

# **Submission to the University of Tasmania's Independent Review of the *End-of-Life Choices (Voluntary Assisted Dying) Bill 2020 (TAS)***

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Thank you for this opportunity to provide a submission to this important review.

I offer my submission from the standpoint of a palliative medicine practitioner of almost 30 years' experience, most of which was as Head of Department of Pain and Palliative Care, Peter MacCallum Cancer Centre, Melbourne (1998 to 2014), followed by a further 6 years as a specialist consultant in that service and at the Western Health network, Melbourne, while completing my PhD Palliative Care. In 1996, I founded Australasian Palliative Link International (APLI, [www.apli.net.au](http://www.apli.net.au)), a charity which aims to foster the development of palliative care in the Asia Pacific region through collegial links, mentoring, teaching and advocacy. Through this charity, I am in contact with many colleagues working in very resource-poor settings with little or no access to effective analgesics or health professionals trained in good end of life care. This experience provides a particular lens to view the advantages we enjoy in Australia while still being reminded in my daily practice, of the room for improvement in the expertise and attitudes to those in our health care system who have advanced, life-threatening, chronic illness and about what is possible in best end-of-life care.

My submission will focus on the following points related to the Terms of Reference Point 5:

1. The impact of VAD legislation on medical practice and practitioners
2. The interrelationship between the VAD Bill and existing palliative care
3. The interrelationship between the VAD Bill and other end-of-life choices

## **1. The impact of VAD legislation on medical practice and practitioners**

There is early evidence of cultural normalization of the practice of the intentional termination of life in Victoria by assisting a person to suicide or giving a lethal drug.

The rapid uptake of this practice in the first year of introduction in Victoria has been accepted with little examination. Much of the reporting around the annual report focused not on the 10-fold higher than anticipated number of deaths (124 deaths vs the 'dozen' anticipated by the Victorian Health Minister Mikakos) under this legislation, but rather on the omissions, barriers to access and call for ways to encourage more doctors to participate as consenting or consulting practitioners. To be regarded as a trained specialist, one needs to undertake only 6 hours online training, however, there is currently evident reluctance among doctors to engage in this process.

A recent article written by leading Canadian palliative care providers Herx, Cottle, & Scott, 2020, and which was supported by 143 others practitioners, detail the negative consequences of this "radical shift for medicine, and particularly for palliative medicine".

P.29. This article reveals the rapidity with which this extreme practice has been normalized and the increasing requirement for Canadian doctors to participate, without regard for individual conscience. The right to conscientious objection is severely curtailed there and is likely to be similarly challenged in Australia as we follow in the footsteps of overseas jurisdictions in this practice.

#### Examples of this normalization in our Victorian experience

- a. Dr Cameron McLaren is a Melbourne based oncologist and trained specialist of VAD, who as of June 2020, reports having been involved in 79 applications of whom 'more than 30' (almost 25% of the annual Victorian deaths by VAD) had died through self-ingestion or administration by Dr McLaren, of the lethal drug (McLaren, 2020). In this reflective article published by Dying with Dignity Victoria, he writes that **"Over this time, we practitioners have grown more comfortable in the service we are providing"**. This admission succinctly captures the very concerns of those of us who are opposed to this practice, and also encapsulates the social dangers inherent and unavoidable in this practice. For well-intentioned and sincere doctors to become comfortable with the deliberate act of helping another person to end their life, albeit with compassionate intent, crosses a rubicon that endangers the life and wellbeing of others less articulate, less well-supported, less coherent, more vulnerable and in its most worrying form, less socially valued. And that value is a fragile, socially determined value, which to date in Australia, is afforded to all by the very fact of their being human.
- b. In my consultative practice at a major hospital in Melbourne, I reviewed a man with a history of chronic depression and now recurrent bowel cancer, who on hearing of the return of his cancer, attempted suicide. He survived this attempt and was reviewed by a psychiatry registrar and consultant while still an inpatient. Their clinical note suggested that perhaps VAD should be offered to him. This is a significant departure from the established practice of care for patients with depressive illness who are suicidal, but the psychiatrist informed me that he was not sure about how his practice should be modified in the environment of VAD. The consultant appeared to be uncertain about how to practice and to care for suicidal patients in this new environment, to be attempting to practice by the law, rather than by best medical standards of psychiatric care. Of note, when this example was described in my MJA article, respondents felt that this was an appropriate response by the psychiatrist, even though the Victorian law clearly states that doctors should not raise or offer VAD to patients. How such a limitation will be guaranteed is unclear and no processes are in place nor can be established, to ensure that doctors do in fact not raise VAD as an end of life option to patients. Surely, in light of this, such a safeguard will disappear in subsequent iterations of VAD laws across Australia, another example of safeguards becoming barriers.
- c. Being a confidant to a wish to die is not uncommon in palliative care practice. We carefully explore this wish and find that in less than 8.5% of people is it a consistent, definite wish to die (Chochinov et al., 1995). In this study, desire for death was strongly associated with depression (58.8% vs 7.7%). More often the expressed wish

to die is an expression of the fear of dying, a fear of the possibility of unrelieved suffering, a sense of loss of self, a wish for a different reality of life (Monforte-Royo, Villavicencio-Chavez, Tomas-Sabado, Mahtani-Chugani, & Balaguer, 2012). Health care practitioners who care for people at the end of life need to be competent and comfortable in exploring the meaning of the wish to hasten death and competent in addressing the issues revealed as much as is possible within our cultural, social and health care environment.

A recent example of a patient with breast cancer, admitted with a fracture of her upper arm, illustrates the distortions of care occasioned by this VAD Bill. She had lived with both chronic depression and breast cancer for many years, but only a week before admission, was diagnosed with metastatic cancer throughout her skeleton. Her depression was well managed but she mused that she could now access VAD as she had metastatic disease, whereas for years, she had struggled with her depression. Is she now 'eligible' provided she does not opt for treatment of her metastatic breast cancer, with the many therapeutic options available to her?

Already I am witnessing a move toward a more automatic referral to the VAD legislative process, whenever a patient expresses a wish to die, which is now interpreted as a wish for VAD. To open a more exploratory conversation in this new environment is more difficult. Only today, in my consultative practice, I reviewed a man with advanced oropharyngeal, incurable cancer who expressed both a wish have any treatment that would lengthen his life and also asked about 'Andrew's pill'. Our hour-long conversation, written rather than spoken, as he had developed deafness and poor vision due to his cancer, explored what symptoms most bothered him (wanting something to eat, wanting to go outside in the fresh air), what he hoped for (to be cared for in a location near to his mother and his family), his prognosis (weeks), and what palliative care services were available to him and the ongoing care and support which could be provided, as part of the public health system ( he was not aware that palliative care was freely available). His expressed wish to die had however, already prompted a diligent email from his treating team to the hospital executive officer as is the policy for patients requesting VAD. Will the VAD specialist similarly explore the above issues and ensure that this man is fully aware of the care and dignity available to him in 'normal' palliative care practice and ensure that he will feel secure enough to trust those services to care for him competently and without fail until he dies? Apart from documentation of eligibility criteria, there is no requirement for trained specialists in VAD to document any further details of their encounters with patients.

Even some colleagues in palliative care express concern that patients who want VAD and do not progress through the bureaucratic processes in time, are being denied their wishes, when they die from their disease rather than by VAD. So dominant has the ethic of autonomy overwhelmed all other ethics at the end of life.

## 2. The interrelationship between the VAD Bill and existing palliative care

The impact on existing palliative care specifically includes:

- a. The above sense of failure felt by some team members who are supportive of VAD, even if the patient dies a good death, if they do not die by the self-administration of lethal drugs; the perception of bullying by senior executive to 'comply or else' which was experienced by palliative care team members following a contentious case of VAD on our palliative care ward in late 2019; the accusations of a lack of compassion, of inflicting personal views upon patients, of having a judgmental attitude and of depriving patients of palliative care, even when there have been no cases of refusing palliative care to any patient in our network; the overall lack of support for the position of conscientious objection in the 'hidden curriculum' of current care, the clear messaging that to not comply and cooperate with VAD is not consistent with this network's position that VAD is just another end-of-life choice to offer our patients. The network has recently offered to fund doctors to undertake the specialist training and to provide a consulting fee for any patients reviewed for VAD.
- b. In the lead up to the introduction of VAD, palliative care providers in Victoria held a number of meetings to discuss the impact of this legislation on our practice. The overriding consensus was that VAD is not part of palliative care practice, as it is defined by the long-standing WHO definition, the 2020 International Association of Hospice and Palliative Care consensus definition, and by the Australia New Zealand Association of Palliative Medicine definition. Despite this differentiation, palliative medicine specialists were concerned that there appeared to be an expectation that VAD would fall to them to do. They expressed concern that just as other medical specialists fail to engage in end-of-life care before VAD legislation, so they would leave VAD to palliative care providers to manage. However, there are very few palliative care doctors who participate in VAD, in Victoria and Australia-wide. It is noteworthy that this very specialty which is most closely involved in caring for people who are dying, sees the least indication for the change in the law. Some would claim that this is motivated by some sort of professional gate-keeping, a claim for maintaining our 'turf'. This diminishes the sincerity and depth of concern expressed and experienced by many palliative care practitioners.

For many palliative care providers who are also conscientious objectors, this first 12 months of VAD legislation in Victoria has been a difficult and distressing time and one which has led to deep questioning of our ability and willingness to continue to work in palliative care. There is a chasm between assisting a patient to die a peaceful death with all the skills, competence and compassion we have, and deliberately providing and/or administering an agent which will inevitably cause their death. No amount of social sanitization of this act changes the reality of what is being asked of doctors as a profession.

- c. There is no suggestion that palliative care practitioners opposed to VAD abandon their patients. We have learnt to continue to provide best palliative care whether or not a patient has VAD processes in place. Conflict does arise when patients are being cared for in an inpatient palliative care unit, as I found in December 2019, when an inpatient took her lethal drugs while an inpatient on the palliative care ward. This encounter has been extensively discussed in our clinical team, amongst nursing staff,

at a hospital clinical ethics committee meeting, within our division and amongst colleagues. For this reflection, I am focusing on the impact upon me as a palliative care provider. To have a patient under my care who was undertaking a course of action which was so against my beliefs as a clinician, but which I had no capacity to influence or discuss, was profoundly disturbing. Similar impact was described by a community palliative care nursing colleague, who described a deep sadness at the death of her patient, by self-administration of lethal drugs at home, a sadness different to that which she usually experienced, that she would probably 'get used to it' but she could not help feeling a sense of having failed this patient somehow, such that she ended her own life.

- d. 'Someone else's problem': related to point (b) above, many doctors have disengaged and avoided the issue of VAD, regarding it as someone else's problem. To cite McLaren (2020) again: "**The few of us actively providing assessments are propping up the system and that it is far from robust**". I would suggest this disengagement is in part arising from a deep regard and respect for the patients they care for and an instinctive distaste for what is being promoted as another end-of-life option.

However, a similar disengagement is witnessed about end-of-life care in general, along with a great deal of misunderstanding about what we do in palliative care. For example, a very experienced anaesthetist/pain specialist in my health network recently told me that she understood that palliative care doctors hasten patients' deaths as a matter of course, when we increase their opioids for pain management. There is substantial evidence in the literature that use of opioids proportionate to pain requirements does not hasten the death of patients in palliative care practice. Her assumption despite close contact with our service was revealing to me and likely to reflect the views of doctors and health professionals even in this day and age.

- e. In my practice, I witness daily evidence of iatrogenic suffering. Patients endure medical investigations without adequate analgesia, delays in diagnosis, falls from beds, inconsistent and confusing communication. Medical care needs to be more cognizant of the burden of suffering inflicted through poor decision-making and systematic failures, suffering which leads people beyond endurance. To introduce legislation that simplistically accepts 'suffering' as an indication that does not need exploration, that suggests that to question and explore the experience of suffering is to interfere with a person's autonomy, suggests a lack of understanding of the realities of daily clinical care and the capacity for people to cope when compassionately and considerately care for.
- f. End-of-life is a time of equal importance to any other period of a person's life, and in fact may be one of the most important periods, equal in impact and intensity to the very beginning of life. Working in palliative care provides unique insight and appreciation of the complexity and uniqueness of death for each patient and family. Key to the relief of suffering is the development of a trusted relationship within which a patient is able to confide their fears, hopes, regrets, concerns for their family, and to share their personal experiences in life. Eighty-year old women weep

over the still-birth of 60 years ago, of their concern for the care of their disabled child, of traumas experienced as refugees, of their sense of being a burden to their children; elderly men speak of experiences of abuse as a young person, of their grief over children who have cut off contact, of their fears about how they will die. They also speak of the love and support of children and grandchildren, of their pride in achievements during life, and of the peace with which they are approaching death.

However, the VAD specialist is very limited in their scope of practice, focused only on ensuring the person meets the current criteria and on enabling that person to take their own life. To quote Dr McLaren (2020) again, “Most of the people I have helped access VAD haven’t been patients of my own with whom I have had a long-term relationship – most are referred by other practitioners who aren’t interested in providing this service for whatever reason. **I do feel as though the assessments would be better done by doctors who have known the patients for longer than one or two clinic meetings.**”

And yet, Tasmania is planning to introduce a law which mimics the Victorian law in this very aspect, recognized by one of the VAD most consistent protagonists, as being inadequate.

- g. Lack of support for practitioners who are conscientious objectors. This past 12 months has demonstrated to me the great difficulty to honour the patient’s wish for assisted suicide and simultaneously honour the position of doctors who are conscientious objectors. There has been no coordinated effort to assist doctors who wish to practice, as is stated under the Victorian legislation, as conscientious objectors. The law states that no doctor is required to participate, but offers no requirement for such doctors to be protected, and supported to honour their conscience in this way (Murphy et al., 2020). We have patient navigators, training of participating docs, funded courses and funded time spend consulting for VAD.

I have helped to form a small group of doctors who meet to share experiences and try to capture the impact this seismic change has had on us all. Without this group, I came close to resigning from palliative care. I have felt considerable bitterness about the rejection of time-honored principles of medical practice, now substituted by the accusations of a lack of compassion and of imposing my values and beliefs on others.

When I first moved to Peter MacCallum Cancer Centre in 1998, my interview included an interrogation about my attitude to euthanasia. Clearly, to answer anything other than being opposed to it would have meant not being appointed. Later, when putting my PhD ethics proposal to the Peter Mac research ethics committee, there was considerable emphasis on mandatory disclosure of any participant doctor who might confide that they had assisted someone to deliberately end their life. Fast forward 10 years, and these values are reversed. Society may have changed, but my understanding of a doctor’s obligation to respect and protect

life, and my commitment to doing all in my power to relieve suffering, short of extinguishing the very life of the person who is suffering, remain the same.

### 3. The interrelationship between the VAD Bill and other end-of-life choices

Other end-of-life choices in Australia include withdrawal /refusal of treatments such as dialysis, surgical interventions, transplantation, and disease-directed therapies such as chemotherapy and radiotherapy in the case of cancers. In addition, people are encouraged to complete advance directives and to discuss their end-of-life wishes with close and trusted person(s) to enable them to act as surrogate decision-makers should that be required.

Safeguards soon become obstacles. VAD is regarded as a right. Safeguards prevent access. Rights should be available for all, not just for some. An example of this narrative is the suicide of a Mr Bareuther which was reported in the Sydney Morning Herald, June 18, 2020. Mr Bareuther was 'denied access to the state's assisted dying laws' because he was not a citizen or permanent resident. In that article, Dr Rodney Symes, a leading advocate for VAD in Australia, was reported to say that "If there was one thing I could change immediately about the (Victorian) laws, it would be getting rid of the clause which says you have to be an Australian citizen". The Coroner Phillip Byrne who reviewed Mr Bareuther's death by suicide, was reportedly moved by the case and "has asked **whether it was possible to introduce "some level of discretion" in the assessment process**".

Discretion within the doctor-patient relationship was and is possible in the care of the dying without resorting to VAD, but was discounted by VAD advocates as lacking transparency. But here we have the very same discretion being called for in the application of the Victorian legislation and within the very first year of its enactment. The discretion possible without VAD allows for avoidance of or withdrawal of life-prolonging therapies, the careful discussion of treatment options consistent with a person's priorities and likely clinical outcomes, careful and attentive management and review of symptoms, availability of 24-hour services and, if suffering in the imminently dying is refractory to best care, deeper sedation for their remaining few days, supportive care of their family and best quality nursing and psychosocial/spiritual care.

A further comment regarding discretion:

In the debates about introducing assisted suicide legislation, it is often claimed that doctors are already assisting people to die behind closed doors, without the 'protection of the law'. If we were unable to trust doctors to act within professional and legal boundaries when the stakes were so high, when they could be prosecuted for breaking the law, why are we more confident that they will not continue to act outside the law, a law which requires much more bureaucratic processes, in the VAD environment? As Australian palliative care pioneer and Tasmanian resident, Professor Norelle Lickiss writes in a personal communication to me, "It also may be said that doctors whose morality is defined by law maybe a danger to society".

#### 4. Conclusion

I trust that this Inquiry will offer the guidance the Tasmanian Parliamentarians need, and will assist people to recognise and follow a path that holds least risk for social harm.

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