Public Health Association of Australia submission on voluntary assisted dying in Western Australia

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Preamble

The Public Health Association of Australia

The Public Health Association of Australia (PHAA) is recognised as the principal non-government organisation for public health in Australia working to promote the health and well-being of all Australians. It is the pre-eminent voice for the public’s health in Australia.

The PHAA works to ensure that the public’s health is improved through sustained and determined efforts of the Board, the National Office, the State and Territory Branches, the Special Interest Groups and members.

The efforts of the PHAA are enhanced by our vision for a healthy Australia and by engaging with like-minded stakeholders in order to build coalitions of interest that influence public opinion, the media, political parties and governments.

Health is a human right, a vital resource for everyday life, and key factor in sustainability. Health equity and inequity do not exist in isolation from the conditions that underpin people’s health. The health status of all people is impacted by the social, cultural, political, environmental and economic determinants of health. Specific focus on these determinants is necessary to reduce the unfair and unjust effects of conditions of living that cause poor health and disease. These determinants underpin the strategic direction of the Association.

All members of the Association are committed to better health outcomes based on these principles.

Vision for a healthy population

A healthy region, a healthy nation, healthy people: living in an equitable society underpinned by a well-functioning ecosystem and a healthy environment, improving and promoting health for all.

The reduction of social and health inequities should be an over-arching goal of national policy and recognised as a key measure of our progress as a society. All public health activities and related government policy should be directed towards reducing social and health inequity nationally and, where possible, internationally.

Mission for the Public Health Association of Australia

As the leading national peak body for public health representation and advocacy, to drive better health outcomes through increased knowledge, better access and equity, evidence informed policy and effective population-based practice in public health.
Introduction

PHAA welcomes the opportunity to provide input to the consultation into voluntary assisted dying in Western Australia. PHAA recognises the diverse and strongly-held views in Australia on the subject of end of life choices. The issues are contentious and difficult to resolve in a purely objective manner. Many people have personal experiences and cultural frameworks and beliefs that inform their opinions. Legislative backing is important in supporting end of life choices, and the beliefs of the individual who is dying should have primary importance in order to respect their autonomy.

PHAA Response to the consultation paper

Guiding principles

Are there other guiding principles that should be considered for the Bill?

The guiding principles as listed in the consultation paper are:

- Every human life has intrinsic value
- A person’s autonomy should be respected
- People have the right to be supported in making informed decisions about their medical treatment, and should be given, in a manner they understand, information about medical treatment options, including comfort and palliative care
- People approaching the end of life should be provided with high quality care to minimise their suffering and maximise their quality of life
- A therapeutic relationship between a person and their health practitioner should, wherever possible, be supported and maintained
- People should be encouraged to openly discuss death and dying and their preferences and values should be encouraged and promoted
- People should be supported in conversations with their health practitioners, family, carers and community about treatment and care preferences
- People are entitled to genuine choices regarding their treatment and care
- People should be supported in their right to privacy and confidentiality regarding their choices about treatment and care preferences
- People who may be vulnerable should be protected from coercion and abuse in relation to end of life choices and decisions
- All people, including health practitioners, have the right to be shown respect for their culture, beliefs, values and personal characteristics

PHAA supports these guiding principles with the beliefs of the individual who is dying having primacy in order to respect their autonomy. End of life communication, such as Advance Care Planning and Directives, help people to overcome communication barriers and provides a structure for ensuring their wishes are clearly outlined and respected.
PHAA submission on voluntary assisted dying - WA

The person

Should there be a specified period during which someone has to be continuously living in Western Australia in order to be considered ‘ordinarily resident’?
The Australian Taxation Office considers a six-month period as consistent with residency. Accordingly, PHAA recommends a six-month period as appropriate for a person to be living in WA to be considered ordinarily resident for the purposes of voluntary assisted dying.

The decision

What safeguards should there be to ensure that a request is voluntary?
The Voluntary Assisted Dying Act 2017 in Victoria creates safeguards to ensure that a request is voluntary in 2 ways. Firstly, it allows for the Secretary to approve training for medication practitioners in “identifying and assessing risk factors for abuse or coercion” (S114 part (c)). Secondly, it requires that the forms signed by the co-ordinating medical practitioner, consulting practitioner, and the patient themselves, each include a statement about the person “acting voluntarily and without coercion”.

Should the assessing medical practitioner be able to refer to other health practitioners with relevant competency to assess that the decision is voluntary?
Assessments of competence and undue influence are complex and may require specific training for health care professionals. It is therefore sensible to make provision for the assessing medical practitioner to be able to refer to other health practitioners with specific expertise in assessing competence and undue influence. However, this should not unduly add to the length and complexity of the assessment process. PHAA recommends that either the co-ordinating practitioner or the consulting practitioner may make a referral, with a maximum of one referral to be made.

Should health practitioners be able to discuss voluntary assisted dying with their patients in the same way as they raise and discuss other health or medical decisions and care options?
PHAA supports the Joint Select Committee recommendation that there not be any prohibition on health practitioners starting a discussion about voluntary assisted dying. Clear communication about end of life care, including voluntary assisted dying, is essential for supporting end of life choices and the autonomy of patients.

The Victorian legislation states:
8. Voluntary assisted dying must not be initiated by registered health practitioner

(1) A registered health practitioner who provides health services or professional care services to a person must not, in the course of providing those services to the person –

(a) initiate discussion with that person that is in substance about voluntary assisted dying;
(b) in substance, suggest voluntary assisted dying to that person

(2) Nothing in subsection (1) prevents a registered health practitioner providing information about voluntary assisted dying to a person at that person’s request.

As the discussion paper notes, this provision is unusual, and is found only in the Victorian legislation. The provision in the Victorian legislation may leave health practitioners feeling unclear whether or not they are able to discuss voluntary assisted dying, depending on the precise wording of the question a patient asks. For example, if a patient asks, “what are my options?” people have the right to expect a comprehensive response to that question, with all available legal options canvassed. With known poor levels of health literacy in Australia, it would be unsafe to assume people know about voluntary assisted dying provisions that they need to ask about it specifically in order to receive information.
Prohibitive provisions requiring patients to know how to word a question in order to receive a complete response are at odds with the stated guiding principles of:

- People have the right to be supported in making informed decisions about their medical treatment, and should be given, in a manner they understand, information about medical treatment options, including comfort and palliative care
- A therapeutic relationship between a person and their health practitioner should, wherever possible, be supported and maintained
- People should be encouraged to openly discuss death and dying and their preferences and values should be encouraged and promoted
- People should be supported in conversations with their health practitioners, family, carers and community about treatment and care preferences
- People are entitled to genuine choices regarding their treatment and care

It is important to note that voluntary assisted dying provisions must not erode continued investment to strengthen the availability of quality palliative care services in Western Australia.

**What are the cultural and linguistic considerations in relation to how people may be informed about voluntary assisted dying?**

In an already difficult space, the provision of information about voluntary assisted dying is further complicated by cultural and linguistic considerations, which go much further than the basic necessity of providing translators where required. Culture includes communication styles, attitudes, values and family relationships. Cultural considerations which may act as barriers may be compounded for refugees and former refugees.

Some of the issues experienced by patients from culturally and linguistically diverse backgrounds include terminology; communication, culture and pain management; not talking about death and dying; and religious faith as a coping strategy – challenging the terminal diagnosis. Willingness to discuss death and dying is influenced by a complex set of factors including individual biography, family relationships, educational attainment, and cultural background including faith and hope.

Given the heterogeneity of Aboriginal and Torres Strait Islander peoples, and other culturally and linguistically diverse communities, tailored information is essential to ensure the decision is fully informed and comprehended.

**What, if any, additional initiatives should be considered to ensure people are properly informed about voluntary assisted dying and supported in the decision making process?**

The complexities around communication about death and voluntary assisted dying are highlighted by a study showing that attitudes towards assisted dying are influenced by the wording and order of questions presented in a survey. The provision of extra contextual information was positively associated with greater acceptance of assisted dying. This highlights the importance of presenting information in a considered and sensitive manner which does not imply that voluntary assisted dying is the preferred approach for terminally ill patients. Information about voluntary assisted dying should be provided as part of a package of information canvassing all available options including palliative care.

Information and support will also need to be provided to the family and carers of people considering or requesting voluntary assisted dying. Counselling, debriefing and support services should be available prior to, at the time of and after death, with information provided to family and carers about the services available and how to access them.

The Productivity Commission report into reforms to human services noted that many clinicians feel unprepared to talk about dying, but that training can improve this. Some guidelines to assist clinicians...
exist, and may provide a useful framework for communicating about death and dying. For example, the
North Sydney Local Health District has produced a framework for supporting Aboriginal and Torres Strait
Islander peoples through Sad News and Sorry Business.¹⁰

Eligible conditions

If voluntary assisted dying only applied to an illness or disease that is terminal, is specification of a
timeframe either desirable or necessary?
PHAA supports the recommendation not to include a timeframe until death in the eligibility criteria. As
noted in the discussion paper, timeframes can be somewhat arbitrary, and the requirement for a terminal
condition should be sufficient.

Would a timeframe help or hinder access to voluntary assisted dying? From the perspective of the
person? Or medical practitioner?
Timeframes, in conjunction with the requirement for the person to maintain capacity throughout the
process, reduce the likelihood that a person with a condition such as dementia with life expectancies up to
8 years following pronounced symptoms,¹¹ would be able to access voluntary assisted dying. With
dementia being the second leading cause of death in Australia,¹² this would render a significant proportion
of deaths ineligible.

Must a person’s suffering be ‘grievous and irremediable’ to be eligible?
The criteria in the Victorian and Canadian legislation, as noted in the discussion paper, includes the eligible
condition causing suffering that cannot be relieved in a manner acceptable to the person. This is sufficient
and removes unnecessary debate about the perceived severity of that suffering.
This requirement may also preclude a person with dementia from accessing voluntary assisted dying –
depending upon the definition and interpretation of ‘grievous and irremediable’. For many people, the
reality that their cognitive function is declining and will continue to do so until they are unable to recognise
their family and loved ones, unable to communicate or look after themselves, and unable to have any real
decision-making capacity, would constitute ‘grievous and irremediable’ suffering of their mental health.
However, as long as the definition and interpretation includes suffering of mental health, eligibility would
remain. PHAA recommends that this be made explicit in the legislation.

The process

How should the process take community, linguistic and cultural beliefs and practices into account
whilst also ensuring human rights, personal autonomy, privacy and choice? What approaches or
initiatives would assist in achieving this balance?
A foundational principle of the process being person-centred and respecting the autonomy of the individual
encompases community, linguistic and cultural beliefs and practices. This should include being able to
access medical practitioners of their choice, such as from Aboriginal Community Controlled Health Services,
and having personal and subjective judgements on criteria such as suffering.
Implementation of a voluntary assisted dying scheme will require careful consideration to ensure that the
community, health practitioners and services are fully informed and prepared, and that monitoring and
evaluation are in place prior to the commencement. PHAA recommends an interdisciplinary steering group
be formed to oversee the translation of any legislation into practice with the drafting of regulations, clinical
guidelines, professional guidance and support.
What other ways are there to appropriately enable access to voluntary assisted dying?
Access to a second medical practitioner may be problematic for some people, for example, those in rural and remote areas, or those with specific cultural or linguistic needs and practices. PHAA supports the recommendation to use telehealth and secure electronic information exchange to enable access. It will be important to understand the number of people who progress through the various stages of the proposed voluntary assisted dying process, and the reasons for their continued progression or not. This will require monitoring and evaluation with the collection and reporting of data at all stages of the process.

Should a medical practitioner or health service that conscientiously objects have an obligation to refer the patient to a practitioner or service that has no objection?
If training for medical practitioners undertaking the process for voluntary assisted dying is mandatory, a registry may be kept which would also allow medical practitioners to access a list of doctors who have no conscientious objection. This is the case in California, where patients may consult with advocacy organisations who provide information about the relevant Act and participating providers. In Western Australia, an organisation such as Dying with Dignity WA may be able to provide this information.

What should the purpose and timing of the written statement be?
Commentary – to formalise the initial request (before the assessments); to formalise the request once the person has been informed of all their options, including palliative care and is approved eligible (after assessments)

Conclusion

Clear communication about voluntary assisted dying is essential for supporting end of life choices and the autonomy of patients. Health practitioners should be freely permitted to initiate or respond to discussion on voluntary assisted dying with their patients.

Cultural and linguistic considerations in practitioner training should include terminology; communication, culture and pain management; not talking about death and dying; and religious faith as a coping strategy.

A timeframe until death should not be included in the eligibility criteria. Timeframes reduce the likelihood that a person would be able to access voluntary assisted dying.

The criteria that the eligible condition is causing suffering that cannot be relieved in a manner acceptable to the person is sufficient and removes unnecessary debate about the perceived severity of that suffering. The definition and interpretation in the legislation should explicitly include suffering of mental health to ensure eligibility for people with conditions such as Dementia.

The PHAA appreciates the opportunity to make this submission. Please do not hesitate to contact us should you require additional information or have any queries in relation to this submission.

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