

## **INQUIRY INTO PROVISIONS OF THE VOLUNTARY ASSISTED DYING BILL 2021**

**Organisation:** Public Health Association of Australia (PHAA)

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**Public Health Association**  
AUSTRALIA

## **Submission on the *Provisions of the Voluntary Assisted Dying Bill 2021 (NSW)***

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**Public Health Association**  
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 our Board, National Office, State and Territory Branches, Special Interest Groups and members.

**We believe** that health is a human right, a vital resource for everyday life, and a 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.

**Our mission** as the leading national organisation for public health representation, policy and advocacy, is to promote better health outcomes through increased knowledge, better access and equity, evidence informed policy and effective population-based practice in public health. Members of the Association are committed to better health outcomes based on these principles.

**Our vision** is for a healthy population, a healthy nation and a healthy world, with all people living in an equitable society underpinned by a well-functioning ecosystem and a healthy environment, improving and promoting health and wellbeing for all.

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

## Introduction

PHAA welcomes the opportunity to provide input to the Committee's inquiry into the Provisions of the *Voluntary Assisted Dying Bill 2021 (NSW)* ("the Bill") proposed by Alex Greenwich MP.

PHAA approaches this submission from the position that while voluntary assisted dying ("VAD") is an issue that arouses strong and diverse views, legislating for a clear legal framework around the issue would help establish a degree of regulation, and increases choices and personal autonomy in end of life decisions.

PHAA adopted a policy position statement in the issue in 2018.<sup>1</sup> We also note that voluntary assisted dying has been introduced in all states of Australia other than New South Wales.

The proposed Bill largely follows Western Australia's *Voluntary Assisted Dying Act 2019*<sup>2</sup>. We note that the bill portrays voluntary assisted dying as part of a suite of palliative care services for individuals facing intolerable suffering from illness.

The PHAA supports the bill and recognises that it intends to,

*"...create a safe framework for people who are in the final stages of a terminal illness and who are experiencing cruel suffering that cannot be relieved by treatment or palliative care to be provided with the choice to die peacefully, with dignity and surrounded by loved ones."* (Alex Greenwich MP, Second reading speech, *Voluntary Assisted Dying Bill 2021*, Hansard (Legislative Assembly), 14 October 2021<sup>2</sup>

## Guiding Principles

The Bill is based on a set of guiding principles that aim to support autonomy in end-of-life decisions and reduce suffering. These principles, as listed in the Bill (clause 4)<sup>2</sup> are -

- every human life has equal value;
- a person's autonomy, including autonomy in relation to end of life choices, should be respected;
- a person has the right to be supported in making informed decisions about the person's medical treatment and should be given, in a way the person understands, information about medical treatment options, including comfort and palliative care and treatment;
- a person approaching the end of life should be provided with high quality care and treatment, including palliative care and treatment, to minimise the person's suffering and maximise the person's quality of life;
- a therapeutic relationship between a person and the person's health practitioner should, wherever possible, be supported and maintained;
- a person should be encouraged to openly discuss death and dying, and the person's preferences and values regarding the person's care, treatment and end of life should be encouraged and promoted;
- a person should be supported in conversations with the person's health practitioners, family, carers and community about care and treatment preferences;
- a person is entitled to genuine choices about the person's care, treatment and end of life, irrespective of where the person lives in New South Wales and having regard to the person's culture and language;
- a person who is a regional resident is entitled to the same level of access to voluntary assisted dying as a person who lives in a metropolitan region;
- there is a need to protect persons who may be subject to pressure or duress;
- all persons, including health practitioners, have the right to be shown respect for their culture, religion, beliefs, values and personal characteristics.

PHAA supports the stated guiding principles, and in particular takes the position that the autonomy of the individual must take precedence in end-of-life choices. We assume that these principles will be maintained in the final legislation. In particular, we highlight the need to encourage advance care planning to ensure the patients' values and wishes are understood and respected in a timely manner, and to protect the rights of each individual in making genuine choices about their care, treatment and end-of-life.

## **Eligibility Considerations**

PHAA supports permitting terminally ill individuals facing unbearable suffering to be eligible to access VAD services. However, we suggest consideration of some possible adjustments to the current criteria, mainly for reasons of equitable access to the services that would become available.

Firstly, we note that in establishing eligibility for VAD services for individuals diagnosed with a terminal disease, a time-limit to access services is proposed in the Bill. A time-limit of 6 to 12 months for terminally ill patients may be discriminatory to many people, especially those with slower, progressively deteriorating health conditions. Moreover, strict time-limits would make ineligible a number of cases displaying progressive capability deterioration with relatively higher life expectancies after diagnoses, such as dementia<sup>3</sup>.

We note that the Bill in its current form does not specifically recognise the suffering of individuals with long-term mental health issues, chronic disorder and disability. The Bill confers the right to access assisted dying services only to individuals declared 'terminally ill' by medical professionals.<sup>4</sup>

The requirement for a written declaration or verbal requests for voluntary assisted dying also presumes a level of communication capability which may disadvantage individuals with some disabilities.

Another issue with the Bill is that in defining a level of suffering deemed sufficient to establish eligibility for VAD services, it fails to account for differences in personal lived experiences. The current definition may exclude many people, especially vulnerable categories mentioned above.

Finally, we recommend that additional provisions be included in the eligibility criteria to safeguard the end of life choices of individuals with disability. Due consideration also needs to be given to mental suffering of people who are enduring chronic disorders and mental illnesses.

## **Process Considerations**

The Bill includes a procedural requirement for two independent assessments by medical practitioners to confirm eligibility for VAD services. In practice, this rule will disproportionately disadvantages individuals in regional and remote areas,<sup>5</sup> as well as individuals from culturally and linguistically diverse communities. To address regional disadvantage, tele-health services should be allowed for assessments in remote and rural areas to ensure equitable access to VAD services. We note that this may also require the consequential amendment of the Commonwealth Criminal Code, which bans the discussion of suicide over a carriage service<sup>6</sup>.

In cases where Aboriginal and Torres Strait Islander people and individuals from culturally and linguistically diverse communities are concerned, it is highly desirable that practitioners be trained to deliver culturally appropriate advice, utilising appropriate language and method of communication<sup>5</sup>.

## Safeguards

PHAA supports the safeguards outlined in the Bill. Safeguards should function to adequately protect the patients, clinicians, carers, and the community.

While the Bill adequately addresses the need for trained practitioners in undertaking VAD service responsibilities, it does not account for the possible lack of VAD training, and willingness for involvement, within the medical professional.<sup>7</sup> Inadequate measures to ensure uptake of VAD training may impede the integration of VAD services into the healthcare system or make its accessibility by patients difficult. Challenges faced by pre-existing VAD services, as have been seen in Victoria, should be reviewed to avoid similar challenges in the implementation of the VAD in NSW. It may be useful for the Bill to make stronger provision for the requirements for training of medical professionals,<sup>8</sup> as well as include a provision to provide patients with a list of trained medical professionals for VAD assessments. This will help ease of system and process navigation for patients.

PHAA also recommends that the Bill make explicitly clear that voluntary assisted dying is a service provided in addition to other palliative care services, and not a replacement for them. While the legislation should respect the autonomy of the patient, the patient should in no way be prompted or coerced into such a decision.

## Conclusion

PHAA acknowledges that being a contentious topic, voluntary assisted dying is the subject of varying viewpoints, often strongly held. However, our underlying position is that policy must ultimately reflect the best interest of the patient, and in particular their own autonomy. For this underlying reason PHAA supports the *Voluntary Assisted Dying Bill 2021 (NSW)*.

Should the bill become law, careful consideration must be given in ensuring equitable access of VAD services. This entails including telehealth services as an option for accessing VAD consultations for individuals in remote or regional areas, as well as individuals with disability in all locations. Further provisions are also necessary to ensure information is provided in a culturally and linguistically appropriate manner. Due consideration needs to be given mental suffering of individuals and safeguards to ensure accessibility by individuals with disability.

Policy making in this difficult area should emphasise the desirability of advance care communications, and accurately position voluntary assisted dying as part of a suite of palliative care services, rather than a preferred or assumed option. Clear safeguards should exist, in particular requirements for training of medical professionals to better aid training completion.

Please do not hesitate to contact me should you require additional information or have any queries in relation to this submission.

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