Calvary | Little Company of Mary Health Care Ltd

Hospitality
Healing
Stewardship
Respect

2 December 2020

[redacted]

Dear Member of the Legislative Assembly,

RE: Calvary Health Care’s concerns regarding the End of Life Choices (Voluntary Assisted Dying) Bill 2020

We write to you to register our concerns with several clauses of the current *End of Life Choices (Voluntary Assisted Dying) Bill 2020* as Chair of the Little Company of Mary Health Care (LCMHC) Board and a Director of the LCMHC Board, respectively. Calvary is a significant provider of health care and community care services in Tasmania. We speak to the notion of ensuring compassionate care for a human being above all else.

Calvary acknowledges the difficult task before you and your colleagues. However, in an issue of such importance, and in the context of many differing values, we must endeavour to give such decisions our best thinking and most careful discernment.

We have attached a paper which discusses Calvary’s concerns with the current Bill in detail. There are considerable weaknesses relating to the current safeguards, particularly in several areas around medical assessment of the VAD person.

We encourage you, if you are supportive of the legislation, at least to consider these very important matters. While Calvary absolutely opposes VAD and will not participate in any VAD scheme if passed, any legislation around assisting a person to end their own life must be as robust as possible.

Calvary will seek to assist the Parliament in any way Calvary can, and would welcome the opportunity to meet with you, or any of your colleagues, if required.

Please direct any questions you may have to Calvary’s National Director of Mission, Mark Green:

E: Mark.Green@calvarycare.org.au

P: (02) 9258 1733 **|** **M:** 0439 828 523

Yours faithfully,

Jim Birch AM
Chair
Little Company of Mary Health Care

David Catchpole
Director
Little Company of Mary Health Care

Calvary Health Care’s concerns regarding the End of Life Choices (Voluntary Assisted Dying) Bill 2020

After being rejected by the Tasmanian Parliament in 2017, the adoption of Voluntary Assisted Dying (VAD) legislation is again before you. What is different this time is that the new Bill is being debated during the COVID-19 pandemic and two Royal Commissions, each dealing with many examples of neglect and abuse of vulnerable people reliant on aged care and disability services in Australia.

Calvary is a significant provider of health care and community care services in Tasmania. We are a Catholic health and aged care organisation whose services have served the Tasmanian community for over 100 years.

We operate four hospitals in Hobart and Launceston and a network of community care services. Our dedicated role in the Tasmanian community is to care for and alleviate the suffering of those in need.

Calvary acknowledges the very difficult task before Honourable Members to make good decisions on behalf of all Tasmanians. Accordingly, we wish to register the very serious concerns we have with the *End of Life Choices (Voluntary Assisted Dying) Bill 2020* currently before the Parliament.

End of life choices for all Tasmanians

Calvary supports a robust and transparent public inquiry into end of life choices for all Tasmanians, consistent with other states and territories examining their own VAD legislation. Such a public inquiry last took place in Tasmania over 20 years ago, in 1997, with the Parliamentary Inquiry into the Need for Legislation in Tasmania on Voluntary Euthanasia for the Terminally Ill.

The subsequent Tasmanian House of Assembly Community Development Committee Report, published in 1998, found:

- While the individual cases may present a strong case for reform, the obligation of the state to protect the right to life of all individuals equally **could not** be delivered by legislation that is based on subjective principles;
- There is evidence to suggest that abuses of the current prohibition on active voluntary euthanasia **do occur** and Tasmania may not be immune to such abuses;
- That the Committee does not consider the legalisation of voluntary euthanasia as an appropriate solution to abuses that may be occurring in the current system; and
- That the codification of voluntary euthanasia legislation **could not** adequately provide the necessary safeguards against abuse.

Further to the House of Assembly Committee findings above, and 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, we ask if MPs are assured that similar abuses, often subtle and clandestine in nature, will not influence the decisions of these particularly vulnerable people. To this point, Mr Paul Santamaria QC recently observed:

> *“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.”*

Examples of particular concerns

Clause 13 of the Bill – *When person is acting voluntarily*

> *For the purposes of this Act, a person is acting voluntarily if the person is not acting under duress, coercion or because of a threat of punishment or unfavourable treatment, or a promise to give a reward or benefit, to the person or another person.*

Practitioners are required to know when a person is acting voluntarily and not acting under the influence of duress, coercion or threat of punishment. Practitioners are not required to consider whether the person may feel burdened or experience a sense of familial or social pressure, particularly when VAD is presented as an effective solution to a person's subjective view of current or potential future states of suffering.

This sense of burden and fear may be further compounded by lack of equitable access to or understanding of *effective pain and symptom control*. 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 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.*
>
> *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."*

We can be more confident that people living with life-limiting disease have true freedom when they have access to effective pain and symptom control together with accompaniment by family and carers. A person is not free when she or he lives with isolation, loneliness and anxiety each day. This kind of suffering impedes genuine and free choice.

Our concern can be best demonstrated in the several clauses of the current Bill that **do not require** the Administering Health Practitioner (AHP) or Consulting Health Practitioner (CHP)—roles expected to be largely performed by general practitioners—to refer the requesting person to relevant clinical experts with specialist knowledge in the person's condition or the treatments available to them, including palliative and end of life care.

Clause 7 of the Bill sets out relevant information about a person's eligibility for VAD. The relevant sub-clauses relating to Calvary's concerns are reproduced below.

> ***7. Relevant information about eligibility***
>
> *For the purposes of this Act, **the relevant information about eligibility**, in relation to a person, is information as to –*
>
> *. . .*
>
> *(e) whether the person is suffering intolerably in relation to a relevant medical condition; and*
>
> *. . .*
>
> *(g) the reasonably available treatment that may relieve the mental or physical suffering of the person that is related to (or that occurs in anticipation of the suffering, or in expectation, based on medical advice, of the suffering, that might arise from) –*
>
> > *. . .*
> >
> > *(iii) complications of a medical kind that have arisen, or may arise, in relation to the treatment of the relevant medical condition or the combination of that treatment with the treatment of other medical conditions of the person.*

Significant prognostication skills are required and yet, as will be seen in Clause 9 below, authorised medical practitioners do not need to have specialised knowledge of a particular disease's trajectory nor of the relevant effective pain and symptom controls. Additionally, if Parliament does not invest in making effective pain and symptom control available to people living with life-limiting diseases, a treatment can hardly be said to be "reasonably available."

Clause 9 requires that authorised medical practitioners have relevant experience in treating or managing the person's condition. However, GPs cannot be expected to have the clinical expertise of an oncologist, palliative care specialist, psychiatrist or neurologist.

> ***9. Authorised medical practitioners***
>
> *For the purposes of this Act, a person is an authorised medical practitioner in relation to a person if –*
>
> *. . .*
>
> *(b) the person –*
>
> > *(i) is a vocationally registered general practitioner; or*
> >
> > *(ii) holds a fellowship with a specialist medical college; and*
>
> *(c) the person has relevant experience in treating or managing the medical condition expected to cause the death of the person; and*
>
> *(d) the medical practitioner has successfully completed an approved voluntary assisted dying training course within the 5-year period immediately before the person makes a first request to the medical practitioner under section 18 or is referred to the medical practitioner under section 37(1); and*
>
> *. . .*

The same weight is given to the completion of a voluntary assisted dying course as is given to experience in managing the medical condition.

Calvary does not believe that the medical practitioner administering the request for VAD should also be judging – or assisting the one requesting VAD to form a judgment – as to whether reasonably available medical treatment may relieve their suffering. This creates risk – the risk that a person chooses to end their life out of ill-informed belief that this is the best antidote to potential suffering.

The concerns Calvary has and the risks we have identified are compounded by the effect of Clause 12.

Clause 12 (3) and (4) allow a medical practitioner to continue assessing for VAD if he or she can determine that a person can make a decision about some things even if they cannot make decisions about others. In other words a lack of capacity to make decisions is ***not*** an indication of that a person may lack capacity to make an informed and conscious choice about VAD. More troubling is that subsection 4 of this clause does not mandate that an appropriate specialist, i.e. a psychiatrist, be engaged to perform such an assessment.

Calvary does not accept that the standards for assessing decision-making capacity in the context of a medically assisted dying or voluntary assisted dying should be ***weaker*** than the standards applied to judgments about capacity to consent to other human interaction.

> ***12. When person has decision-making capacity***
>
> *(3) In determining whether or not a person has decision-making capacity in relation to a decision, regard must be had to each of the following:*
>
> > *(a) a person may have the capacity to make some decisions and not others;*
> >
> > *(b) a person's lack of capacity to make a decision may be temporary and not permanent;*
> >
> > *. . .*

> *(4) If a person's CMP, PMP or AHP is unable to determine whether the person has decision-making capacity in relation to a decision, the CMP, PMP, or AHP, respectively, must refer the person, under section 25, section 32, section 46, section 54 or section 79, as the case may be, to a medical practitioner, psychiatrist, or psychologist, who has the skills and training that are appropriate to make such a determination.*

What improvements to our society and to our health and aged care systems are we seeking to make?

In addition to the concerns we have outlined with several clauses of the Bill, it is equally important to note that **physical pain is *often not* the reason that individuals seek an assisted death.** This is evidenced in reports from overseas jurisdictions offering legalised assisted suicide, as well as Victoria.

Oregon, in the United States, has offered legalised assisted suicide for over 20 years. Linda Ganzini and colleagues in a study from 2000 looked at the reasons why people already euthanised had requested their lives be terminated – an important question for our Tasmanian legislators to consider.

Physical pain was cited as a motivator in 43% of cases, as one might expect, but perhaps other reasons may come as a surprise. **Things like poor quality of life (55%), viewing themselves as a burden (38%) and seeing continued existence as pointless (47%) were all reasons accepted in people's bid to be medically assisted to die.**

Closer to home, in Victoria, reasons for accessing voluntary assisted dying under its regime have been reported in the Voluntary Assisted Dying Review Board's *Report of Operations January - June 2020*. Loss of autonomy was frequently cited by applicants as a reason for requesting voluntary assisted dying.

Other reasons for accessing voluntary assisted dying which were commonly reported included being less able to engage in activities that make life enjoyable, losing control of body functions, and loss of dignity.

The leading reason to pursue assisted suicide in Oregon was loss of independence, not physical pain – a motivator in 57% of cases. This reinforces the point that a person is not truly free when she or he lives with isolation, loneliness and anxiety each day. This kind of suffering impedes genuine and free choice. This is why we must ensure that people living with life-limiting disease *first* have access to effective pain and symptom control together with accompaniment by family, friends and carers.

A better path for better care

Given Calvary's and others' concerns with the Bill before you, we respectfully request that you consider voting down the current Bill and re-focusing your efforts on securing the pathway for a thorough and transparent public inquiry into end of life choices in Tasmania and, critically, improved access to appropriate palliative and end of life care services, regardless of a person's geographical location and socio-economic status.

A new inquiry would allow for Tasmanians to better understand their choices at end of life as well as the services available to them, and the gaps in need of dedicated work to improve; its findings would support a more holistic and considered approach to care of people at the end of life; and – if a VAD Bill is to be developed (which Calvary does not advocate) – that its scope would be well defined, unable to be misused as a substitute for inadequate care, and its operation well governed with adequate safeguards so as to protect vulnerable people from the abuse and coercion we know can and does occur in human society.

In our work across six states and territories in Australia, Calvary has developed considerable expertise in providing effective palliative treatments to care for those who are terminally ill and provide a positive end of life experience for them, their families and significant others in the community.

We oppose this and any proposed VAD legislation in Tasmania. We do not believe assisting a suffering person to end their own life addresses that suffering. Rather, it ignores the complex physical and psycho-social causes of a person's suffering at end of life; suffering that can so often be addressed and relieved with the appropriate high-quality care, symptom control, pain relief and human accompaniment. Our shared challenge, as it has always been, is to continue **to find better ways to address the real and often difficult to determine reasons that leads a person to seek an assisted death**. Once addressed, a person is much freer to live with a sense of dignity, control and to pursue the goals for which they wish to live until they die. This is now, as much as it has ever been, Calvary's commitment to Tasmanians.

If the Bill is passed, Calvary will not participate in any form of medically assisted or voluntary assisted dying. This is a service which we do not offer. Our focus is always to accompany people and relieve suffering and never to harm nor intentionally bring about the death of a person who is not dying.

We are conscious that VAD legislation is an emotive issue for many in the community and there may well be some negative feedback from some quarters, however the matters raised here should be properly and freely considered by all MPs involved in the decision making process.

Calvary will seek to assist the Parliament in any way Calvary can, and would welcome the opportunity to meet with you, or any of your colleagues, if required.

Please direct any questions you may have to Calvary's National Director of Mission, Mark Green:

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