Submission into the Voluntary Assisted Dying Bill 2021

Submission No.:	278
Submitted by:	Dying with Dignity Queensland Inc.
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Position:	I/We support the Voluntary Assisted Dying Bill
Comments in relation to:	Eligibility criteria* ,The request and assessment process,Administration of the substance,Safeguards,Conscientious objection by either individuals or entities,Oversight and review,Other
Attachments:	See attachment
Submitter Comments:	

Dying With Dignity Queensland Inc.

DYING WITH DIGNITY QUEENSLAND

SUBMISSION

PRESENTED TO:

HEALTH AND ENVIRONMENT COMMITTEE

INQUIRY INTO THE

VOLUNTARY ASSISTED DYING BILL 2021

JUNE 2021

Introduction

Dying with Dignity Queensland (DWDQ) is the peak body that has for more than 30 years lobbied for law reform to allow those who meet strict eligibility criteria to legally access medical assistance to end their life should this be their request.

DWDQ supports the proposed legislation tabled by the Premier in parliament.

DWDQ makes the comment that it also fully supports best palliative care practice for all Queenslanders. Most of those who will request Voluntary Assisted Dying (VAD) will also make welcome use of palliative care[1].

DWDQ does make the following observations about the proposed VAD legislation.

Viewing the proposed legislation as a whole

DWDQ agrees with the QLRC's statement that the proposed legislation be viewed as a whole. DWDQ advises Members of parliament not to become focused on one aspect and not to make amendments that would damage the overall integrity of the bill. As stated by the QLRC "it may be politically attractive to add numerous safeguards to [voluntary assisted dying] legislation" but there are more than enough well thought out and adequate safeguards in the legislation. There are anecdotal stories emerging in Victoria that some safeguards are overly burdensome, do not add to safety and impair VAD access[2]. This legislation, as it is proposed, will serve well those Queenslanders who are suffering and dying, and give them an additional end-of-life choice.

Timeframe until death

DWDQ accepts the 12-month expectation-of-death timeframe as an eligibility criterion even though it is wary of any time frames in the face of known difficulties with prognostication and variability of disease progression.

Clinical evidence attests that clinicians consistently overestimate survival, that predictive accuracy decreases with longer estimates of time-of-death and overestimates of three months or more occur[3], thus a shorter 6-month timeframe is fraught with the high possibility of otherwise eligible persons being excluded when 'clinicians' predictions are frequently inaccurate"[4] and the person is often much closer to death than predicted.

The 12-month timeframe does give guidance to health practitioners about what constitutes end-of-life. A 12-month timeframe is more encompassing of the varied clinical trajectories of different diseases, illnesses, and medical conditions. It also allows the dying person more time to come to terms with their situation and make preparations in a timely way.

The Victorian experience has shown that unexpected difficulties in navigating the VAD process has meant that for some clearly eligible people, the whole process has taken months to get approval. This has meant that some of the eligible persons wanting to access VAD have suffered needlessly.

DWDQ is baffled by the 6 month/12 month split timeframe in the Victorian and Western Australian VAD legislations particularly in the face of their expert panels recommending a 12-month time frame. It is discriminatory to single out motor neurone disease in the face of other conditions such as Chronic Obstructive Pulmonary Disease and Chronic Heart Failure for example. Persons with many conditions can have a long period of unrelenting suffering at the end-of-life.

Any concerns that a 12-month time frame will result in people eligible for Voluntary Assisted Dying using the substance earlier than if it was a 6-month time frame, are allayed by data from Oregon[5]. This data shows that terminally ill people, once granted Voluntary Assisted Dying eligibility, delay using the medication for as long as their symptoms allow, with 1 in 3 actually holding off use of the substance altogether.

Doctor initiated discussion about VAD

DWDQ welcomes the opportunity for medical practitioners and nurse practitioners to initiate discussion about Voluntary Assisted Dying in the framework of a wider discussion about the person's treatment and palliative care options, and their likely outcomes. This is entirely within the norm of ethical medical practice whereby patients are to be fully informed of all management options.

The Victorian legislation prohibition of doctor-initiated discussion about Voluntary Assisted Dying interferes with the doctor/nurse-patient relationship by being insulting to the professionalism of doctors and nurses, obstructive to patients seeking health information and undermining trust.

Such a prohibition is also discriminatory in that it disproportionately disadvantages marginalized groups and disadvantaged groups. Examples are those who do not have internet access, those who do not have a good grasp of English language, those in ethic groups where this topic is not discussed and those older people who have difficulty using technology. Many of these groups rely on and trust their doctors and nurses to provide them with reliable health information.

Witnesses to the second request

DWDQ commends the proposed legislation's process of witnessing and certification of the second request. It fulfils a necessary independent safeguard against coercion for or against VAD. It removes the coordinating practitioner and the consulting practitioner from the second request-making process to safeguard against influence by practitioners.

A barrier to Voluntary Assisted Dying access in Queensland is removed by not requiring the health practitioner to physically be present at the time of making the second request. This is important in Queensland with its geographical remoteness and decentralization. It eliminates a barrier to accessing Voluntary Assisted Dying for a person who may suffer distress or discomfort with movement or travel that would occur if the health practitioner cannot visit the person.

Death or loss of decision-making capacity likely before final request

DWDQ commends that the proposed legislation allows that the final request can be made before the end of the 9 day prescribed period if the person is likely to die, or to lose decision-making capacity in relation to Voluntary Assisted Dying.

Self-administration or practitioner administration

DWDQ commends the proposed legislation for having self-administration as the default method and for allowing flexibility for practitioner administration availability based on the person's concerns about, ability to, and suitability for self-administration. DWDQ finds personal choice in self administration or practitioner administration consistent with the overall legislation being voluntary and enabling of choice.

Medical Practitioner qualifications

DWDQ commends the proposed legislation for not requiring the coordinating practitioner or consulting practitioner to be a specialist in a specific disease. In Victoria, this has led to unacceptable and distressing delays to the person in finding a specialist willing to be involved[6]. This would be a barrier to access the scheme in regional and remote areas of Queensland. Good medical practice, across the full range of medical conditions, has practitioners seeking multiple specialists' opinions every day and then implementing management based on those opinions. Dying patients will already have been through diagnostic, therapeutic and commonly palliative care processes. This is an unnecessary barrier to accessing Voluntary Assisted Dying and potentially distressing to a person as has occurred in Victoria.

Conscientious objection by individuals

DWDQ strongly supports the right of individuals to conscientiously object to Voluntary Assisted Dying.

DWDQ therefore supports the proposed legislation as drafted regarding registered health practitioners' and speech pathologists' right to conscientious objection.

Institutional conscientious objection

DWDQ finds the thrust of the proposed legislation does meet the needs of those persons wanting to access Voluntary Assisted Dying in institutions. DWDQ accepts the even-handedness of the accommodations made to the perceived rights and interests of entities against the rights of the individual.

The proposed legislation's detail to the balance of competing rights and interests of individuals and entities, depending on the person's permanent residency status in a facility and the different rules for the different stages of the Voluntary Assisted Dying process, is particularly helpful in giving clarity to those accessing Voluntary Assisted Dying and those delivering Voluntary Assisted Dying.

DWDQ urges Members of Parliament to embrace the careful and considered balance of individual rights and entity rights in the proposed legislation and to strongly resist any calls to amend it. Any watering down of this aspect of the legislation would have inevitable consequences in the practical application and access to Voluntary Assisted Dying. Some possible consequences are; persons not being able to access Voluntary Assisted Dying just because their home happens to be in a care facility; transfer to another facility results in increased pain and suffering; increased medication to allow a transfer to another facility results in loss of decision-making capacity; transfer to another facility results in undue delay in accessing Voluntary Assisted Dying resulting in prolonged suffering; lack of suitable facility to which to transfer a person, stops that person accessing Voluntary Assisted Dying.

Residency

DWDQ accepts the residency criteria as per the proposed legislation and the compassion it shows to persons with difficult circumstances such as living outside Queensland but close to the Queensland border with close family or treating doctors in Queensland.

DWDQ welcomes the QLRC's foresight in recommending that the residency requirement be reviewed as part of a future review on the legislation. There may be adjustments warranted when all Australian States adopt Voluntary Assisted Dying legislation.

Voluntary Assisted Dying is not suicide

DWDQ wants to make clear that Voluntary Assisted Dying is not suicide, and it supports the following QLRC statement. “Voluntary assisted dying laws provide that someone who ends their life in accordance with the process does not commit suicide, and that the health practitioners who assisted them to die are not liable for homicide or the crime of assisting suicide.”

Dementia and Advance Health Directives

DWDQ wants specifically to bring to the attention of the Health and Environment Committee, a condition that is frequently brought to the attention of DWDQ by many of its members and supporters across Queensland, it is that of dementia which is of great concern and indeed fear for them.

Dementia is the second leading cause of death in Australia, and it is particularly devastating for families and their loved ones. Dementia is a terminal illness.

DWDQ recognises the disease specific difficulties in relation to Voluntary Assisted Dying that dementia poses.

DWDQ supports those members’ and supporters' future aspirations to have access to Voluntary Assisted Dying if they develop dementia resulting in unbearable suffering with no prospect of improvement.

DWDQ recommends that in the future, the Queensland government take steps to develop a dementia specific Advance Health Directive, while people have decision-making capacity, and steps to foster community discussion about dementia related end-of-life choice.

Conclusion

DWDQ commends and fully supports the proposed Queensland Voluntary Assisted Dying legislation as well drafted, carefully thought out and balanced in its approach. It is conservative in that it has many safeguards and strict eligibility criteria. DWDQ advises members of parliament to view this historic legislation as a whole and be wary of making changes that would break that balance.

References

1. Big Ideas programme, Justice Betty King. https://wheeler-centre-heracles.s3.amazonaws.com/0da/890/e08/0da890e080db6883d6df1965b5f489e6aebf5df036ff6b22a3b618f76504/Better%20Off%20Dead%20s02e14%20transcript.docx.pdf
2. Better Off Dead, Andrew Denton. Episode 13. https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead
3. A systematic review of physicians' survival predictions in terminally ill cancer patients https://www.ncbi.nlm.nih.gov/pmc/articles/PMC166124/
4. A Systematic Review of Predictions of Survival in Palliative Care: How Accurate Are Clinicians and Who Are the Experts? https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4999179/
5. Oregon Death with Dignity Act 2018 Data Summary https://www.oregon.gov/oha/ph/providerpartnerresources/evaluationresearch/deathwithdignityact/documents/year21.pdf
6. Better Off Dead, Andrew Denton. Episode 13. https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead

Submission authors: DWDQ Committee

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