Calvary | Little Company of Mary Health Care Ltd

Hospitality
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4 January 2021

Submission to the University of Tasmania (UTAS) independent review of the *End-of-Life Choices (Voluntary Assisted Dying) Bill 2020*

Introductory Remarks

Calvary notes the following statement within the Terms of Reference of the UTAS Panel. "The *targeted call* for submissions should indicate that submissions are to address the processes allowed by the legislation, safeguards and protections for vulnerable people; and the interrelationship between the VAD Bill and other end-of-life choices."

Calvary's submission is predominantly concerned with the *targeted call* and some matters related to the fifth numbered item in the Terms of Reference as follows:

> Objective analysis of:
> - the safeguards put in place in other jurisdictions relating to the impact of VAD legislation on medical practice and practitioners, allied health and care professionals, family and social relationships, and provision for and practices in aged care.
> - any interrelationship between the VAD Bill and existing palliative care and advance care directives in Tasmania and the experience of other jurisdictions in implementing VAD legislation to identify matters that might need to be addressed or monitored should the legislation pass into law.
> - stakeholder feedback relevant to all matters previously described.

As noted in our covering letter, Calvary supports the matters raised by Catholic Health Australia in its submission to the panel.

Definitions utilised in this submission

End of Life Care[1] includes physical, spiritual and psychosocial assessment, and care and treatment delivered by health professionals and ancillary staff. It also includes support of families and carers, and care of the person's body after their death.

People are 'approaching the end-of-life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:

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[1] Australian Commission on Safety and Quality in Health Care. National Consensus Statement: Essential elements for safe high quality end of life care. 2015.

- advanced, progressive, incurable conditions;
- general frailty and co-existing conditions that mean that they are expected to die within 12 months;
- existing conditions, if they are at risk of dying from a sudden acute crisis in their condition;
- life-threatening acute conditions caused by sudden catastrophic events.

Palliative Care[5] an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- aims to enhance quality of life, and may also positively influence the course of illness; is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications;
- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- neither hastens nor postpones death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients' illness and in their own bereavement; and
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated.

Euthanasia: the intentional bringing about of the death of a person in order to relieve suffering. It can be either voluntary or non-voluntary.

Physician Assisted Suicide (PAS): the intentional giving of assistance, by a doctor, to someone to suicide.

Voluntary Assisted Dying (VAD): the term used to describe physician-assisted suicide and euthanasia in the *End-of-Life Choices* (*Voluntary Assisted Dying) Bill 2020* ('the VAD Bill') tabled in the Legislative Council by the Hon Michael Gaffney MLC on 27 August 2020.

Interrelationship between the VAD Bill and existing palliative care services in Tasmania

Clause 3 – Objectives and Principles

This clause was inserted during the debate in the Legislative Council.

There are a number of questions which Calvary submits the Panel needs to address.

- In clause 3 (1) (a), why is the first objective the *efficiency and effectiveness* of the VAD process?
- The choice of a person to end their lives in the manner set out in the Bill may result in suffering for those who love and care for them. How is this to be addressed? What weight and value is this suffering to be given? What provision is made to address the spiritual, emotional and psychological needs of VAD persons? Primary Medical Practitioners (PMP) are not required to address these important human matters.
- Choice implies alternatives. If efficient and effective, publically funded, cost effective and accessible choices for the relief of suffering through palliative care and good medical care are not made available throughout Tasmania by the Parliament, what end of life *choices* are essentially and practically being

made available? Principle (h) in Clause 3 (2) acknowledges this.

- Principle (i) in Clause 3 (2) states that "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 no principle which states that "a person who is a regional resident is entitled to the same level of access to *high quality care and treatment, including palliative care and treatment, to minimise the person's suffering and maximise the person's quality of life* as a person who lives in a metropolitan region." Is this consistent with the stated objectives of the Bill? Could Parliament be perceived as opting to preference VAD over palliative care in the regions of Tasmania?
- Principle (d) of Clause 3 (2) is laudable. But without appropriate, accessible and visible models of care and resourcing, the principle remains a statement of aspiration.

More generally with respect to the objectives and intent of the Bill, Calvary submits, in words written by Dr Frank Brennan, Departments of Palliative Medicine and Nephrology, St George and Calvary Hospitals, Sydney, New South Wales, Australia in Internal Medicine Journal 49 (2019) 689–693, Royal Australasian College of Physicians:

> Law aims for precision. Medicine, on the other hand, operates in a landscape of uncertainty. So, when the two disciplines meet to focus on issues vital to E/PAS [VAD] legislation, there may be problems. Those issues include the prognostication of illness, decision-making capacity, screening for depression, the possibility of undue influence and the use of life-ending medications (with likely inter-individual variability in effect). As physicians, we know we cannot be certain about these issues. The laws strain to achieve certainty in language and effect. The law seeks, but medicine cannot provide, such certainty, and yet, with E/PAS, both disciplines must be highly conscious of the irreversible consequences for not getting things right. There is, therefore, an inherent tension at the centre of any E/PAS law. For law is entering the domain of not only medical uncertainty but also the mystery of the human psyche and interpersonal relationships. Uncertainty and mystery are not solid foundations for any legal statute.
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> All E/PAS laws face a series of identical challenges. Those challenges are significant and, arguably, insuperable. Challenges include the criteria of eligibility; prognostication; the assessment of capacity; ensuring the person is not acting under undue influence; the role of doctors, nurses and pharmacists in the process; the role, if any, of palliative medicine and psychiatry and the structure of the process leading up to the final act. Flowing from that are the medical questions that pour out upon this landscape to make this exquisitely vexed area even more problematic for doctors. What lethal medications are used and in what doses? What level of training in counselling, communicating and the use of these medicines should occur? What happens if there is a complication? How prepared is any doctor to commit an act, however legal, that has hitherto been completely contrary to both the law and professional ethics? Ultimately, what will be the experience of the patients, families, doctors, nurses and pharmacists involved in this process? Away from the glare of the public debate, their encounter will be intimate and intense. No law, no public campaign, no training can ever truly prepare the participants.

For these reasons, along with many others, it is important to note at this juncture in our submission that the Tasmanian Government would not be able to purchase any services associated with any form of physician-assisted suicide, voluntary assisted dying or euthanasia from Calvary. While Calvary accepts that there are a plurality of views on the subject of voluntary assisted dying, Calvary will not offer such a service.

Calvary's approach to care at end of life

- supports the patient/resident/client to actively participate in decision-making regarding their treatment and care;
- honours their self-determination through the use of advance care planning;
- recognises the role of substitute decision makers/medical treatment decision makers and any other agents acting on behalf of the patient/resident/client;
- provides holistic, comprehensive end of life care; address the physical, spiritual, psychological and social needs of the patient/resident/client and their families, including existential distress, with the goal of reducing suffering.

In line with the *Code of Ethical Standards for Catholic Health and Aged Care Services in Australia*, Calvary

- will neither hasten nor prolong death;[2]
- will not intentionally inflict death on patients (that is, provide euthanasia or VAD), nor intentionally assist patients, residents or clients to take their own lives (that is, provide physician-assisted suicide or medically assisted dying);
- will, in alignment with the principles set out in the *Spirit of Calvary*, respond openly, respectfully, without discrimination and sensitively to anyone within our care who expresses a wish to explore or consider physician-assisted suicide;
- Will actively listen to and accompany[3] any person who is nearing end of life, and will not abandon anyone who is in need of care; and
- Will not facilitate or participate in assessments undertaken for the purpose of a patient or resident having access to or making use of the interventions allowed under the *End-of-Life Choices* (*Voluntary Assisted Dying) Bill 2020* ('the VAD Bill'), nor similar statutes in other jurisdictions nor will we provide (or facilitate the provision of) a substance for the same purpose.

Palliative care provides holistic care to patients with debilitating and terminal illness. It is coordinated between the patient, the clinician, and necessary allied supports (including pastoral care) to address the physical, psychological, spiritual, and social needs of the individual. Clinicians assist patients and their family in the progression of their condition to improve quality of life, relieve suffering, and provide support for their comfort and wellbeing until their natural death.

The proposed Bill addresses few of these important matters including the holistic and integrated nature of a multi-disciplinary model of care.

In other states, recent parliamentary public inquiries into end of life choices offer some scrutiny of the effectiveness,

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[2] World Health Organization, definition of palliative care, 2004 and WHO fact sheet 2015.

[3] Apostolic Exhortation *Evangelii Gaudium* of the Holy Father Francis to the Bishops, Clergy, Consecrated Persons and the Lay Faithful Chapter 3, *N.169-173, Personal accompaniment in process of growth*[i]

quality, reach and accessibility of palliative care services. Calvary submits that such public analysis has not informed the drafting of the VAD Bill. An argument that people have effective choice cannot be sustained if Tasmanians do not have access to palliative care regardless of where they live, their physical, economic, cultural and social circumstances.

The PM Glynn Institute's report, *A snapshot of palliative care services in Australia* (2020), articulates how problematic this inequity is in the context of proposed VAD legislation:

> *"Considered strictly from a public policy perspective, there is a major argument to be made against the legalisation of assisted dying or euthanasia when access to palliative care for those at the end of life or suffering from life-limiting illnesses is neither universal nor equitable. This is especially so when the case for euthanasia and assisted suicide is advanced on the grounds of choice and autonomy.*
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> *If in some places and for some people there is no effective access to palliative care, it is difficult to see how a genuine choice is offered to a suffering person by giving them the option of assisted dying. If the choice is between assisted dying on the one hand, and the absence of effective pain and symptom control and accompaniment by family and carers on the other, it is a false choice and one which it is unjust to offer."*

Safeguards and protections for vulnerable people

It takes time and some degree of continuity of relationship to discover precisely how a person may be vulnerable. Calvary submits that the application of the clauses of the Bill as presently drafted makes it possible for a person to receive a final determination in less than two weeks after making the initial request. Effectively only two medical practitioners are essential to the process. With regards to the speed of the assessment and referral process Calvary queries how the Parliament can safeguard against doctors forming common cause. Given the very short time frame between first request, first assessment, second request, referral and final determination by a PMP, how can the Parliament prevent two doctors from forming common cause to agree to assess and review each other's cases and fast track the process? How is Parliament going to ensure effective scrutiny of a process that could take as little as eight to ten days?

Calvary submits that the combined effects of clauses 122 and 134 is to create an illusory culture of safety. The clauses offer the semblance of safety but do not oblige the Commission or those charged with administration of Bill to investigate a matter raised nor to provide reasons for choosing not to investigate a matter raised. Calvary submits that the Panel consider when the word, *may* (which appears frequently throughout the Bill) should be replaced with the word *must* (or a word of equivalent effect) in order to strengthen the protections proposed throughout the Bill.

It is serious things to consider assisting someone to end their life and, once achieved, irreversible. The panel may wish to consider the balance between efficiency and effectiveness of process on the one hand and the implications of hastening too quickly. Good faith (clause 134) is important. Several Royal Commissions have recently made the point that good faith is not sufficient to protect the most vulnerable of people.

In the context of the ongoing work of the Royal Commission into Aged Care Quality and Safety and the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, Calvary submits that the Bill as presently drafted does not ensure that similar abuses, often subtle and clandestine in nature, will not influence the decisions of particularly vulnerable people.

> *"It is one thing to respect personal autonomy; it is quite another to pass legislation where vulnerable members of the community may be led into a VAD death not by a genuine exercise of personal autonomy, but rather because they feel pressured to agree [whether directly or indirectly through subtle social pressure]—or, worse, are actually unaware of the nature of the process being undertaken [by interested*

> *third parties] "for" them."*[4]

Calvary submits that the Bill contains insufficient safeguards to protect vulnerable populations, especially those with incurable cancer, progressive neurological illness, the aged, the infirm, and people who live with disability. These groups of people can experience high rates of depression and isolation. The risks that this legislation poses for the majority of these human beings are great.

The processes allowed by the legislation

Calvary has noted the emphasis in clause 3 on the *efficiency and effectiveness* of the VAD process.

Determining how long a person has to live is not an exact science and is a challenge even for the most qualified doctors. Under the proposed Bill, is a person at risk of ending their life when they could potentially have several more years to live? Could we fail as a community to offer a person with a terminal illness the chance to live the life remaining to them as fully and as richly as possible because of a suffering they anticipate but don't yet experience?

Such an outcome, Calvary submits, is not in the interests of the common good.

As noted above, without easy access to quality pain management (palliative care), a social safety net and good community support systems, some people may request VAD as they feel they have no other choice. This is especially so for people who live in rural, regional and remote areas and for people from culturally and linguistically diverse communities who have less access to palliative care services. People with little support from family, who are socially isolated and with access to limited economic resources may also come to believe it is better that they die rather than *seek help to live with less suffering*.

It is submitted that the Panel review clauses in Division 2 of the Bill which permit to the person's Administering Health Practitioner (AHP) administer a VAD substance to the person.

Calvary has concerns with respect to the **lack of information** about the proposed clinical regimen for voluntary assisted dying in the draft legislation; including any reference to the known complications, safety and effectiveness, let alone how risks would be managed.

In particular Clause 82 (3) (d) (i) and (ii) warrant scrutiny.

If the clinical regimen is unsafe, gives rise to complications or is ineffective, the legislation will fail to achieve its stated intention and will put people at risk of the very suffering they had hoped to avoid.

These are threshold considerations which cannot be left to be resolved in the 18 months between the passing and commencement of the legislation. These are, it is submitted, issues to be resolved before the law is introduced.

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[4] Paul Santamaria QC. Accessed at https://www.catholiclawyers.com.au/Portals/1/Victoria's%20Assisted%20Suicide%20Legislation.pdf?ver=Wv4PrnXJ3p1zJdLeSOEcDw%3d%3d

Interrelationship between the VAD Bill and other end-of-life choices

As noted earlier, high-quality palliative care that treats the person holistically is arguably under-resourced in Tasmania. Recommendations made by a Parliamentary Inquiry into palliative care in 2017 have not yet been fully acted upon[5].

Calvary believes that good medical care requires that patients are presented with a full range of treatment options and are assisted to understand the implications of proposed treatment plans. Effective choice cannot be maintained if Tasmanians do not have equal access to palliative care.

It is submitted that the Panel should scrutinise the effectiveness of current palliative services throughout the State.

Concluding Remarks

Calvary would be happy to make further submissions, either orally or in writing, as the Panel desires. In particular, we would be willing to make further submissions in relation to our models of Palliative care.

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[5] https://www.parliament.tas.gov.au/ctee/house/Reports/Report%20-%20Inquiry%20into%20Palliative%20Care%20in%20Tasmania%20(TABLED).pdf