

**Submission  
No 14**

## **INQUIRY INTO PROVISIONS OF THE VOLUNTARY ASSISTED DYING BILL 2021**

**Organisation:** Voluntary Assisted Dying South Australia (VADSA)

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Voluntary assisted dying (VAD) has been made legal in 5 Australian States and in 20 jurisdictions overseas to stop people suffering; to show care and compassion to people who are suffering unbearably with a progressive, life limiting illness.

Without choice for voluntary assisted dying, people in New South Wales are effectively being forced to endure their suffering or take their own lives as the only means of escape.

### The Challenge of Intractable Symptoms

Australia's palliative care is highly regarded but it can never be completely effective. This is widely acknowledged, including by Palliative Care Australia and the Australian Medical Association. Some patients suffer intractable symptoms which arise from, for example,

- cancer invasion of nerve-rich areas such as the abdominal cavity, chest cavity, spine, pelvis, or throat that leads to pain and, if in the pelvis, possible incontinence of urine and faeces. Cancer growth also leads to obstruction of swallowing, obstruction of the intestine, with vomiting and, ultimately, starvation
- paralysing diseases of nerves supplying the muscles of the chest and throat that cause gasping or choking to death (such as with motor neurone disease)
- mesothelioma (associated with asbestosis, which is incurable) which produces severe chest pain with each breath, causing difficulty in breathing and feelings of suffocation
- difficult to treat neuralgia that causes experiences similar to electric shock, with stabbing, agonising and jolting pain <sup>1</sup>

<sup>1</sup> Maltoni et al. 2012; SAVES Newsletter 11, 2015, SAVES Factsheet 23, 2017

## The Limitations of Palliative Care

Suffering is not confined to physical experience or pain, and many symptoms experienced by people suffering life-limiting illnesses are more difficult for the medical profession to assess and treat. Even with the best palliative care, both dying and incurably ill people face a range of concurrent symptoms that are difficult to manage.

For palliative care patients in the last two to three days of their life, one in five patients of Australian palliative care services experience moderate to severe pain, one in five patients experience moderate to severe dyspnoea (shortness of breath), while even more patients experience moderate to severe weakness and fatigue.

It is estimated that overall, in approximately five percent of palliative care patients, medical interventions are unable to relieve the pain and suffering at the end of life: the treatment is either ineffective or intolerable <sup>2</sup>.

<sup>2</sup> Palliative Care Outcomes Collaboration, National Report on Patient Outcomes in Palliative Care in Australia, March 2015

Em Prof Ian Maddocks, AM, known as the ‘father’ of palliative care in Australia, views voluntary assisted dying as part of the continuum of care which would be provided by a palliative care team if VAD was a legal option.

Writing in The Medical Journal of Australia prior to the passage of Victoria’s Voluntary Assisted Dying Act in 2017, Prof Maddocks wrote

*VAD can be good medicine if a request for assistance to die brings to bear an unhurried, thoughtful and comprehensive approach of the experienced clinician. To ensure full attention to informed consent, underlying disease, symptoms, prognosis, other options for care and support of family throughout, VAD needs to embrace that clinical dimension. Palliative care will continue to carry the greater responsibility to provide relief for those patients, and the demand on its services will continue to increase. VAD will provide only a very small part of the great mix of medical, social and political interventions that contribute to the public health. In countries where it is legal, VAD is available only to individuals fully capable of an informed and independent decision about the best management for them when the end of life is threatened by intolerable suffering.*<sup>3</sup>

<sup>3</sup> Maddocks, I, Palliative Care and voluntary assisted dying: the common ground, Medical Journal of Australia, Feb 6, 2017

## Elderly Suicide

The Australian Bureau of Statistics (ABS) reports that the highest rate of suicide is among men aged over 85, at 39.3 per 100,000 <sup>4</sup>.

In evidence to the Victorian Parliamentary Inquiry on End of Life Choices, Victorian Coroner, Caitlin English, stated that

*There is a cohort within the suicide group that it has been very difficult to come up with recommendations or comments that could contribute to the prevention (of that suicide). ... These are people who are suffering from irreversible physical terminal decline or disease, and they are taking their lives in desperate, determined and violent ways. (p2-3)*

In evidence to the same hearing, Coroner John Olle, identified this cohort as 50 suicides per year between 2009 and 2012, where the person's 'death was foreseeable; (where there was) incurable, chronic disease but death not imminent; (and where there was) permanent physical incapacity and pain'.<sup>5</sup> Almost half of the 197 people identified in the four year period had cancer. One third of the people died from poisoning, with hanging the second most common option and firearms were involved in about 14 percent of cases. Coroner Olle provided harrowing stories of the circumstances in which people died and the impact on those who later found them. Anecdotal evidence suggests that there is every reason to believe the situation in relation to elderly suicide is similar in New South Wales.

<sup>4</sup> ABS 3303.0, Causes of Death, Australia, 2017; while suicide is the leading cause of death for people aged 15-44, the death rate per 100,000 is lower; for example, for males aged 15-19, the rate is 11.9 per 100,000.

<sup>5</sup> Standing Committee on Legal and Social Issues, Inquiry into end-of-life-choices, Oct 7, 2015, p3

### Religious Support for Compassion

Religious support for VAD has been consistent and overwhelming in regular public opinion polls.<sup>6</sup> Leading religious figures have expressed their support for compassion and care at the end of life by supporting voluntary assisted dying. For example, the former Archbishop of Canterbury, Lord George Carey, said "it would not be 'anti-Christian' to ensure that terminally ill patients avoid unbearable pain" and making VAD lawful would be "profoundly Christian and moral". Archbishop Emeritus Desmond Tutu similarly supports compassion and care at the end of life, explaining in a statement on his 85th birthday in 2016

*Just as I have argued firmly for compassion and fairness in life, I believe that terminally ill people should be treated with the same compassion and fairness when it comes to their deaths. ... Dying people should have the right to choose how and when they leave Mother Earth. I believe that, alongside the wonderful palliative care that exists, their choices should include a dignified assisted death. I believe in the sanctity of life. I know that we will all die and that death is a part of life.*

*Terminally ill people have control over their lives, so why should they be refused control over their deaths? Why are so many instead forced to endure terrible pain and suffering against their wishes? I welcome anyone who has the courage to say, as a Christian, that we should give dying people the right to leave this world with dignity.<sup>7</sup>*

<sup>6</sup> SAVES Newsletter 46, June 19, 2017,

<sup>7</sup> Tutu, D, Washington Post, October 6, 2016

A dichotomy is often posed between palliative care and VAD based upon the founding religious values of the hospice movement and thereby contemporary palliative care. However, both are complementary concepts of care and both offer a palliative effect.

They share compassion for suffering, respect for personal autonomy, and support a person's own conception of dignity when facing death. This complementarity has been endorsed by research evidence over many years from jurisdictions that have introduced VAD laws. More recently, a commissioned report by Palliative Care Australia provided evidence on the intersection between VAD and palliative care, including the impact on palliative care services in those jurisdictions which have legislated for VAD <sup>8</sup>

The report shows that the implementation of VAD legislation leads to an increased focus on, and public policy attention towards, end of life care. It may also drive a stronger focus on upholding patient choice and autonomy, and may provide opportunities to introduce system improvements in palliative care. Another key finding is that there is no evidence of a 'slippery slope', or the contention that once VAD is introduced it will inevitably be broadened to apply to those for whom it was never intended. Instead, the report states that although there have been amendments to eligibility criteria over time, there is no evidence that VAD has substituted for palliative care due to an erosion of safeguards

<sup>8</sup> Aspex Consulting, 2018, report prepared for Palliative Care Australia, Experience Internationally of the legalisation of assisted dying on the palliative care sector, Oct 28, 2018, [https://palliativecare.org.au/wpcontent/uploads/dlm\\_uploads/2018/12/Experience-internationally-of-the-legalisation-of-assisted-dying-onthe-palliative-care-sector-APEX-FINAL.pdf](https://palliativecare.org.au/wpcontent/uploads/dlm_uploads/2018/12/Experience-internationally-of-the-legalisation-of-assisted-dying-onthe-palliative-care-sector-APEX-FINAL.pdf)

I urge the New South Wales Parliament to look to the evidence and pass the *Voluntary Assisted Dying Bill 2021*.

Frances Coombe

President - Voluntary Assisted Dying South Australia (VADSA)

<sup>1</sup> Maltoni et al. 2012; SAVES Newsletter 11, 2015, SAVES Factsheet 23, 2017

<sup>2</sup> Palliative Care Outcomes Collaboration, National Report on Patient Outcomes in Palliative Care in Australia, March 201

<sup>3</sup> Maddocks, I, Palliative Care and voluntary assisted dying: the common ground, Medical Journal of Australia, Feb 6, 2017

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