

Submission into the Voluntary Assisted Dying Bill 2021

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Improving the Queensland VAD Bill to secure both real choice and real protection

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Summary

The QLD VAD bill aims to balance individual choice with protection of the vulnerable. In its current form, and in the current state of health affairs in QLD, the bill does neither. VAD should not be legalised until access to treatment and specialist palliative care is assured for all. In addition, several improvements could be made to ensure that, once adequate access to treatment and palliative care are assured, VAD legislation in QLD actually furthers real choice and real protections against abuse.

The key theme in the proposed changes is *transparency and accountability*. The changes widen the circle of people involved in a VAD request, whilst not increasing barriers to access, so that:

- Quality of free choice is improved because people are able to make more informed decisions about treatment, palliative care, and VAD thanks to a requirement to consult with a palliative care expert and with an expert in the treatment of their condition;
- medical practitioners involved in providing VAD are more accountable because they have to consult treating practitioners and other experts, and because they have to provide evidence of eligibility to the Review Board;
- QCAT is better empowered to ensure that those who are eligible can access it, and that those who aren't or who are being coerced can be protected, because practitioners are required to inform other practitioners and inform entities in which the person resides;
- the Review Board is better equipped to monitor the application of the bill and ensure that the practice is genuinely being accessed by those eligible because practitioners are required to provide evidence of diagnosis and prognosis, and evidence of capacity in cases of mental illness;
- vulnerable people are better protected by ensuring that they have quality information about treatment options and palliative care, that they feel they can safely turn to their treating doctors or the institution in which they reside if they have any doubts, and that treating doctors or the entities in which people reside can raise concerns to QCAT;
- conscientious objection is genuinely protected because practitioners who have a conscientious objection are not required to provide any information about VAD. This is not a barrier to access because of the provision of a navigator service;
- entities that do not provide VAD can effectively carry out their duty of care to their staff, other residents, and the person requesting VAD because they are adequately informed by the person and the coordinating practitioner, the entity has the option to transfer the person for any or all steps if this is reasonably possible, and the decision to transfer rests with the entity rather than the coordinating practitioner;
- Our liberal pluralist democracy is enhanced because people who want nothing to do with VAD can seek out institutions for their employment or their health and aged care in which they know that exposure to VAD will be minimised and they will not be put under any pressure to consider it, because entities who choose not to provide VAD will be empowered to exercise their duty of care to all their staff and residents.

¹ Note, these changes are proposed by an ethicist, not a lawyer. They are proposed in an effort to improve the ethical effects of the law, such that the law is better able to achieve the ethical principles that the bill claims serve as its foundation. The views of the author are his own, and do not represent the views of the Australian Catholic University, the Roman Catholic Archdiocese of Queensland, or any other agency associated with the Queensland Bioethics Centre.

List of Proposed Improvements with Explanatory Notes

The QLD VAD bill aims to balance individual choice and protection of the vulnerable. In its current form, and in the current state of health affairs in QLD, the bill does not do this adequately. However, several improvements could be made to ensure that VAD legislation in QLD actually furthers real choice and real protections against abuse.

- 1) VAD should only be legalised once just access is assured to both:**
 - a. reasonable treatment options in the public health system and**
 - b. high-quality palliative care.**

As of January 2021, over 23% of Category 1 Oncology patients needing treatment on waitlists were not seen within the recommended 30 days.² Palliative Care Queensland estimates that an extra \$275 Million per year is required to provide adequate access to palliative care services.³

Though the bill presupposes that a person requesting VAD is informed of treatment options and palliative care options [e.g. 5(a) and 7(2)], in the current state of public healthcare in Queensland, this is an artificial choice since adequate access to both treatment and palliative care is not yet assured.

Queenslanders who rely on government for the provision of public healthcare are therefore more vulnerable, and more likely to be facing the choice between VAD and a painful death. Those who can afford private health care may have more options. No government that genuinely cares about the well-being of all Queenslanders should accept this discrepancy.

- 2) A consultation with a palliative care specialist should be required to ensure that a person is adequately informed about what palliative care is and how it can help.**

The current bill does not require any of the health practitioners involved in the VAD process to have specialist knowledge of palliative care (Section 82), which begs the question of how well informed and how 'free' a choice for VAD would be.

Moreover, the bill requires a person to be suffering physically or mentally from a disease or from treatment for a disease [10(2)(a-b)]. But this criterion is entirely subjective, i.e., based on the person's experience [10(1)(a)(iii)]. Since these are precisely the elements of care that are the focus of palliative care, and are largely treatable by palliative care, a requirement to consult with a palliative care specialist should be a minimum to ensure that a person's choice is really based on knowledge about what treatment options there are for both physical and mental suffering. For this reason, specialist palliative care consultation should be required.

If palliative care is adequately provided for by Queensland Health, then there is no reason why this would be a barrier to access VAD for those who meet eligibility requirements. Moreover, since the criterion of 'suffering' in the bill is entirely subjective, a person who has had access to adequate treatment for pain or mental suffering can still be eligible for VAD, since they need only report that they are still suffering.

² <http://www.performance.health.qld.gov.au/Hospital/SpecialistOutpatient/99999>

³ <https://palliativecareqld.org.au/truechoicecampaign/>

- 3) **The person requesting VAD and the coordinating and consulting practitioners should be required to inform and consult with treating practitioners. Where the person's treating practitioner is not a specialist in the disease that would form the basis of the person's eligibility, then at least either the coordinating practitioner or the consulting practitioner should be a specialist in the disease, or they should be required to refer to a specialist.**

The current bill does not require the person requesting VAD to inform anyone other than the coordinating practitioner [22(1)(j)]. The bill does not require either the coordinating practitioner or the consulting practitioner to have expertise in the disease affecting the person (82). Nor does it require that a specialist be consulted. Section 21 (1) and (2) only says a coordinating practitioner 'may' refer if they are unable to determine eligibility. There is no requirement to do so. This means two things:

- a. The bill allows *non-experts* to make diagnosis of terminal conditions and life-expectancy prognosis for eligibility purposes [22(1)(a)]. This leaves far too much room for inaccurate diagnosis and prognosis estimates. This weakens the extent to which a person is making a truly informed decision.
- b. The bill allows *non-experts* to provide information about treatment options [22(1)(b)]. In addition to the problem of access for treatment in the public health system, this further imperils the extent to which a person is making an adequately informed choice about VAD.

Therefore, in the interests of both the person requesting VAD and the integrity of the coordinating and consulting doctors, the bill should require treating practitioners to be informed and specialist consultation to be sought if necessary. This would be in accordance with the *Hospitals and Health Boards Act 2011* (Qld) Sections 143, 145, 146(b), 147, 160. This is also in accordance with the Medical Board AHPRA guidelines set out in *Good Medical Practice* (2020), sections 5 and 6.

This should not be a significant barrier to access, since in most cases one assumes that people are either being treated by a specialist already or would want to be adequately informed by a specialist if they are not yet doing so.

Moreover, this will improve the integrity of the bill to protect the interests of people reliant on public healthcare, and those vulnerable to coercion, since health practitioners involved in the VAD process will have to account to a higher standard of proof with regards to eligibility than under the current bill.

Finally, this will make the bill's current inclusion of possible referral to QCAT (s99) more meaningful. At present, whilst referral to QCAT is possible, it is not clear how some of the most important people who might raise an objection in protection of a person who might be vulnerable to coercion [s100(c)] would come to know that the person is in the process of accessing VAD. A requirement to inform treating practitioners and consult specialists would widen the circle of parties who could raise concerns about eligibility, especially on grounds of capacity. This would therefore improve the integrity of the bill in terms of protecting vulnerable people, whilst at the same time protecting free choice by improving the quality of informed consent.

4) Reports to the Review Board should require evidence in support of the assessment of the coordinating and consulting practitioners

The bill requires that the coordinating and consulting practitioners file a report to the board confirming a person's eligibility to access VAD [24(2) and 35(2)]. However, the bill does not require any evidence; the bill only states that documents supporting the decision 'may' be attached [24(3)(b) and 35(3)(b)].

The provision of such evidence should be a requirement because this will both enhance the ability of the bill to protect vulnerable people, and improve the quality of information and therefore the quality of the free choice made by people accessing VAD.

There is little point in having a review board and a series of steps in the process of accessing VAD if there is no objective way of ascertaining whether the claim that a person is eligible for VAD is legitimate. In the current bill, the purpose of the review board is limited to determining whether all the steps in the process have been followed. Though the bill says that the review board could refer cases to the police, the coroner, the health ombudsman, and so on [117 (1)(c)], it is unclear upon what grounds they would do this other than procedural grounds. There is little in the bill that ensures the integrity of these steps in the process themselves.

In order to ensure the integrity of the coordinating and consulting assessments in a way that holds the relevant practitioners to account, and so that 117 (1)(c) and the penalties regarding providing misleading information to the board outlined in Sections 143-145 have some relevance, the practitioners should be required to provide evidence in support of the diagnosis and prognosis such that the review board would actually be able to assess the credibility of their decisions.

This does not create an unreasonable barrier to access but does strengthen protections of the vulnerable. It also allows the review board to conduct their assessments with a higher degree of certainty that people who access VAD are actually eligible to do so.

5) Requiring consultation with treating practitioners and requiring evidence for eligibility would enhance protections for people with mental illness or disability.

Under the current bill, mental illness or disability does not disqualify a person from eligibility for accessing VAD, provided other criteria are met (Section 13). Leaving aside the highly disputed notion that mental illness does not affect one's capacity to make decisions of this sort,⁴ there are no explicit protections for people who may be suffering from a mental illness or disability, where one might expect the bar for the capacity criterion to be higher.

Indeed, the bar around 'suffering' is extremely low, since there is no requirement beyond a person's own experience of suffering. In the bill, this suffering can be purely 'mental suffering' that results from a disease or treatment for a disease [10(2)(a-b)].

⁴ The bill refers to the Mental Health Act for its definition of mental illness. The Mental Health Act defines mental illness as "a condition characterised by a clinically significant disturbance of thought, mood, perception or memory."

Requiring consultation with treating practitioners would at least bring to light any mental health issues that might be impairing capacity so that the coordinating practitioner or consulting practitioner can also provide better information about possible treatment and palliative care including treatment for 'mental suffering' which is a key part of modern palliative care, and be better able to refer for expert assessment of capacity if necessary.

Requiring them to provide evidence of eligibility would at least mean they would have to note these mental health issues and provide evidence for why the person nonetheless had capacity. These measures will also mean that people who feel that a person with a mental illness or disability is being coerced or does not have capacity can raise it with QCAT.

In sum, requiring palliative consult, informing treating practitioners, and requiring evidence in reports to the review board, all contribute to protecting people with mental illness or disability that could affect capacity, whilst ensuring greater respect for individual autonomy by improving the quality of informed choice for those who are eligible.

6) A practitioner who objects to providing VAD should not be required to refer a person to another practitioner or service.

The bill requires a medical practitioner who refuses to participate in VAD to inform the person of another practitioner who provides this service or information about the official navigator service [84(2)(b)]. This requirement misunderstands the idea of a conscientious objection, and ultimately undermines the intention of the clause itself.

A person who conscientiously objects does so because they have reached a judgment of conscience that the practice in question is morally wrong. This judgment does not mean that they believe only that this is morally wrong for themselves, but that it is morally wrong for everyone. To provide information to someone about how they can do something morally wrong would make the provider complicit in the act of wrongdoing, and so providing such information would itself be morally wrong. It is for this reason that a person who is an accomplice to a crime is also treated as a wrongdoer under the law. So, to require a person to assist a person even by providing information under law is to force them to act against their conscience, which defeats the whole purpose of a conscientious objection clause in the first place.

Consider a mother who thinks the consumption of alcohol to be morally wrong or even just bad for your health. If her 18-year-old son asked her to give him alcohol and she refused, it would be absurd to say that by law she must refer him to the bottle shop down the road. Knowledge of bottle shops and how to access them is well within the capacity of an 18-year-old.

Similarly, given the concerns about ensuring just access to VAD and the bill's provision for a navigator service, and given the expectation that a person who wants to access VAD has decision-making capacity, it seems finding information about VAD and how to access it will be well within the capacity of an eligible person without requiring a referral from an objecting practitioner.

Thus, this provision would not limit access but would further protect the autonomy of objectors, which is in accordance with the intentions of the bill.

- 7) **Division 2: Participation of Entities should be revised so that entities who do not provide or facilitate VAD can effectively carry out their duty of care to the person requesting VAD, to other patients/residents and their families, and to employees.**
- a. **For entities in which the person requesting VAD is not a permanent resident,**
 - i. **no entity should be required to provide access to an external medical practitioner for purposes associated with VAD. Entities may be required to not hinder access to an official VAD navigator for information purposes at the request of a person in the entity's care. Section 90 (2)(b)(i) should delete 'registered health practitioner'.**
 - ii. **For requests, assessments, and administration, the bill should be worded so that the default position is that the person will be transferred temporarily or permanently [Sections 92(2), 93(2), 94(3)(a), 95(3)(a), 96(3)(a), 97(3)a]. Access within the facility should only be granted if transfer is not reasonably possible.**
 - iii. **The decision not to transfer a person for any of the steps should rest with the entity in consultation with the person in their care and not with the coordinating practitioner.**
 - b. **For entities in which the person requesting VAD is a permanent resident,**
 - i. **there is no need for the bill to specify that medical practitioners must be allowed access, since this is already the case under Federal law.**
 - ii. **However, in order that an entity can effectively carry out its duty of care, the bill should require that the entity be informed by the person requesting VAD and the relevant medical practitioners. At present, whilst the entity is required to admit medical practitioners, there is no requirement for residents or medical practitioners to inform the entity. Such knowledge would enable the entity to better care for the person in every other respect, and ensure that the person is acting freely and with capacity. They will also be better able to care for staff and other residents.**
 - iii. **Entities should be permitted to discuss and propose transfer for any or all of the steps of the procedures in line with the entity's policies (with which residents will be acquainted). The decision to transfer should be the entity's in consultation with the resident, not the coordinating doctor's decision.**
 - c. **In the event that it is believed that an entity is acting unreasonably towards a permanent or non-permanent resident—for example, where there is suspicion of forcible transfer of a person--then provision should be made for an appeal to QCAT.**

The bill currently makes a distinction between permanent and non-permanent residents. The former would apply primarily to residential aged care facilities, the latter would apply to primarily to hospitals, hospices and respite care.

In all cases, however, though the bill allows entities not to offer or participate in VAD, the bill requires these facilities to allow access by external medical practitioners for all steps of VAD. Moreover, all decision-making power rests, by default, with the coordinating practitioner (s86), not with the entity.

Regardless of whether it is permanent or non-permanent, under the present bill the entity must allow access by an external health practitioner who is providing information about VAD to a person requesting it [90(2)(b)] and allow access by an external medical practitioner (the coordinating practitioner) for the first, second, and final requests.

For assessments and administration decisions and administration, for non-permanent residents (which would affect primarily hospitals or hospices), the bill states that, in the first instance, the entity must take reasonable steps to transfer the person so that they can access the VAD process. However, this transfer can ONLY take place if the deciding practitioner (which in the bill defaults to the coordinating practitioner) deems it appropriate. The bill provides a number of criteria by which transfer could be deemed inappropriate, but all of these are in the opinion of the coordinating practitioner and there is no scope in the bill to challenge that opinion. Thus, in effect, entities in which the person requesting is not a permanent resident must still allow *all* elements of VAD to occur. Any possibility of transfer is at the behest of the coordinating practitioner.

For permanent residents (which would affect primarily residential aged care), the bill does not presuppose transfer as a first option for assessments and the administration decision, and makes NO provision for transfer for administration of the VAD substance. Rather, the first option is that the facility must allow access to the person for all elements of VAD. The entity is only required to take reasonable steps to transfer the person for assessment and administration decision to *and from* somewhere else to access VAD if the relevant practitioner is *unavailable* to attend in person. In other words, there is *no* provision for transfer of the person to an alternative facility, and all decision-making power rests with the practitioners involved in providing VAD and not with the facility or the person requesting it.

Thus, though the bill allows entities to say they object to or not provide VAD, the entities are powerless to prevent it from occurring in their facilities. This means that the bill does not take their objections seriously, and, moreover, weakens the protection of vulnerable people living in these facilities, since the facilities have no means of acting in those individuals' interests, including their free choice. Rather, the entities are entirely beholden to the decisions of an external medical practitioner.

Entities have a duty of care to their staff, to other residents (permanent or otherwise), and to the person requesting VAD. Under the current bill, entities are unable to exercise the duty of care effectively. The entities would be unable to protect their staff from exposure to VAD, even if many or all of them had chosen to work there precisely because it refuses to provide VAD. Similarly, entities would be unable to protect other residents from exposure to VAD, even if many or all of them had chosen to be treated or reside there because that entity refuses to provide VAD. Finally, entities would be unable to act in the interests of the person requesting VAD because all decision-making power regarding transfer rests with the coordinating practitioner (who may not be acting in the interests of the person requesting VAD, and who certainly has no obligation to act in the interests of the other people in the facility). Legalising the bill in its current form, therefore, would be irresponsible.

In a liberal pluralist democracy like Australia, premised as it is on respect for individual choice, it is necessary that any legalisation of VAD also make provision for those people in our society who want nothing to do with VAD. This is achieved firstly by ensuring that adequate access to specialised treatment and palliative care is available in the public healthcare system (which it currently is not). This is achieved secondly by ensuring that there are health and aged care institutions that not only clearly state that they will have nothing to do with VAD and will not subject a person to it, but that are also empowered to transfer when reasonable those people in their care who choose to opt for VAD. Only in so doing does a society adequately respect the full range of choices about VAD that the bill presupposes.

Finally, strengthening Division 2 in the way proposed does not create unreasonable barriers to access. The possibility of transfer is considered first, and where this is considered unreasonable by the facility, access will still be granted. However, by increasing transparency and with it the accountability of the coordinating and consulting practitioners (like the other amendments suggested already), it enhances the quality of the decisions made by people considering VAD. At the same time it increases the protection of vulnerable people, not only by ensuring that there are facilities in which people will never have to face the prospect of a subtle suggestion to consider VAD, but also because entities can act in the interests of a person whom they believe does not meet the eligibility criteria, or is being coerced, and refer to QCAT if necessary.