Calvary | Little Company of Mary Health Care Ltd

Hospitality
Healing
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Respect

28 January 2022

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

Response to Supplementary Question Four to Dr Rachel Hughes from Legislative Council Law & Justice Committee *Voluntary Assisted Dying Bill 2021* (NSW) per Mark Green

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

Supplementary Question

4. In regard to the evidence referred to above in question 3 and the issue of "choice", what would be the real and actual implications for citizens who, while potentially meeting eligibility and other requirements of the Voluntary Assisted Dying Bill 2021, are not able to have provided to them high quality, readily available palliative care, particularly with respect to those residing in rural, regional and remote NSW?

Response

We refer to *Response to Supplementary Question Three to Dr Rachel Hughes from Legislative Council Law & Justice Committee Voluntary Assisted Dying Bill 2021 (NSW) per Mark Green* Calvary makes the following observations about the real and actual implications for citizens who may have access to VAD but who are not able to have provided to them high quality, readily available palliative care, particularly with respect to those residing in rural, regional and remote NSW.

As noted in our original submission to this inquiry, First Nations Peoples experience a much higher burden of disease and live shorter lives than their non-Indigenous counterparts. Existing mistrust of the health care system will only be exacerbated by the introduction of a practice so radically at odds with cultural practice. Many of our First Nations people reside in rural, regional and remote NSW.

In the eyes of our First Nations Peoples, dying holds particular significance. Their ancient culture recognises the inherent interconnectedness between people. Their strong connection to Family and Country enables to see more clearly that even the expression of individual autonomy occurs in relation to other people and that at a societal level this means the right to do something must be weighed up against the impact on the others. Many Elders have expressed concern at the introduction of VAD in other states and much is lost by not listening to their insights and wisdom.

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. 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. 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.

We quote from the research.

> Recent reports highlight an inconsistent provision of palliative and end-of-life (palliative) care across Australia, particularly in regional, rural and remote areas. They recommend that systematic solutions be developed to address the identified gaps and improve the access to and quality of palliative care and support for patients, their families and carers.[1,2]
>
> Palliative care improves quality of life and the experience of dying, and all people should have equitable access to quality needs-based care as they approach and reach the end of their lives.[3,4] Palliative care is provided by specialists (clinicians with advanced palliative training), generalists (other clinicians, including general practitioners), and even lay carers, making it "everyone's business".[3-6] Specialist palliative care, where available, is most effective when it is provided early in accordance with assessed need and for complex cases.[5] In Australia, 12% of those who died in 2014-15 from a known chronic or life-limiting disease received specialist palliative care in their last year of life.[7] There is a reliance on generalists to provide palliative care, particularly in rural and remote regions where there is a shortage of specialists and providing quality healthcare faces well-recognised challenges of a limited workforce, poor access, and vast geography.[8] These clinicians are expected to have appropriate skills, knowledge and access to training and support; however, generalist staff report that they feel ill-equipped to provide palliative care to their patients.[9,10]
>
> A 'palliative approach' to care aims to improve quality of life for a person with a life-limiting illness by identifying and treating their physical, emotional, spiritual, cultural and social symptoms, and providing support to their families and carers by any provider.[11] This approach is usually associated with aged care and generalist services, offering evidence-based processes from a specialist palliative care perspective for a generalist doctor audience. A palliative approach has been documented to improve patient care and outcomes in the last year of life, including resulting in fewer hospital admissions and an increased likelihood of dying at home.[6] This palliative approach is crucial in rural and remote Australia.

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.

Legalising VAD does not address this inequity. Legalising VAD offers those persons with a terminal illness residing in rural, regional and remote NSW access to voluntary assisted dying – or more precisely "to the administration of a voluntary assisted dying substance". If we do not address this existing inequity, we do not offer 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. We do not offer them improved patient care and outcomes in the last year of their lives.

And yet the Bill espouses, in Clause 4, the following principles (emphasis added):

> (a) **every** human life has equal value,
>
> (b) a person's autonomy, including autonomy in relation to end of life choices, should be respected,
>
> (c) a person has the right to be supported in making informed decisions about the person's medical treatment and **should be given, in a way the person understands, information about medical treatment options, including comfort and palliative care and treatment**,
>
> (d) **a person approaching the end of life should be provided with high quality care and treatment, including palliative care and treatment, to minimise the person's suffering and maximise the person's quality of life**,
>
> (e) a therapeutic relationship between a person and the person's health practitioner should, wherever possible, be supported and maintained,
>
> (f) a person should be encouraged to openly discuss death and dying, and the person's preferences and values regarding the person's care, treatment and end of life should be encouraged and promoted,
>
> (g) a person should be supported in conversations with the person's health practitioners, family, carers and

community about care and treatment preferences,

(h) **a person is entitled to genuine choices about the person's care, treatment and end of life, irrespective of where the person lives in New South Wales** and having regard to the person's culture and language,

There is a real risk here of sending a message that the lives of people in remote, regional, and rural parts of NSW are welcome to VAD but not "high quality care and treatment, including palliative care and treatment, to minimise the person's suffering and maximise the person's quality of life."

The operation and continuing operation of a Bill like this must be predicated on year-on-year investment in high quality care and treatment, including palliative care and treatment in remote, regional and rural NSW.

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For more information

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