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10 December 2021

Verbal Submission to the Legislative Council Law & Justice Committee *Voluntary Assisted Dying Bill 2021 (NSW)*

Introductory Remarks

We acknowledge the Gadigal people of the Eora nation and pay our respects to the Elders, traditional custodians, and First Nations peoples who live on these lands.

We acknowledge each of you, the Members of the Legislative Council who constitute this Committee and thank you for your invitation to appear.

Dr Rachel Hughes, who joins me this afternoon, is our Director of Palliative Care at Calvary Mater Newcastle. Rachel is a palliative medicine specialist with a background in rural and remote primary care and aeromedical retrieval. Rachel is currently working in partnership across a number of co-design projects locally and regionally to improve access of patients and carers to needs based palliative care. Dr Hughes will assist by addressing some of the particular clinical questions members may have. I will provide our opening submission.

Position

Our submission sets out our organisation's credentials and scale of our services in NSW. 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.

Calvary is concerned that the legalisation of Voluntary Assisted Dying in NSW, while ostensibly benefiting a small percentage of people (perhaps 1 in 200 of those who die) who want the option of euthanasia available to them, **poses a greater unintended but foreseeable risk to people living with significant vulnerability.**

In addition, 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.**¹ 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 effective care as a person comes to the end of their life.

Value-add of the Bill?

By legalising VAD, do we really address this inequity for 199 out of 200 people who will die and who will not access or seek VAD?

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?

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.ⁱⁱ

Uncertainty and fear mandate comprehensive information provision and symptom management. The unmet need and distress is highly complex and VAD legislation simply does not and cannot address this.

Principles

Few would disagree with the general thrust of the principles in Clause 4 that a person exercising a power of function under the Bill must have regard to. In the operation of the Act, particularly the role of the coordinating practitioner in Division 3, there is little attention paid to ensuring that these principles set out in Clause 4 are evident in the process. Clause 28 speaks about the information to be provided but the clause does not address the greater questions of solidarity, accompaniment and the preparation for the journey which is each of our deaths. We risk selling many people short.

Assisted dying legislation takes one kind of death and aims to make it easier. It’s a deeply sympathetic goal.

It may also open the door to new kinds of failure, missed opportunities, suffering and abuse, unintended but not unforeseeable.

On 9 December, 2021 one of our patients wrote

I am dying. I've never done it before, I have no idea of what I'm going to face and this unknown is very daunting

Where do I turn to for help, who can help me with the unique experience of having to face my own death, fully knowing it is imminent?

Mentally and emotionally I'm dealing with an enormous amount

My wife and family are also going through this experience and they need help dealing with it as well

Where do I go for information to help demystify the great unknown of facing my own death?

This is where I hope Palliative Care can help me, help me with all of this; and the things I haven't even thought of yet

I hope Palliative Care can ensure I'm comfortable as I can be, as informed as I can be, my loved ones are also considered in this situation and they make the whole process as easy as possible and help reduce the stress of the whole issue.

Calvary is presently reviewing our entire Palliative and End of Life Strategy. Rachel and I are both involved. Our challenges are not unique – they reflect those we all face. Calvary must focus on these things, regardless of the outcome of these deliberations.

One of the tasks has been to consult a wide range of stakeholders including people like the person who just wrote to you through us yesterday.

Key areas identified requiring dedicated attention as part of our model of care design are:

- **Public Awareness and Death Literacy:** A societal shift is needed in how we talk about death and dying and equip ourselves for our death and the deaths of loved ones and the people in our care.
- **Training and education:** Palliative and end of life care is not recognised as being the business of all people working in health care including our own Calvary VMO, GP and allied health care partners.
- **Ambulatory specialist multidisciplinary support:** the difficult symptoms that often accompany life limiting illnesses and the comorbidities that often accompany older people, with overnight symptom management often required.
- **Workforce, fragmentation and funding are major barriers:** workload and time constraints, expertise, confidence and competency levels, gaps in death literacy and carer burnout where staff provide exceptional care but are not adequately supported.

- **We need to know the person - holistic care requires holistic data:** the importance of the person's individual needs and preferences being accommodated, particularly at end of life.
- **Welcoming and accommodating care environments:** the need for dedicated spaces for PEoLC in both the general hospital space and critically, the emergency department, where applicable.
- **Care that respects the person's identity and choices:** responding to and managing the person's symptoms to the extent they can do and achieve whatever it is they want to achieve, and in as much comfort as possible.
- **Death and dying is hard on our people, too:** our staff are members of a death denying society, too. Our staff represent various cultures which all approach death and dying differently. Important to understand is that a death of a patient, resident or client has an impact on the staff, particularly for those who practice person-centred care and build meaningful relationships. Post-death support for staff is critical to enabling best practice end of life care; we need to give special consideration, too, to how we support staff who have witnessed violent or otherwise difficult deaths.

People living in Residential Aged care facilities

We conclude with a word about people in Residential Care – a particularly important group to consider and already vulnerable precisely because they are in this form of care. The operation of clause 97 (2) is particularly problematic for Calvary. In the same environment and indeed in the same room may reside a person or people who do not want to be associated with any form of euthanasia. As we stand aside to allow their fellow resident to take the VAD substance, how are we to deal with that person's rights, beliefs, fears, anxiety and even anger that we have allowed this to happen in their home without their consent? How do we explain to them that we are upholding principle 4(k):

All persons have the right to be shown respect for their culture, religion, beliefs, values and personal characteristics.

This person might say, this act has violated my sanctuary and left me with grief and suffering I did not expect to have to bare at this point in my life.

And so we end where we began

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.

¹ 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.

¹¹ 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.