able to assess cognitive state and competence in many situations. However, as stated above, the assessment of "sound mind" in many instances surrounding terminal illness is extremely complex and requires specific skills and experience. Further, the APS would like some clarification that "reasonable grounds" includes being satisfied that the previous conditions (as stated in Sections 12, 1a-k) have been complied with.

The medical practitioner must be satisfied that the patient has given fully informed consent, and has considered the possible implications. This eliminates the applicability of the Act to those patients who are unable to communicate their wishes and consent. However, there are unlikely to be many patients with whom some sort of communication could not be established.

Adequacy of the current health system (Section 12, 1hii)

Section 12 (1hii) states that a precondition is for the first medical practitioner to inform the person of "the medical treatment, including palliative care, counselling, psychiatric services and extraordinary measures for keeping the person alive that may be available to the person". Terminally ill patients 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 dying with dignity medical services 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 care provided to the patient (and family) by the current health system, with special reference to palliative care but also including physical, medical, psychiatric and psychological care. This is particularly the case in rural and remote parts of Australia, as well as for many people from non-English speaking backgrounds.

Right to rescind request (Section 15)

The APS is concerned about quality assurance around the response to either an initial request or a rescinding of that request, and that adequate standards of care are maintained during that period. Care should also be extended to the family in such circumstances. Furthermore, withdrawing the request should not result in prejudice, discrimination or recrimination, and the person must not have been subject to undue pressure and influence from others.

Claim for payment for the provision of dying with dignity medical services (Section 16)

If psychologists are involved in the provision of dying with dignity services, specifically to undertake psychological assessment and diagnosis, they need to be renumerated in the same way as medical practitioners. Therefore we propose that claims for payment be extended to include "registered health practitioners" or suitably qualified others.

Other issues for consideration not covered by the exposure draft

Conscientious objectors

In Victoria, if a medical practitioner is a conscientious objector to abortion, they are required to refer to another practitioner who does not hold such an objection. The APS proposes that the Bill is explicit about requiring conscientious objectors to dying with dignity medical services to identify themselves as such. While it might not be appropriate to force them to refer onwards, they should be strongly urged to do so, if the Bill is passed and such services become legally available.

Family perspectives

The APS is concerned that the current Bill does not address or acknowledge the role of families. Families can be a strong influence, both in support and against the use of medical treatment to assist dying. Therefore, there needs to be appropriate support for the family as well as adequate protection for the individual. Neither the Bill nor its regulations make provision for addressing the needs of close relatives of the patient through counselling. A psychologist, as long as they are not involved in the actual process of the administration of dying with dignity medical services, could reasonably be involved in such counselling both during and after the process (refer to APS Ethical Guidelines for working with older adults https://www.psychology.org.au/Assets/Files/EG-Older-adults.pdf).

The issue of families, their dynamics, influence and impact is a very significant one. There are two main aspects. First, and the more benign issue which should be addressed, is the pain family members feel in watching a loved one suffering. Their wish to see an end to their loved one's suffering and allow him/her to die earlier rather than later, may be at least partly if not significantly influenced by their own pain, discomfort and mental anguish. The second issue of concern which is often raised in Guardianship tribunals is the self-interest (financial or otherwise) of members or some members of the family, especially when they are consulted by doctors and there is no valid medical power of attorney. There are additional concerns when people make decisions to die based on "not wanting to be a burden" to others. These are factors largely external to the illness and, in essence, become push factors not necessarily concerned with the wellbeing or welfare of the patient.

It is also not clear if there is any provision under the Bill for spouses or close relatives who may have significant concerns about the decision of the individual to choose to end their life in this way, to challenge the decision and if so, under what circumstances.

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 this deficit in the research should be addressed immediately.

There are also gender differences in access to legal dying with dignity medical 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

dying with dignity medical services, and medical practitioners are likely to react differently to requests based on gender (Allen, 2002). Given the limited understanding of gender differences, more research is recommended.

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 that there is never the possibility of mentally competent decision-making, or that depression in itself equates to mental incompetence.

Conclusion

The current model proposed under the Bill is very medically oriented and does not consider the broader psychological and psychiatric dimensions of introducing this option into the death trajectory. It is therefore inconsistent with the Object of the Bill and the critical issue of "mental competence" as a threshold for requests to access dying with dignity medical services. For this reason, the APS takes the following position:

- We underscore the critical element of mental competence and thus the need for a holistic assessment (not just medical assessment)
- We urge greater input on this debate, such as via a more considered discussion paper or Senate Inquiry.

References

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