VOLUNTARY ASSISTED DYING - SUBMISSION TO THE VICTORIAN AND TASMANIAN UNITING CHURCH SYNOD

Should The Synod support Voluntary Assisted Dying (VAD) legislation? God created humans and has given us the choice to live or die (spiritually). Why should we not afford the same courtesy to those who are (physically) dying with unbearable pain or distress?

The debate around VAD is once again topical in the media. Victorian VAD legislation has been drafted from the report from the ministerial advisory panel on Voluntary Assisted Dying (July 2017). Should the UCA Synod respond? Why should the Church not support legalisation of VAD?

These questions can be approached from several different directions – theological, social, ethical, moral, philosophical, medical, etc. In this submission we focus on the medical implications of the proposed legislation.

Terminology

Words and their definition are important. Much confusion arises from incorrect use of terminology. The Victorian VAD proposal focuses on physician assisted suicide, or 'voluntary assisted dying', where a medical practitioner provides medication for the purpose of ending life. This should be distinguished from palliative care aimed at the relief of pain and distress in a terminally ill patient in which the patient dies from the disease not the medical treatment provided.

A Biblical Perspective?

There many biblical principles that speak to this situation. In brief, these include the biblical explanation why suffering, pain, and death exist in the first place. All human beings are created by God, endowed with a unique dignity, and in relationship to Him. Furthermore, God has paid us the incredible compliment of giving us true freedom - freedom to accept or reject His offer of life. How do we uphold this freedom of choice, the dignity of all humans, and remove or reduce this God-given freedom?

Does the proposed legislation support freedom and dignity for all or diminish it? Irrespective of the moral and ethical arguments we have several concerns regarding the safety of patients under the proposed legislation and the potential for their freedom to be diminished.

Medical Implications of Proposed VAD Legislation

Some of the medical concerns arising from the current model for VAD in Victoria include the following:

1. Absence of any requirement for involvement in the patient's primary care provider or medical specialist.
2. Doctors do not require formal training in palliative care or the management of terminal disease.
3. Absence of any requirement to assess mental health, or requirement to treat mental illness if present.
4. Absence of any genuine engagement with palliative care services and alternative treatment options.
5. Danger to others of having a lethal medication distributed to a potentially uncontrolled environment.
6. Requirement for doctors to provide incomplete, even misleading, information in the death certificate in that they are not to include the true cause of death (ingestion of lethal medicine)
7. Recommendation that VAD not affect life insurance claims and the associated legal issues that will no doubt arise as well as the potential for financial exploitation of this situation.
8. Lack of adequate reporting of VAD in other jurisdictions where it has been legalised.
9. Mores than one-half of palliative care services in Victoria are unable to meet the current demand.

Independent of any moral, ethical or philosophical arguments for or against VAD we have concerns regarding the safety of patients under the proposed legislation and the potential for their freedom to be diminished.

Further details and references for some of these points are provided below.

Depression, Mental Illness, and VAD.

The proposed Victorian VAD legislation will result in the misapplication of VAD to patients with undiagnosed mental illness, impaired capacity or who are under the influence of coercion or other unconscious motivations. The proposed safeguards against these issues may reduce but cannot prevent wrongful deaths as a result of the misapplication of the legislation.

Of greatest concern, the current model for VAD in Victoria does not require consideration of the presence of active mental illness as a contraindication to approving VAD and nor does it require the treatment of it. Mental illness is common in patients with a terminal illness and can significantly impact on their symptoms near the end of their life.

Up to one third of cancer patients and those with progressive degenerative neurological conditions experience depression. Suicidal thoughts are a common part of a depressive illness and depression is well known to impair decision making. Depression can be difficult to recognise, diagnose and treat. Even after training, GPs recognise only 39% of depressed patients in their practices[i] and oncologists only 33% of their cancer patients.[2]

Despite high rates of depression in patients with terminal illness, experience in other jurisdictions where VAD is performed has shown that as few as 5% of patients are referred to a psychiatrist. The current plans for VAD in Victoria will allow depressed patients to choose to end their life. If depression is adequately treated, they may be alleviated of their symptoms and may instead choose to engage with active palliative care instead of seeking VAD.

A decision to access voluntary assisted dying is complex, requiring a person to have a well-developed capacity for abstract reasoning. Assessing decision-making capacity can be difficult and require repeated assessments over a prolonged period of time by a specialist clinician. At times, formal neuropsychiatric evaluation is required. The recommendations from the advisory panel allow assessment of capacity by doctors

who are not experts in this area and with potentially just one consultation with the patient.

Patients with terminal illnesses, particularly older patients, are vulnerable to coercion in VAD requests[32]. Coercion could potentially affect any stage of the VAD process from the initial request, whether the dose of life-ending medication is taken and when it is taken. The exact prevalence of coercion is unknown and likely under-reported, however case studies demonstrate its existence in other jurisdictions with controls similar to those proposed in Victoria[ii]. Unfortunately, different forms of abuse of the vulnerable is common in our communities, with up to 6% of all older adults and 25% of vulnerable adults experiencing some form of physical, emotional or financial exploitation each month[333]. Given exploitation and abuse of the vulnerable is often subtle and hidden in the home, no safeguard on legislation can possibly prevent family or friends from coercing a patient to undergo VAD. Even in the absence of coercion it would be understandable for patients come to think that they are a burden on their family and should end it all for their family's sake.

Access to Palliative Care Services

In the proposed Victorian VAD model, there is no requirement for genuine engagement with palliative care services. Some people may access VAD without knowing fully how palliative care could address their concerns and relieve suffering whilst maintaining a sense of control over their situation.

Under the proposed model, a person can apply for VAD if their illness causes suffering that cannot be relieved in a manner tolerable to them. Two doctors can make that assessment, neither of whom needs formal training in the management of terminal diseases. Most GPs, and indeed most specialists, do not have the training or the experience to know of and properly advise a patient about the best practice palliative care options available to them. Assessing suffering and the treatments available requires specialised skills, such as those of a palliative care physician, who could more readily address a patient's suffering.

Australia has very good palliative care services however many miss out due to inadequate resourcing. It is estimated that there is an unmet demand of palliative services care of up to 40%.

55% of Victorian palliative care services state they are unable to meet the demand for their services. Investment in palliative care will have a much greater impact for ending pain and distress for patients with terminal illnesses in our state than making VAD legal.[4]

Requirement to Predict Time of Death

Determining how long a person has to live is not an exact science and is a challenge even for the most qualified doctors. The Victorian model provides for a patient to request assisted suicide if they are expected to die within 12 months.

At 12 months, the margin for error significantly increases and many clinicians would find it a difficult assessment to make. Patients are at risk of ending their life when they could potentially have several more years to live.

Scientific Evidence for Novel Interventions

Assisted suicide and euthanasia are public health care interventions. Australia's National Health and Medical Research Council has clear guidelines on the steps required to develop and implement a new intervention, including sufficient evidence to underpin it, pilot testing, and exploring the implementation and health resource costs.

If it passes the parliament, Victoria's assisted suicide model will be legalised without any formal review of its application and impact. No other major health care intervention would be introduced in this way.

The Therapeutic Goods Administration (Australia) regulation says the Nembutal medication proposed is illegal to import or prescribe in Australia; a special permit would need to be obtained. The Medical Board banned a Victorian doctor from using it but a VCAT decision overturned this agreeing with the doctor that he was using it as 'palliative care.'

The panel declared the doctor could continue to supply the (illegal) drug Nembutal to patients he assessed would get significant psychological or existential relief from

it. This would be a new indication for its use and a new way of interpreting "palliative care".

Experience from Other States and Nations

The UK House of Commons, less than two years ago, overwhelmingly rejected VAD legislation with even tighter controls to that being proposed in Victoria. The conclusion of many in that parliament was that it couldn't be made safe, no matter how many safeguards were in place, and that wrongful deaths would result.

Euthanasia has been a recurring issue for decades, highlighted by the Northern Territory Parliament 'Rights of the Terminally Ill Act 1995' and now by the proposed Victorian 'Voluntary Assisted Dying' legislation. At the outset there is a need for clearer terminology.

The Northern Territory legislation made provision for both physician assisted suicide and physician conducted homicide, both of which are legal in The Netherlands. The Victorian proposal focuses on physician assisted suicide which is called 'voluntary assisted dying.' The media sometimes also refer to palliative care as 'passive euthanasia' which is incorrect.

Palliative Care is aimed at the relief of distress in a terminally ill patient in which the patient dies from the disease, not medical action. This becomes very relevant in the writing of death certificates as in both the Netherlands and some states in the USA doctors are pressured to falsify these to state the cause of death was the original illness and not suicide.

The reason for physician assisted suicide is usually given as unbearable suffering, but the stated reasons for seeking assisted death in Oregon USA are loss of autonomy, loss of dignity and loss of the ability to enjoy things which make life worthwhile.

In the Netherlands the numbers dying under VAD is growing but likely to be under-reported. There are regular reports of incomplete documentation and cases of misuse. How many unnecessary deaths in the elderly and the vulnerable are we willing to ignore?[6]

Protection of the most vulnerable members of our society is an important task of the Church. We believe that the focus of our parliament and health services should be

turned to ensuring that all Victorians receive the highest standards of palliative care available through improved funding, organisation and research. [7]

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