SUBMISSION TO THE HEALTH AND ENVIRONMENT PARLIAMENTARY COMMITTEE

VOLUNTARY ASSISTED DYING BILL 2021

I confirm that I support the passing of this Bill, subject to the following submissions:

ADVANCE HEALTH DIRECTIVES

In my view, it is imperative that the Bill/Act includes provisions for Advance Health Directives in certain circumstances.

The Bill as presented states that people with a mental illness may be eligible. However, the manner in which the Bill is currently worded would preclude access to VAD for many (if not all) progressive brain diseases which normally result in death as a result of life-threatening complications of the disease and/or decline of the brain function. Specifically, I would mention brain tumors, Huntington's Disease, Dementia, and Alzheimer's Disease. Dementia, including Alzheimer's Disease, for example, is the second leading cause of death in Australia. Both can result in a good deal of suffering, pain, loss of dignity and quality of life but in circumstances where the person is unable to speak or make themselves understood in the later stages.

Death is unlikely to occur within 12 months of initial diagnosis. By the time that the person sat within that 12 month window it is unlikely that they would meet the requirement to have decision making capacity in relation to VAD. The Bill should afford everyone the opportunity, at the time of initial diagnosis and prior to the disease becoming so severe that decision making capacity would be severely affected, to write an Advance Health Directive and to lodge this in advance with the Chief Executive, or other such appropriate body.

Such a provision could be limited to specific progressive brain diseases, and allows the person to state their wish (if it be so) to access VAD:

- at the point at which the illness/disease has significantly affected dignity, quality of life, or ability to think, communicate or act on their own.
- face any situation in which they have become totally dependent on others to perform normal daily activities such as movement, feeding, bathing, toileting

As written, the Bill would also preclude a person who suffers from a sudden and severe stroke or other sudden, traumatic and unexpected event resulting in a Permanent Vegetative State. Once again, the Bill should offer every person the ability to incorporate these circumstances in an Advance Health Directive enabling them to state their wish (if it be so) to access VAD. As stated above, the Advance Health Directive should be lodged in advance with the Chief Executive or other such appropriate body.

I fully accept that there must be additional safeguards which must be included in an Advance Health Directive to protect the person and/or their wishes from any form of abuse. In these very specific circumstances it must be accepted that the person would not be able personally to present their request, or to provide in writing a second request, and the Advance Health Directive must provide for appropriate representation. Nor would the person be able to "self-administer" a voluntary assisted dying substance. Provisions would need to be made within the Advance Health Directive to allow a suitably qualified and trained health care professional to

administer the substance on their behalf, or to allow a next of kin to do so under the supervision of a qualified and trained health care professional.

I am more than willing to present my Living Will (as it is known in the UK) for reference purposes.

TERM OF RESIDENCY (Division 4, Part 2)

I offer my wife's situation as a reference in regard to this. She has been living in Australia since August 2018 under part 1 of a Spousal visa. She is married to an Australian, has a tax file number, pays taxes here and also medicare. She was eligible for the granting of PR in March 2020. However, as at this date (16th June 2021) she is still waiting for the final PR to be approved, with the prospect that this may take a further 14-24 months. It is through no fault of her own that she have been unable to obtain her PR within a more reasonable timescale.

I feel that there must be provisions for people like my wife where there have been considerable delays in visa applications being processed. The Residency Exemptions that may be granted by the Chief Executive as outlined under **CLAUSE 12** do not cover someone in my wife's circumstances. Whilst she could demonstrate a substantial connection to Queensland, she cannot meet the additional requirements outlined therein:

(2) The chief executive must grant the exemption if satisfied that:

a) the person has substantial connection to Queensland **and**

Examples:

- a person who is a long term resident of a place close to the Queensland border and who works in Queensland and receives medical treatment in Queensland
- a person who resides outside Queensland but who is a former resident of Queensland and whose family resides in Queensland

I propose that a further example be included:

- a person is married to an Australian Citizen, has been resident in Queensland for at least 12 months before making the first request, and receives medical treatment in Queensland

PRESENTATION OF REQUESTS/CONSULTING ASSESSMENTS/REFERRAL TO ANOTHER HEALTH CARE PROFESSIONAL FOR ASSESSMENT (Part 3, Several Divisions)

Queensland is a very large state with many people living in very isolated, remote and rural areas with limited access to medical practitioners. Add to this the fact that some medical practitioners will not be willing to participate in VAD, the requirement to make requests personally to a medical practitioner may be difficult in some circumstances and should, in my view, allow for the request to be made via video link. In such circumstances, it may be appropriate for the person to be accompanied by a JP or legal representative who can swear on camera that the identity of the person making the request has been checked and verified.

The same comment applies where the Co-ordinating Practitioner or the Consulting Practitioner makes a referral to another registered health care professional where it is necessary to speak personally to the person requesting access to VAD.

DIVISION 3 – CONSULTING ASSESSMENT

1. **CLAUSE 26** – Surely the Co-ordinating Practitioner should be required to refer the person to a medical practitioner who is entered on the register held by the Voluntary Assisted Dying Care Navigator Service as being willing and able to support the Consulting process. Why would a Co-ordinating Practitioner waste time by sending the person to someone who may decline on grounds of conscientious objection??? I believe that this should be made a requirement of the Co-ordinating Practitioner.

ADMINISTERING PRACTITIONER (Division 4, Part 5)

Queensland is a very large state with many people living in very isolated and rural areas with limited access to nurse practitioners (namely a registered nurse, educated at Masters level, and endorsed by the Nurses & Midwives Board of Australia). Add to this the fact that some nurse practitioners may not be willing to accept this role, it may become almost impossible in some extreme cases for a person to access a nurse practitioner. I believe that the Bill should recognize that in certain circumstances a Registered Nurse with over 5 years or even 10 years' experience should be authorized to be an administering practitioner.

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