Submission
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INQUIRY INTO PROVISIONS OF THE VOLUNTARY ASSISTED DYING BILL 2021

Organisation: Doctors for Assisted Dying Choice

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for Assisted
Dying Choice

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SUBMISSION TO THE STANDING COMMITTEE ON LAW AND JUSTICE OF THE NEW SOUTH WALES LEGISLATIVE COUNCIL ON ITS INQUIRY INTO THE PROVISIONS OF THE *VOLUNTARY ASSISTED DYING BILL 2021*

Who we are

We are a national organisation of Australian medical practitioners, with New Zealand affiliates, who are committed to attaining a legal choice for rational adults with intolerable suffering for which there is no realistic chance of cure or relief, and who wish to end their lives at a time of their choosing and in the presence of those whom they choose, through voluntary assisted dying (VAD). Assistance may be by doctor prescription of medication for personal consumption, or by doctor administration <http://drs4assisteddyingchoice.org/>.

The WA Convenor Group of Doctors for Assisted Dying Choice has the advantage of having been through all this before. In October 2017 we made a 16-page submission to the WA Parliamentary Inquiry into End of Life Choices <http://www.parliament.wa.gov.au/Parliament/commit.nsf/(Evidence+Lookup+by+Com+ID)/9E289DFA443FB0EF4825822C0026286A/$file/20171019+-+EOLC+-+Sub+402+-+Doctors+for+Assisted+Dying+Choice.pdf>, followed by a 5-page supplementary submission in May 2018. Six of us gave evidence to the Inquiry on behalf of the Group. In May 2018, following the establishment of a WA Ministerial Expert Panel on Voluntary Assisted Dying, the Group made a 40-page submission to the Panel <https://www.dropbox.com/s/2ibayk8xvtw4lza/Drs4%20submission%20v5.docx?dl=0>.

These submissions, along with evidence from Group members, were cited 16 times (11 times in the Report of the Inquiry and 5 times in the Report of the Panel). There were also numerous footnoted references. These citations make the Group one of the most influential contributors to the evolution of the VAD process in WA.

The present system is broken

Our laws, and our ethical standards, date back to times well before the development of modern medicine, and in many instances no longer reflect contemporary practices and attitudes. For example, the Hippocratic Oath of the fourth or fifth century BC contains an injunction against a doctor administering a poison to anybody when asked to do so, yet doctors today administer lethal poisons all the time to permit the performance of life-saving surgery undreamt of in the time of Hippocrates. They just do so in carefully controlled doses.

The key to understanding this injunction lies in the words immediately preceding it: "never with a view to injury or wrong-doing." That is the real mischief that the doctor is pledging not to commit. What's not to like about that?

Up until recent times, there was no prospect of patients with terminal illnesses lingering for weeks or months while doctors undertake heroic treatments to keep them alive for just a little longer. The emergence of so-called "futile treatments" at the end of life is a phenomenon of modern medicine, and one doctors are grappling to come to terms with.

A paradoxical consequence in many cases is an increase in the duration of intolerable suffering, hardly something that Hippocrates would have approved of. This has led to the development of the new medical specialty of palliative care, in which the doctor's aim is to relieve suffering, rather than prolong life (or, for that matter, hasten death).

From palliative care has sprung the practice of "terminal sedation" (sometimes known as "palliative sedation"), in which a terminally ill patient with distressing symptoms refractory to all normal treatments is kept unconscious, and hopefully free from suffering, while dying ostensibly from natural causes (though in reality usually from the withholding of intravenous nutrition and hydration while unconscious).

The intent of terminal sedation is consistent with the dictum that doctors should heal wherever possible, but relieve suffering always. But it is imperfect for a number of reasons:

- for the patient, it is a lottery, because some doctors are willing to try it, while others are not, and patients are unlikely to know in advance which way their doctor will jump;
- because it is not recognised by the criminal law, it is an undocumented and unregulated activity, so that the usual checks and balances for the protection of the patient are missing;
- the doctor is in the driving seat, not the patient, who is not always aware that they are to be subjected to terminal sedation;
- time to death is unpredictable, with the patient often lingering in a dehydrated and deteriorating state, to the great distress of family and friends.

The law has not caught up with many advances in modern medicine, and as mentioned above, this is a particular problem when it comes to terminal sedation.

Importantly, the law has been slow to catch up with public opinion regarding VAD. Numerous surveys around Australia show that support for VAD cuts across all groups in society, including all religious affiliations, and is now regularly in excess of 80 per cent overall. This is reflected in the sudden emergence of VAD legislation in all Australian States apart from New South Wales.

The advantages of voluntary assisted dying

VAD offers a real and practical solution to the problems outlined above. It is fundamentally a response to the change in the balance of power between the patient and the doctor, as reflected in a recent addition to the modern version of the Hippocratic Oath, namely the Physician's Pledge, and unanimously approved in 2017 by all national medical associations in the World Medical Association <https://www.wma.net/policies-post/wma-declaration-of-geneva/>:

> I WILL RESPECT the autonomy and dignity of my patient.

VAD is a vast improvement on terminal sedation, as reflected in the following contrast with the dot points given above:

- it is not a lottery for the patient, but a legal option (subject to statutory safeguards) open to all terminally ill patients, who are competent and ask for it because their existing treatment is no longer capable of relieving their suffering in a manner they consider tolerable;

- it is properly regulated and documented as required by law, and open to scrutiny to ensure that the interests of the patient are fully protected;
- the patient is empowered to make the decision, rather than the doctor;
- the process is quick and certain, to the relief and gratitude of family and friends, who are spared the horror of waiting around interminably to see which breath of the patient will turn out to be their last.

Nor should it be forgotten that the mere existence of a lawful VAD option is in itself an enormous relief for many terminally ill patients, including many who in the end, will never have to choose that option. Even for those who make the choice, the mere fact that VAD is available when they want it is a huge relief; in Oregon, a third of patients who qualify for and receive a prescription for lethal medication, never have to use it.

VAD and palliative care

VAD is not palliative care (which by definition neither prolongs life nor hastens death), but is fully compatible with palliative care, giving the patient the opportunity to move seamlessly between the two in the care they receive at the end of life.

Similarly, VAD constitutes no threat to palliative care, despite what some scaremongers would have us believe. Experience around the world shows that where VAD is legalised, palliative care rides on its coat tails to receive more community support and public funding.

This is attributable to the greater public awareness and acceptance of medical care issues at the end of life, when palliative care will always be called upon to do the heavy lifting. Fortunately, VAD will only ever be the preferred option for a tiny minority of patients at the end of life, which fact is in itself a tribute to the effectiveness of most palliative care.

It is nevertheless important to dispel the myth, peddled by some interests, that palliative care is capable of relieving all severe symptoms at the end of life. Data supplied by a large majority of leading palliative care services in Australia to the Palliative Care Outcomes Collaboration at the University of Wollongong, show convincingly that not all severe physical symptoms are relieved by palliative care at the end of life (Appendix 1).

Still less is so-called existential suffering capable of being effectively relieved by palliative care. By existential suffering we mean the individual's subjective response to the loss of dignity associated with some physical symptoms (such as incontinence), loss of control over their life, inability to communicate, loss of meaning and enjoyment of life, etc., all of which are notoriously difficult for carers to manage,

It is also important to dispel the myth that palliative care is some sort of underdog in this debate. As with all types of medical care, there will never be enough money to meet the full demand for palliative care services, and always a reason to push for more resources. But this should not blind us to the fact that compared to the rest of the world, we are well off when it comes to the provision of palliative care.

Overall, Australia ranked second out of 80 countries surveyed by the Economist Intelligence Unit's Quality of Death Index 2015, which focussed on the quality and availability of palliative care to adults <https://www.eiuperspectives.economist.com/sites/default/files/2015%20EIU%20Quality%20of%20Death%20Index%20Oct%2029%20FINAL.pdf>. In terms of the availability of appropriately trained staff capable of providing palliative care in hospitals or in the community, Australia ranked first, and in terms of affordability of palliative care, it ranked equal first.

Lessons from the WA experience

After an 18-month implementation period following the passage of the *Voluntary Assisted Dying Act 2019*, WA has now had almost five months of the lawful availability of VAD. As the NSW *Voluntary Assisted Dying Bill 2021* is modelled on the WA Act, our experience is particularly germane to the NSW debate.

The first lesson is that the demand for VAD may be higher than anticipated. Even a small mismatch between supply and demand can lead to undesirable delays in the provision of VAD services, and to the potential for burnout of the doctors who are called upon to do more than is reasonable.

For this reason, it is important to make early provision for the training of VAD-friendly doctors, and to ensure that no unnecessary barriers are placed in the way of the way of their recruitment. WA requirements to do more than the minimal number of hours necessary for continuing registration, and particularly the requirement for doctors to provide professional references to do the training, have proved counter-productive. These requirements are unique to WA and should not be duplicated.

Secondly, the attempt to recruit nurse practitioners as administering VAD practitioners has been a failure. Neglecting to provide separate training for administering practitioners, tailored to their needs, is the obvious reason for this failure; it is certainly not due to lack of interest. WA will need to consider authorising registered nurses to be administering practitioners. In this respect the NSW Bill is ahead of WA.

Thirdly, the legislative attempt to steer eligible patients towards self-administration rather than practitioner administration has been a failure – the vast bulk of cases have involved practitioner administration. If VAD legislation rests upon the fundamental tenet of patient empowerment, it follows that there should be no such attempt in the NSW legislation. We regard clause 57(1) of the NSW Bill as satisfactory from this point of view.

This should permit the abolition of the two pathways of administration in the legislation, allowing for more flexibility; in particular, for the doctor to intervene in the event of complications arising during self-administration. While the risk of the patient awakening after self-administration is a very low, the consequences for the patient of this happening would be devastating, and for family and friends, hardly less so.

The absence of provisions in the WA Act equivalent of clauses 59(7) and 68(1) of the NSW Bill, authorising an agent of the patient or the contact person, respectively, to prepare and supply the lethal medication for self-administration, has proved a problem in WA. We will be recommending the incorporation of such provisions in the WA Act when it comes up for review in 2023-24.

The WA Act has nothing like Part 4 Division 4 of the NSW Bill, requiring the authorisation of the VAD Board for each patient making an administration decision. An attempt to introduce such a requirement in the WA Legislative Assembly was decisively defeated by 38 votes to 11. In a short speech of rebuttal, the Minister for Health, the Hon Roger Cook, said it would turn the Board into an additional coordinating practitioner, providing an extra opinion, and would amount to an extra burden or obstacle for the patient, without improving the legislation <https://parliament.wa.gov.au/WebCMS/webcms.nsf/resources/file-vad-bill-2019---la/$file/Voluntary%20Assisted%20Dying%20Bill%202019%20-%20All%20Stages%20-%20Assembly%20-%20Hansard.pdf, page 390>.

In the WA Legislative Council, which made 50 amendments to the WA Bill, there was reference to the above debate, but no amendment was moved. The Minister in charge of the Bill at the time, the Hon Sue Ellery, said:

> We have taken the view that it is an extra bureaucratic layer that does not provide additional protection. We do not believe it will add any further safety, but it will cause delays to access for people … the bill already enables the board to raise any concerns and refer matters for investigation, if it has concerns about the processes not being followed <https://parliament.wa.gov.au/WebCMS/webcms.nsf/resources/file-vad-bill-2019---lc/$file/Voluntary%20Assisted%20Dying%20Bill%202019%20-%20All%20Stages%20-%20Hansard%20-%20Council.pdf, page 649>.

With these views we heartily agree. The experience in Victoria, where a similar system has operated for over two years, has numerous examples of bureaucratic delays, sometimes vitiating the VAD outcome sought by the patient. In at least one notorious case, a patient who had lived in Victoria for some forty years committed suicide after being denied a permit because he didn't have the papers to prove he was a permanent resident, a problem that thankfully will not arise in NSW if clause 16(b)(3) of the Bill is enacted.

Nevertheless, these Victorian experiences have brought this whole authorisation system (unique to Australia) into disrepute, and we are frankly astonished to see it emerging in the NSW Bill. We earnestly urge its rejection.

Progressive features of the NSW Bill

On the other hand, we applaud Part 5 of the NSW Bill, which has no equivalent in the WA Act. Early experiences in WA are already underlining the importance of making provision for accessing VAD for people who are residents of residential facilities, and for patients in private health facilities, including hospitals and hospices.

Residential facilities are less of a problem, because of Commonwealth legislation applying to them, but private health facilities are emerging as a real problem, and the formula adopted in Part 5 is essential to prevent significant discrimination against some terminally ill patients, purely of the basis of where they end up in the health care system.

We are already aware of at least one case where the patient was unable to access VAD after he became too ill to be transported off the premises for the provision of VAD services. His death was a miserable one, notwithstanding the palliative care available at the facility where he died. No one should be forced to undergo a bad death under such circumstances.

Conclusion

We thank the Legislative Council for the opportunity to comment on the NSW Bill. Overall, this is a good Bill, and subject to the few amendments recommended above, is worthy of strong support. We hope this submission has been of value to the Council.

Respectfully submitted on behalf of the WA doctors in Doctors for Assisted Dying Choice,

Dr Richard Lugg
Western Australian Convenor

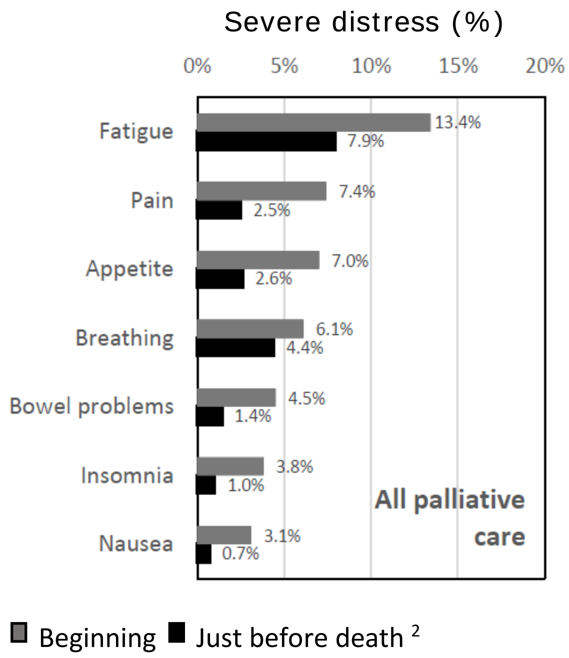
APPENDIX 1

Doctors for Assisted Dying Choice

Palliative Care cannot relieve all suffering.

The Palliative Care Outcomes Collaboration (PCOC) is a national programme which collects data on outcomes of 80% of patients seen annually by specialist palliative care units in Australia.[1] A Symptom Assessment Scale (SAS) is used to assess physical symptom outcomes by patients rating their distress, on a scale of 0 (no distress) to 10 (worst distress possible).

In the years 2015 and 2016, PCOC recorded data of 40004 patients who died while receiving specialist palliative care; 25,679 patients had SAS scores at the beginning of an episode of palliative care and just prior to death. The graph shows the percentage of patients reporting severe distress (SAS score 8-10) for each of the seven physical symptoms recorded in the SAS assessment.[2]



When symptoms are considered individually, a decrease in suffering can be seen. Overall, however, 26% of all palliative care patients reported having severe distress from at least one symptom at the start of their palliative care episode.

This decreased to 13.9% just prior to death.

While this is a commendable outcome, these evidence-based data from palliative care specialist services indicate that at the end of life, all physical suffering cannot be relieved by palliative care.

Dr Richard Lugg

Associate Professor Arnold Gillespie

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1. Palliative Care Outcomes Collaboration (PCOC). http://pcoc.org.au
2. K. Eagar, S. Clapham & S. Allingham, "Palliative care is effective: But hospital symptom outcomes superior", BMJ Supportive and Palliative Care Online First (2018) 1-5. https://ro.uow.edu.au/cgi/viewcontent.cgi?article=1966&context=ahsri