Calvary | Little Company of Mary Health Care Ltd

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28 January 2022

Hon. Wes Fang, MLC
Committee Chair, Legislative Council
Standing Committee on Law and Justice

# Response to Question on Notice from Legislative Council Law & Justice Committee *Voluntary Assisted Dying Bill 2021* (NSW)

*Friday, 10 December 2021 at page 56 of the uncorrected transcript*

We refer to the above subject. Calvary submits the following response to the question from the Committee.

## Question

Mr DAVID SHOEBRIDGE: It is really to Mr Green and Mr Montague. In both of your submissions, you state the adverse potential consequences for people in the palliative care system. The only rigorous evidence we have had in relation to that is reference in submission No. 1a and a very recent Canadian journal which found quite the opposite: A study of hospice palliative care providers found a very positive response and a very positive outcome for palliative care providers in the last four to five years of the Canadian experience. So I just give you the opportunity, if you choose, on notice to persuade us why that evidence is not compelling.

## Response

### Calvary's earlier submission

We refer to our submission dated, 22 November 2021.

To be clear, we did not speak about 'adverse potential consequences for people in the palliative care system' as a direct consequence of introducing a Bill such as the present Bill.

Calvary's point was a broader one about our approach to end of life care. Our submission is that *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.* In order words, *if we do not address this existing inequity, we are not 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.* The purpose of this Bill is "to provide for, and regulate access to, voluntary assisted dying for persons with a terminal illness; to establish the Voluntary Assisted Dying Board; and to make consequential amendments to other Acts."

We quote from our submission (emphasis added)

> 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*.[ii] Despite experiencing higher levels of morbidity and mortality, people living in rural and remote areas have poorer access healthcare, including palliative care

> services. 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?*

In fact, requests for euthanasia or VAD are more often associated with inadequate palliative care services.

## The study

We refer to the study: *Joolaee S, Ho A, Serota K, Hubert M, Buchman DZ. Medical assistance in dying legislation: Hospice palliative care providers' perspectives. Nursing Ethics. September 2021. doi:10.1177/09697330211012049*

We observe that the study is limited to participants who have engaged in end-of-life care planning *with patients who have inquired about and/or requested medical assistance in dying.*

We submit that to conclude from this study "a very positive response and a very positive outcome for palliative care providers in the last four to five years of the Canadian experience". In short the study is not offer compelling evidence.

> The 48 participants in the study are multi-disciplinary hospice palliative care providers in acute, community, residential, and hospice care in Vancouver and Toronto, Canada, who have engaged in end-of-life care planning *with patients who have inquired about and/or requested medical assistance in dying.*
>
> Positive aspects of medical assistance in dying legalization were identified at (1) the individual level: (a) a new end-of-life option, (b) patients' last chance to express control over their lives, (c) patient and family comfort and relief, and (d) a unique learning experience for hospice palliative care providers; (2) the team level: (a) supportive collegial relationships, (b) broadened discussions about end-of-life and palliative care, and (c) team debriefs provide opportunities for education and support; and (3) the institutional level: (a) improved processes to facilitate the implementation logistics.

## Analysis of the Study

We make the following further submissions and distinctions:

The study in question is a qualitative study, which posits that MAID has had positive effects at:

1. Individual Level
2. Team Level
3. Institutional Level

**1. Individual Effects**

- **A new EOL option for patients**. This section of the paper rests on the premise that sometimes palliative care cannot alleviate "intolerable suffering". Special mention is made of younger patients who may take a long time to die. In March 2021, Canada removed from their MAiD eligibility criteria the requirement for a person's natural death to be reasonably foreseeable. As the NSW VAD Bill's eligibility criteria require a person's death to be expected within 6 months or 12 months for neurodegenerative conditions, it is doubtful whether this point about younger patients is relevant to the NSW VAD debate, except as a reminder that safeguards can be removed by parliaments.
- **Patient's last chance to express control over their lives.** This raises questions about the purpose of VAD. Is it about alleviating intractable suffering or is it about control? The latter is a very natural human desire in the face of suffering, and yet total control for any individual is impossible because our human condition is inherently vulnerable and dependent. MAID interventions do not always proceed as well as a person might hope.
- **Patient and family comfort and relief.** This is closely tied to the desire to express control. A doctor quoted in the study says, "… even if they just want to know more information about it, just the confirmation that it is

available to them seems to provide a lot of relief". Again this demonstrates the emphasis on the fear of what may come and the desire for control.

- **A unique learning experience for HSPCs.** The learning experiences mentioned in this section relate entirely to the provision of MAID and its implementation. There is no evidence that this has a positive effect on the provision of palliative care.

**2. Team Level Effects**

- **Supportive collegial relationships.** Again this is self-referential. This relates entirely to the process of MAID and does not extend further to palliative care.
- **Broadened discussions about end of life and palliative care.** One participant noted, "Now, when people request MAID, it does need to be confirmed that they have had counselling; in terms of what their palliative care options are". If patients were not being offered all their options before the introduction of MAID this reflects a failing on the part of the system.
- **Team debriefs provide opportunities for education and support.** Again this relates entirely to MAID.

**3. Institutional Level Effects**

- **Improved processes facilitate implementation logistics.** Again this is entirely related to MAID. The study states:

  "HPCPs described how the institutional logistics related to MAID conversations, referrals, assessments, and provision have improved in the years since legalization. Improved logistics at the institutional level facilitate MAID processes and make this option more accessible to patients seeking this EOL option."

## Conclusion

Finally we quote from the following Irish study: *The debate about physician assisted suicide and euthanasia in Ireland – Implications for psychiatry*. Data International Journal of Law and Psychiatry, ISSN: 0160-2527, Vol: 79, Page: 101747. Publication Year2021. https://www.sciencedirect.com/science/article/pii/S0160252721000765

The study observes that **requests for PAS-E are often associated with inadequate palliative care services**.

> Pain and suffering are not univocal contexts, and cannot be understood apart from psychosocial and existential considerations. The way one experiences illness relates as much to personal factors such as coping style, social circumstances, and supports, as well as one's interaction with healthcare providers and the healthcare system. Patients with chronic pain are at increased risk of suicidal ideation or completed suicide (Racine, 2018). Requests for PAS-E are often associated with inadequate palliative care services. In the U.S. state of Oregon, where PAS is legal, inadequate pain control, or concern about it was the reason given by one in three people who underwent PAS in 2019 (Oregon Health Authority, 2019). That most people in Oregon who underwent PAS had hospice (palliative) care does not gainsay this, there the hospice movement is an active supporter of PAS (Gerson, Koksvik, Richards, Materstvedt, & Clark, 2021). In Ireland, waiting lists for outpatient pain treatment are lengthy. As at January 2020, 11,932 people are on outpatient waiting lists, 3034 of these more than 18 months) (National Treatment Purchase Fund, 2021). In Canada, where fewer than 30% of people have access to any form of palliative care, PAS is considered a right, but there is no similar right for access to palliative care (Herx, Cottle, & Scott, 2020; Shariff & Gingerich, 2018). In her 2019 the UN special rapporteur on the rights of persons with disabilities was led to conclude that she is "extremely concerned about the implementation of the legislation on medical assistance in dying from a disability perspective..." and she urged Canada to do more to "...ensure that persons with disabilities do not request assistive [sic] dying simply because of the absence of community-based alternatives and palliative care" (Devandas-Aguilar, 2019).

The Committee would be wise not to rely on the recent Canadian study as rigorous evidence in the face of so many discussions which offer an alternative view. Calvary's submission is that requests for euthanasia or VAD are often associated with inadequate palliative care services.

**Mark Green**

National Director of Mission
Little Company of Mary Health Care Ltd.

(Calvary Health Care)

## For more information

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