LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON VOLUNTARY ASSISTED DYING BILL
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Submission Cover Sheet

Inquiry into the Voluntary Assisted Dying Bill 2023

Submission Number: 059

Date Authorised for Publication: 12 January 2024

To the ACT Select Committee for the inquiry into the Voluntary Assisted Dying Bill 2023,

Thank you for the opportunity to respond to this legislation for inquiry. My name is Michael Chapman, and I am a palliative care specialist, and geriatrician working in Canberra. I am also active within clinical ethics and have specific academic roles and contributions focusing on VAD, dementia care, palliative care and decision making. I am currently employed within Canberra Health Services as the director of palliative care at Canberra Hospital, however, I am seeking to contribute to this inquiry in a personal capacity, as an ACT resident with specific training and interest in this area, rather than speaking for CHS or for the ACT palliative care services on any issue relating to VAD.

I'd like to begin by commending all involved in developing this important and well-balanced legislation for our community. While I've made several recommendations for your committee to consider I feel that this legislation has managed to achieve a balance of multiple complex issues. My congratulations for this achievement.

This legislation removes the need for prognostication as part of eligibility for VAD which has been a focus within the Australian Model. This change, in 11(1), relating to prognostication implies a greater emphasis on other criteria such as the presence of intolerable suffering and the determination of "advanced" condition for people who request VAD and who may be further away from an anticipated death. This is further complicated by the legislation clarifying that intolerable suffering can in "anticipation or expectation" 11(3)(a)(ii), creating a situation where a person with an advanced illness who is suffering due to an expected intolerable future may validly apply for VAD.

For people who may be earlier in their disease journey, and anticipating suffering in their future and wanting access to VAD the result of this is, in my opinion, a significant additional importance on the definition of an advanced condition and, as I will proceed to later, the determination of capacity. The determination of an advanced condition 11(4) defines this based on the deterioration of functioning and quality of life, the absence of available and acceptable treatments, and that the person is in the last stages of their life 11(4)(a-c). As above, the decision about whether a condition is "advanced" carries significant weight for decision making within the context of people who be earlier within their journey with progressing illness. Language denoting decline due to progressive illness and proximity to dying is notoriously euphemistic and contextual. Multiple competing definitions exist for even readily used terms and phrases (like for instance, "end of life"). For instance, "last stages of life" could be easily misconstrued as being associated with advanced age (akin to popularised work on the human life cycle and Ages of life) rather than, I assume, the intended sense that to be eligible for VAD a person who applies needs to be in a situation where they are preparing for dying and where dying is proximate, foreseeable and unavoidable.

While it would be reasonable to expect that this terminology will be further explored within regulation, there seems to be further need for this within legislation given the significant relevance of the phrase "last stages of life" to determining who should and who shouldn't have access to VAD within this legislative framework. Additionally, the definition of advanced based on an "individual's functioning and quality of life" having declined does not clarify whether this is based on the interpretation of that individual or based on the interpretation of the clinician determining whether their condition is advanced. This may, again, be highly relevant for people with earlier disease who may wish to access VAD. I would recommend further clarification of the intended meaning of "last stages of life" and whether the perception of diminished function and quality of life is based on the

assessment of the clinician or the person making the request could clarify how this legislation should be utilised in practice.

I would also recommend additional clarification of the role of supported decision making in decision-making processes in the ACT generally and within the context of VAD. 12(3)(b) discusses the need for capacity to be assessed with "adequate and appropriate support" . 16(3) highlights the need for "practicable steps for support", and the need to not assume that a person has impaired capacity if that has been determined in another area. These are reasonable steps which anticipate the potential, predictable challenges that may occur when people request VAD in the context of a risk of impaired capacity.

The legislation does not seem to clarify what "practicable" "appropriate" or "adequate" supports for decision making entail and specifically doesn't talk about the idea "supported decision-making" as a legal and clinical response to the complexity of making decisions when capacity is impaired or variable. There is an opportunity for further clarification here of what practicable supports mean and to what extent these should be provided. “Supported decision making” is a recent way of reconciling the ethical and legal complexity of decision-making in dementia through attention to moral justice (Behuniak, 2010; Nuffield Council on Bioethics, 2009). In essence this approach signals a move away from the historic focus on a decision-making surrogacy (where a decision-making surrogate is legally appointed through a variety of means for a person with impaired decision-making capacity) to providing support for a person with impaired capacity to be able to remain central to decision-making. As the committee will be aware in 2023 ACT guardianship and power of attorney legislation was changed to embrace a more explicit focus of the principle of supported decision making (Guardianship and Management of Property Act 1991 | Acts, 1991). This principle has not yet extended to a specific legal role within the ACT beyond the endorsement that support for decision making should be a component of surrogacy and the function of the ACT tribunal as far as I'm aware.

Supported decision has some specific conceptual and ethical advantages over the idea of precedent decision-making through an advance care directive as a way of supporting appropriate participation of people with dementia or cognitive impairment from another cause in VAD. The most critical of these is the presumed lower risk of a precedent decision for VAD through the use of an advanced care directive where that is a legal use of such a document seeming to be out of step with the occurrent preferences of a person with impaired cognition at the time that decision needs to be made. Put another way, there is risk with an ACD relating to VAD that the historic person would want to die but the current cognitively impaired person may not. Supported decision making is a mechanism which could, with further legal clarification and implementation, create an alternative response to this specific issue.

As a result I'd suggest, additional clarification of the nature of practicable supports for decision making within this legislation and additional consideration of legislative moves to clarify supported decision making within the ACT if there remains interest in exploring the potential for people with cognitive impairment and impaired capacity to have access to VAD processes.

While not specifically an issue for legislation I note that the legislation implies a need for a high degree of education for clinicians who are involved in providing VAD. Specific elements beyond the legislated elements of VAD assessment and provision include capacity assessment and the provision of information regarding available palliative supports. These tasks can be nuanced and complex when distress is high, particularly with additional issues such as the presence of cognitive

impairment as confounders. I'd note that for this to be safe and successful a significant amount of work will be required to support clinicians developing these skills in a feasible manner to enable safe implementation of this legislation.

I'd also note that my discussions with many VAD providers around Australia suggest that self-care and education to support understanding and working with grief are key skills which don't receive enough exposure due to their not seeming part of the legislated requirements for care. While it seems unlikely that these should feature in the ACT legislation I'd highly recommend these be part of further education and support packages developed within implementation.

Behuniak, S. M. (2010). Toward a political model of dementia: Power as compassionate care. Journal of Aging Studies, 24(4), 231–240. https://doi.org/10.1016/j.jaging.2010.05.003 Nuffield Council on Bioethics. (2009). Dementia: Ethical issues. Cambridge Publishers Ltd

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Thank you for considering these points and for your ongoing work in this important space.

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