Calvary | Little Company of Mary Health Care Ltd

Hospitality
Healing
Stewardship
Respect

17 November 2021

[redacted]
Member of the Legislative Assembly
E: [redacted]

Dear [redacted]

Re: NSW Voluntary Assisted Dying (VAD) Bill 2021

Introductory Remarks

Calvary has a 136 year history and providing care to people who are reaching the end of their life has been our specialty in NSW since our beginnings on 4 November 1885. On 5 November 2021, Calvary took responsibility for 55 residential care services previously operated by Japara. Many of these services are located in NSW as the map below illustrates.

We recently provided evidence to the Royal Commission into Aged Care Quality and Safety on palliative care in aged care.[i] One of our nurse practitioners, Mr Joshua Cohen, made some observations about palliative care and pain management in residential care which we submit are relevant more generally. We quote directly from the Commission's report:

> Mr Joshua Cohen, a palliative care nurse practitioner, explained that the most important aspects of palliative care in aged care are adapting the care to the individual and the family, and keeping the care recipient at the centre of that care. However, pain management in residential care is often difficult because of the care setting and the absence of staff knowledge in how to manage the medications and the pain. Training is also essential.[ii]

Calvary agrees with Dr Natasha Moore who writes,

> For an early death to be on the table – legally and medically sanctioned – it changes the "table" for everyone. The evidence from other jurisdictions suggests that adding it to the mix does not leave other elements unaffected: the resources available for palliative care; the patient-doctor relationship; family dynamics at the end; our understanding of dementia, disability, suffering in general. And as is so often the case, it's the already vulnerable who have most to fear.[iii]

In 2020/21, Calvary cared for 1,084 residents and 9,719 clients. We had 115,282 emergency admissions, 205,380 hospital admissions and cared for 554, 986 outpatients.[iv] We care for many people who experience vulnerability and we care for many people as they die.

Calvary is concerned that the legalisation of Voluntary Assisted Dying in NSW, while ostensibly benefiting the small percentage of people who want this option, poses a greater unintended but foreseeable risk to people living with significant vulnerability.

In addition, while our capacity as a State to provide palliative and end-of-life care, particularly in regional, rural and remote areas, is at best inconsistent, people cannot be said to have equitable access to quality needs-based care as they approach and reach the end of their lives.[v] Despite experiencing higher levels of morbidity and mortality, people living in rural and remote areas have poorer access to health care, including palliative care services. As noted above, pain management, medication management, staff knowledge and training are critical ingredients of an effective palliative care service.

By legalising VAD, do we really address this inequity? And if we do not address this existing inequity, are we offering any semblance of a real choice to people who are living with a serious and potentially very frightening disease to find a way to live as fully as they can until they die?

Who we are

Calvary is a charitable Catholic not-for-profit organisation with over 18,000 staff and volunteers, we have a national network of 14 public and private hospitals, 72 residential care and retirement communities and 19 community care service centres. Calvary operates across seven states and territories within Australia. We provide aged and community care, acute and sub-acute health care; and specialist palliative care and comprehensive care for people in the final stage of life.

In NSW we operate:

- 21 residential care and retirement communities;
- 2 public hospitals (Calvary Health Care Kogarah and Calvary Mater Newcastle);
- 1 private hospital (Calvary Riverina Hospital, encompassing also a Surgicentre and a Drug and Alcohol Centre); and
- a network of home care services in Sydney, Hunter New England and Wagga Wagga.

Founded on 4 November 1885 by the Sisters of the Little Company of Mary, our mission is to provide quality, compassionate health care to the most vulnerable, including those reaching the end of their life.

Full details of the extent of our footprint and the services we operate in NSW are set out in the graphic which follows.

Our NSW Locations

Hunter Newcastle

- **Calvary Cessnock Retirement Community,** Cessnock
- **Calvary Cooinda Retirement Community,** Singleton
- **Calvary Ephesus Retirement Community,** Lambton
- **Calvary Mater Newcastle,** Waratah
- **Calvary Mt Carmel Retirement Community,** Maitland
- **Calvary Muswellbrook Retirement Community,** Muswellbrook
- **Calvary Nazareth Retirement Community,** Belmont
- **Calvary St Francis Retirement Community,** Eleebana
- **Calvary St Joseph's Retirement Community,** Sandgate
- **Calvary St Luke's Retirement Community,** Cooks Hill
- **Calvary St Martin de Porres Retirement Community,** Waratah
- **Calvary Tanilba Shores Retirement Community,** Tanilba Bay
- **Calvary Tours Terrace Retirement Community,** Hamilton South

Sydney

- **Calvary Bayview Gardens,** Bayview
- **Calvary Brighton-Le-Sands,** Brighton-Le-Sands
- **Calvary Corymbia,** Belrose
- **Calvary Health Care Kogarah,** Kogarah
- **Calvary Henley Manor,** Doonside
- **Calvary Ryde Retirement Community,** Ryde

Other Regions

- **Calvary Albury and District,** Glenroy
- **Calvary Community Care,** Sydney, Taree, Riverina, Hunter/Newcastle, Forster, Lakelands
- **Calvary Riverina Hospital,** Wagga Wagga includes Calvary Riverina Drug and Alcohol Centre, and Calvary Riverina Surgicentre
- **Calvary St Paul's Retirement Community,** Taree
- **Calvary The Brelsford,** Coffs Harbour
- **Calvary The Mariner,** South West Rocks

● Community Care
● Hospitals - Private
● Hospitals - Public
● Retirement Communities

Calvary's core concerns

> *". . . illness and dying involve suffering, and we don't know how to eliminate it entirely.*
>
> *Assisted dying legislation takes one kind of death and aims to make it easier. It's a deeply sympathetic goal. It also opens the door to new kinds of suffering and abuse, unintended but not unforeseeable.*
>
> *So, the question cannot be: how do we eliminate suffering? The law can't do that. The question must be: what kind of society are we? What are our bedrock values? And who do they advantage – or disadvantage – the most?"*

Dr Natasha Moore[vi]

We cannot entirely eliminate suffering from dying

Law aims for precision. Medicine, on the other hand, operates in a landscape of uncertainty.

When the two disciplines meet to focus on issues vital to VAD legislation, we can expect substantial challenges. Challenges 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).

Physicians know we cannot be certain about these issues. Law strains to achieve certainty in language and effect. The law seeks, but medicine cannot provide, substantial certainty. In a debate such as the one currently underway in the NSW Parliament on the merits of introducing an Act to allow for *Voluntary Assisted Dying* or physician assisted euthanasia both disciplines must be **highly conscious of the irreversible consequences for not getting things right.**[vii]

Who is most advantaged and who is most disadvantaged?

The intrinsically relational nature of being human means that we cannot legislate this Bill for the few who want it without (unintentionally but foreseeably) endangering many vulnerable and marginalised members of society, who typically have poorer access to health care and lower health literacy.

Our First Nations Peoples understand this relationality better than many people in our society. Their ancient culture recognises the inherent connection between all of us, in the same way their ancient culture recognises the embodied connection to Family and to Country.[viii]

Many Elders have raised concerns about the impact of legalising VAD on First Peoples' already fragile trust in the health care system, particularly in remote areas. Aboriginal and Torres Strait Islander people already experience poorer health outcomes and live shorter lives. Their voices, for the most part, have not been heard on this issue.

The risk of ageism

Our society frequently dehumanises older people, as well as those people who are sick and frail. The Final Report of the Royal Commission into Aged Care Quality and Standards emphatically demonstrated that older people are often seen as being of lesser value. It also repeatedly stressed that palliative care, which was an area marked for immediate attention, must be a "core business" for aged care providers.

Clauses enshrining safeguards can be amended

It has been submitted that NSW's VAD legislation is safe and conservative. When Victoria legalised VAD in 2017, it was frequently argued that the legislation was "the safest and most conservative in the world". The legislation came into effect in 2019 and less than two years later, there are already calls being made for the removal of safeguards.

In 2020, an article in the *Journal of Law and Medicine* addressed "severe limitations" to the legislation.[ix] This included the "arbitrary" minimum age of 18 and the "severe difficulties" of assessing capacity in patients with mental illness and cognitive impairment. Another 2020 journal article entitled "Too much safety?" cites the much touted safeguards as "significant barriers" which "create a stigma" around VAD. A 2021 article in the *Journal of Bioethical Inquiry* argued that the eligibility criteria of being "already dying" makes doctors the gatekeepers of VAD and effectively limits the "realisation of autonomy at the end of life."[x]

The risk of acting prematurely

People who are dying often have so many unforeseen reasons to live well for the remainder of their lives.

Dr Frank Brennan, a palliative care specialist at Calvary, St George and Sutherland hospitals, recalls an 82 year old woman, who was dying of metastatic cervical cancer. Her son told health care staff that "we would not treat a dog like this." The woman said to the doctors, "My son said I should ask for a needle to end my life." But the doctors told her that this was not possible. About sixteen days later, the woman was unexpectedly reunited with her daughter, with whom she had been estranged for many years. After their tearful reunion, the woman was much more settled. When the daughter heard the full story, she said, "My God, if VAD was legal I may have missed seeing

Mum altogether."

Care of the dying is an art

Palliative care is essential to Calvary's mission. Our models of care seek to make people feel welcome, heard and cared for whatever their experience and situation. There is a risk that a VAD culture may undermine such a message by making the value of the lives of people living with a terminal illness *conditional on their own appraisal*. Doubt and/or existential suffering is often part of the journey. The fact that a person is experiencing this kind of suffering does not take away from the value of their lives. Dr Frank Brennan cites the following case.

> A 62 year old man with mesothelioma is dying. His physical symptoms are reasonably well controlled but he is emotionally and spiritually anguished. He is referred to Palliative Care. The family say later "We didn't think this would help at all. You can't mend a broken spirit."
>
> The Palliative Care team met him and through careful communication and support allowed the patient to express his upset, fears and distress. He began to feel much better.

One of the myths about palliative care is that it is powerless to assist patients who are intractably burdened by symptoms or anguish. **At precisely the moment medicine may say 'I'm sorry there is nothing more I can do' palliative care engages intensely with the person who is suffering and aims to support them throughout their illness until their death.** The profound and complex communication skills of a clinician in the face of this suffering broaden medicine from the purely technical to the deeply personal.[xi] This is critical.

We fear a medicalised death

We fear death and dying and a natural reluctance to address our mortality often adds much confusion and existential suffering to people who are dying and their families. Many people do not understand the physiological process of dying and they do not understand the administrative processes surrounding dying. They can be overwhelmed and unsure of their options. 70% of Australians want to die at home, but only 14% have that privilege.[xii] Many people fear a medicalised death and, without provision of community care services, VAD could seem like their only option. Family members of people who are dying are often deeply distressed and the need to provide them with comprehensive support and an understanding of what happens when someone is dying. They are understandably distressed by parts of the dying process which doctors and healthcare professionals might term 'normal'.

Calls for better palliative care access by VAD opponents do not represent attempts to shift the goal posts. Australians die at home only half as much as people in the United States, Canada and New Zealand. In Australia, dying is medicalised and highly institutionalised, with about 50% of Australians dying in hospital and another 30% dying in residential care.[xiii] Access to palliative care is patchy and dependent on factors such as location and financial ability. Legalising VAD is not a solution to these challenges; nor is, Calvary hopes, anyone proposing that VAD has a future as the pathway of 'choice' to enable the vast majority to die at home.

Risks to Medicine itself

There is a risk to medicine itself. A real risk, in the intermediate to longer term, as VAD becomes more and more available in Australia, is that there will be a cohort of participating doctors who are so convinced that they are doing a humane act that they do not see an alternative.[xiv]

Many people fear the possibility of unbearable suffering as a consequence of illness or accident. Five States have already legalised VAD in the hope that this will both reduce fear of an intolerable future for the many and provide an early death as an alternative to suffering for the few.[xv] And yet, even the most carefully-thought-through changes can have perverse and unintended consequences. The following example is illustrative of the cultural risk - a risk of failing to see a non-VAD alternative.

> *"They didn't mean to frighten me. I think they thought it was a comfort. But it was every day, every ward*

> *round, they told me that if I want to, I could choose to die…"* Ujjal was explaining why he recently ran away from a hospital in his adopted home town in the Netherlands and returned to live with his mother in England, bringing his toddler and his Dutch wife with him.
>
> The GP found a large tumour in Ujjal's rectum, and referred him for treatment. They diagnosed a sarcoma of the rectum, a very rare cancer that can be cured by complete surgical removal, provided it has not already spread. Ujjal's rectum, lower bowel and bladder were removed. A false bladder was made using a portion of his intestines. He had a bag on his belly to collect his urine and another to collect his faeces. He felt lucky to be alive.
>
> The wound never fully recovered. Ujjal developed an oozing sore at one end of it that wept smelly pus. Antibiotics made no difference. Somehow, the pus was leaking through a minute crack in the skin behind his scrotum. A wine-cork-sized tumour in the pelvis was removed and radiotherapy followed. The ooze continued.
>
> The lower part of Ujjal's bowel had shriveled up in reaction to the radiotherapy and burst. His pelvis was filled with excrement, germs swarmed into his bloodstream, he had unbearable abdominal pain. More surgery. Now Ujjal had a third bag on his belly to collect discharge from the damaged bowels. But the ooze continued.
>
> The kind Professor of Surgery explained Ujjal still had some tumour in his pelvis and this would continue to grow. *"The cancer is hollow, like a tennis ball, and germs are growing inside, making a filling of pus. Every now and then the pressure builds up and the pus leaks out. There is no further surgery that could help. Many people would not wish to live in that state. Here in the Netherlands, there is an extra choice for you. If you would not like to live like this, then we have the euthanasia."*
>
> Ujjal understood how that thought might be a comfort to someone else. But he also knew that his heart lay at home. Once the possibility of euthanasia was raised for him, Ujjal found that he was afraid to admit to new symptoms, in case euthanasia rather than symptom management was recommended. Ujjal demanded his bag and his belongings… Within a week he was a resident in his mother's house in the UK.
>
> Ujjal was admitted to a single room at the hospice the day after his assessment. A day-bed in the room was made up for his wife, and we borrowed a travel cot for his daughter. In effect, they took up residence while we considered how best to support Ujjal's decision to live with his most beloved women for the rest of his foreshortened life. He was enthusiastic to try any experiment that might improve his wellbeing. Thus, we devised ways to use tampons to collect the pus from the open wound, we used drugs to alter the consistency of his faeces to reduce leakages, we used special wound dressing to contain and reduce the smelly ooze and we used a spinal line to numb the pain. Ujjal adapted to wheelchair mobility, taking his daughter for rides around the hospice and grounds.
>
> Ujjal lived with us for two months. His cancer eventually obstructed his kidneys, and he became comatose after a few days before dying very quietly while his daughter was running and laughing in the garden outside his room.[xvi]

This case demonstrates one of the challenges of a culture which allows doctors and health care staff to initiate discussions about VAD with their patients. While doctors may consider that they are being objective and impartial by presenting patients with all the options, the suggestion of VAD may be taken by patients as a negative value judgement on the worth of their lives and it may contribute to making them feel like a burden.

Medically hopeless is not the same as being without hope or without the capacity for hope and good palliative care recognises and address this. As the distinguished bioethicist, the late Nicholas Tonti-Filippini once said,

> *"…I would argue that legislation that permits euthanasia could never be made safe for those of us who have serious chronic illnesses, because the essence of such legislation is to make respect for our lives contingent upon the strength of our will to survive."*

People may well go through the VAD process without being exposed to the best of palliative care and experiencing this care as real option for them. If the only real choices in the public mind are to suffer to your death or to access VAD, this would be a tragedy. Equally worrying is a risk that people could miss out. By choosing a VAD pathway people lose opportunities to experience the unexpected things that may have happened: a conversation, sitting out in the sun, being centred and being enriched by things unfolding around them, more years and more memories.

> *"I have seen many wonderful things that patients and families have experienced in the end stage of illness. These may not have occurred if there was on opportunity to end a life prematurely."*
>
> Kevin Hardy, Calvary Nurse Practitioner.

Concluding Remarks

Calvary's position on Voluntary assisted Dying is well known and well documented.

We believe that legalising the action of taking a lethal substance to bring about death is an action which is the source of an unintended but foreseeable harm: the failure to seriously and actively address the complex physical, psycho-social and spiritual causes of a person's suffering at end of life. This harm is foreseeably further compounded when a person is living with significant additional vulnerabilities.

It concerns Calvary that there is a popular perception that many people in the terminal phase of their illnesses are in agony and distress. That is not our experience of working with the dying. If this was the case, it is hard to comprehend how our doctors, nurses and other health professionals would be able to continue in palliative care.

Finally, if Voluntary Assisted Dying is to be voluntary for the public, then any VAD scheme should be voluntary for clinical staff and medical officers and for the organisations that they work for. This expectation is grounded in the Bill's title–*voluntary*–and the expectation must be honoured.

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

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Yours faithfully,

Richard Matthews

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[i] See the Royal Commission into Aged Care Quality and Safety Interim Report: Neglect at 193 of 336 accessed at https://www.palliaged.com.au/Portals/5/Documents/Australian_Context/Royal-Commission-interim-report-volume-2.pdf on 16 November 2021

[ii] See the Royal Commission into Aged Care Quality and Safety Interim Report: Neglect at 193 of 336 accessed at https://www.palliaged.com.au/Portals/5/Documents/Australian_Context/Royal-Commission-interim-report-volume-2.pdf on 16 November 2021

[iii] Dr Natasha Moore, *Assisted dying laws will not end suffering, WA Today, 16 November 2021 accessed at https://www.watoday.com.au/national/nsw/assisted-dying-laws-will-not-end-suffering-20211112-p598e3.html on 16 November 2021.*

[iv] See Calvary's Annual Review accessed at https://www.calvarycare.org.au/wp-content/uploads/2021/09/fy1920-annual-review-v2.pdf#page=2 on 16 November 2021 at 3 of 64.

[v] See Wenham S, Cumming M, Saurman E. Improving palliative and end-of-life care for rural and remote Australians. Public Health Res Pract. 2020;30(1):e3012001 accessed at https://www.phrp.com.au/issues/march-2020-volume-30-issue-1/improving-palliative-and-end-of-life-care-for-rural-and-remote-australians/ on 16 November 2021.

[vi] Dr Natasha Moore, *Assisted dying laws will not end suffering, WA Today, 16 November 2021 accessed at https://www.watoday.com.au/national/nsw/assisted-dying-laws-will-not-end-suffering-20211112-p598e3.html on 16 November 2021.*

[vii] Dr Frank Brennan, Departments of Palliative Medicine and Nephrology, St George and Calvary Hospitals, Sydney, New South Wales, Australia, Royal Australasian College of Physicians, *Internal Medicine Journal* **49** (2019) 689-693 at 689.

[viii] See, for example, the evidence of Ms Bridges to the Royal Commission into Aged Care Quality and Safety Interim Report: Neglect at 180 of 336 accessed at https://www.palliaged.com.au/Portals/5/Documents/Australian_Context/Royal-Commission-interim-report-volume-2.pdf on 16 November 2021

> For many Aboriginal and Torres Strait Islander people, there is a distrust of institutions and a reluctance to enter care. This distrust results from the history of marginalisation, racism and mistreatment of Aboriginal and Torres Strait Islander people, including forced removal of people from Country. The theme here is the need for 'connection' for an Aboriginal and Torres Strait Islander person; connection not only to people but also to every facet of Country and how they are integral to, and inseparable from, that existence. Connection is central to a person's identity, sense of self and purposeful life. Much distrust has come from the intentional and incidental, breaking of that connection by non-Indigenous people, services and government.

[ix] Savulescu J. (April 2020). The Voluntary Assisted Dying Law in Victoria - A Good First Step but Many Problems Remain. J Law Med. 27(3):535-550. PMID: 32406618.

[x] Hempton, C., & Mills, C. (2021). Constitution of "The Already Dying": The Emergence of Voluntary Assisted Dying in Victoria. *Journal of Bioethical Inquiry*, *18*(2), 265–276. https://doi.org/10.1007/s11673-021-10107-1

[xi] Dr Frank Brennan, Departments of Palliative Medicine and Nephrology, St George and Calvary Hospitals, Sydney, New South Wales, Australia, Royal Australasian College of Physicians, "To die with dignity"- an update on Palliative Care. *Internal Medicine Journal* **47** (2017) 865-871.

[xii] Dying Well Report 2014, Grattan Institute, available at https://grattan.edu.au/report/dying-well/ accessed 16 November 2021.

[xiii] Dying Well Report 2014, Grattan Institute, available at https://grattan.edu.au/report/dying-well/ accessed 16 November 2021.

[xiv] Dr Frank Brennan, Departments of Palliative Medicine and Nephrology, St George and Calvary Hospitals, Sydney, New South Wales, Australia, Royal Australasian College of Physicians, *Internal Medicine Journal* **49** (2019) 689-693 at 692.

[xv] The fifth Report of the VAD Review Board, Victoria (to 30 June 2021) shows that since June 2019 (when the Act commenced) until 30 June 2021:

- 836 people have been assessed for eligibility to access voluntary assisted dying
- 674 permit applications have been made
- 597 permits have been issued
- 331 people have died from taking the prescribed medications.

[xvi] From *With the End in Mind How to Live and Die Well*, Dr Kathryn Mannix (2017).