

1 July 2021

For the Attention Of:

Health and Environment Committee
Parliament House
George Street
BRISBANE QLD 4000

Dear Health and Environment Committee,

ANZSPM Submission re: Voluntary Assisted Dying Bill 2021

The Australian and New Zealand Society of Palliative Medicine (ANZSPM) notes the important work the Health and Environment Committee (the Committee) is doing to inform Queensland Members of Parliament as they consider the Voluntary Assisted Dying Bill 2021 (the Bill).

ANZSPM is a specialty medical society that facilitates professional development and support for its members. ANZSPM promotes the discipline and practice of Palliative Medicine to improve the quality of care delivered to patients and families living with life-limiting illnesses. ANZSPM members are medical practitioners. Our members include Palliative Medicine Specialists as well as other medical practitioners, who either practice or have an interest in palliative medicine. As such, we have a particular concern and interest in the implementation of voluntary assisted dying (VAD) legislation across Australia and New Zealand.

Our Position Statement on Euthanasia and Physician-assisted Suicide is available on our website. We hope that this can inform the Panel's consideration of matters relating to the practice of palliative medicine more broadly, and in particular the specialty's potential intersection with practices enabled by the new legislation.

We also bring to your attention, and strongly support, the RACP submission into this Inquiry to which we have contributed. We would also recommend the following considerations in addition to those raised in the RACP submission.

ACKNOWLEDGEMENT OF THE RIGHTS AND NEEDS OF VULNERABLE POPULATIONS

ANZSPM acknowledges the safeguards proposed in this Bill to protect persons considering VAD from improper influence and coercion, however the elimination of this risk is impossible. ANZSPM shares the RACP's concerns about the potential for VAD to be abused, disadvantage underserved populations, expose health practitioners to professional risk, harm patients and families, and erode trust in the medical profession.

We reiterate RACP feedback regarding the expression of legitimate concerns for under-served individuals and groups around access to quality palliative and end-of-life care. It will be critical to the success of VAD implementation that relationships of trust within and between communities, as well as with the broader health system, are not jeopardised. Specific regard must be given to cultural and Indigenous experiences. Cultural concerns have been raised in the translation and dissemination of VAD information in certain communities. In Victoria, there have been advertisements placed for VAD in non-English newspapers, with associated translations that do not accurately convey the acts undertaken in VAD.

IMPORTANCE OF END-OF-LIFE AND PALLIATIVE CARE

We note that the Bill's principles are aspirational, as 5 (b), (c), (d), (f) and (g) have not been achieved in any current society. In addition, the assessment of one person's suffering as being eligible for VAD over another supports the idea that not all lives are equally respected. We note the importance of providing high quality care and treatment, including palliative care, at the end of life as a principle in the Act. Unfortunately, this does not occur at present and hence the argument for equity in end-of-life choices cannot be supported. Furthermore, the attempt to permit informed consent alongside the mitigation of coercion by health care workers is likely to negate the latter. Although the Act suggests clear and unambiguous expression of the first request, in practice we know that "wish-to-die statements", where people are expressing an emotion rather than an intent, have been perceived as VAD requests in Victoria.

However, the lack of medical education in palliative care, the taboo nature of the topic, and the poor communication skills of some doctors all hinder access to quality palliative care for many patients. Queensland should be cautious not to bridge these gaps with specialist palliative care services in the VAD patient pathway, as this could make them the 'gatekeepers' to VAD. Other misunderstandings would also be more likely, including accusations of 'delaying the process' being made at palliative care services which have the specific intent of ensuring ongoing high-quality care at end-of-life. It should be noted that reducing the conflation between VAD and palliative care has been an extremely difficult task in Victoria. This has been due to the lack of training in, and understanding of, palliative care and the utilisation of specialist palliative care services, especially in the community, to provide holistic care concomitantly with VAD patient pathways.

ANZSPM reiterates the RACP position that to ensure that funding committed to end-of-life care leads to sustained improvement in patient outcomes, it is imperative that all state and territory governments, including the Queensland Government, endorse palliative care and end-of-life care as a key priority for the National Cabinet. Appropriate palliative care services must be prioritised and funded across all age groups and settings, including an expanded presence in the community. End-of-life and palliative care cannot be ignored, as it spans multiple health sectors, including aged care, paediatric care, community care, disability care and mental health.

CONSCIENTIOUS OBJECTION

ANZSPM acknowledges that a physician's decision to assist patients under the new legislation should and will be informed by their individual conscience. Similarly, the right for institutions to assign themselves and participatory or not, in relation to VAD is important to uphold. ANZSPM considers that it is important to allow institutions and individuals to exercise these expressed positions, but that this raises complex issues that need to be fully explored and resolved.

Clarity on the stance of institutions, health care practitioners, or care providers will be essential for people navigating the VAD pathway with their families. Similarly, health care practitioners benefit from such knowledge, but service provision can be problematic, and staff will find it difficult to conscientiously object and not burden their colleagues. This part of the legislation should be reviewed, as it places conditions on the ability for staff to express their views freely. There are many levels of decision-making and governance involved in implementation of the legislation. Clarity in communicating conscientious objection will ensure an individual patient's rights can be exercised with full vision of the patient pathway and gaining this clarity should be a foundation principle in implementation planning.

Physicians and institutions should be required to work closely together to review current governance around practice and ensure an appropriate governance framework is established. In instances where there is conscientious objection, both communication and governance aspects should be closely and continuously monitored and evaluated.

ANZSPM draws the Inquiry's attention to the fact that, in jurisdictions where VAD has been implemented, some staff on specialist palliative care units have been unable to exercise their individual right to conscientious objection because of an overriding institutional position. Employee rights on transition to the new arrangements should be carefully considered. Guidelines should be provided to services that either oblige or encourage VAD services to consult with their employees, with a view to conferring rights to conscientious objection and/or compensation if departure from the organisation is the only feasible option for them.

The Queensland Inquiry recognises that conscientious objection may present issues in certain settings, for example, amongst objecting staff within a VAD-supportive hospital or hospice, and in cases where patients cannot be transferred to a supportive setting. We note that the Bill attempts to address some of these issues through its provisions that provide access to VAD advice and delivery on site through external practitioners in certain instances. For example, where transfer to another facility could cause serious harm, or where a patient's access to VAD might be adversely affected by the transfer. Allowing medical practitioners to enter and perform a procedure on a patient in an institution without any oversight, credentialing or governance of that institution is not accepted medical practice nor accepted patient care. This is not done in any other part of medicine, nor is it accepted by any institution. In this situation, it is important to ask who would be ultimately responsible for an adverse outcome and to firmly reject the possibility of procedures being performed outside of the governance and staffing arrangements of the patient's hospital or care facility.

We are also concerned that providing for both institutional and individual conscientious objection may conflate VAD with palliative care. For example, an organisation may decide to participate in VAD provision, but how would this affect a palliative care unit in that organisation? Every individual on the unit would need to conscientiously object to prevent VAD from occurring on the unit and thereby avoid any conflation between VAD and palliative care.

Queensland may wish to consider the percentage of physicians that have been actively participating in VAD in Victoria (which is anecdotally small) since its legislation came into effect. This may help establish likely professional willingness to engage with an intervention, as well as help to assess the size and scale of any practical issues arising from the exercise of conscientious objection.

DECISION-MAKING, CONSENT, AND SAFEGUARDS AGAINST COERCION

Coercion of patients will be difficult to safeguard against completely, however, we note that the Bill attempts to do this by providing multiple decision points and by enlisting a range of expert opinions in the VAD decision. A VAD service provider will only be able to safeguard against coercion if they have appropriate training, the support of other health service professionals and a strong and continuing relationship with the patient, their families and carers. We discuss these aspects of VAD implementation below.

EXPERTISE AND TRAINING REQUIRED OF PARTICIPATING PRACTITIONERS

Specialist palliative care training lasts three years, following the attainment of a Fellowship from a recognised College. Non-specialist palliative care providers usually have an average of a week of undergraduate palliative care education in their curricula, topped-up by available organisational postgraduate education. ANZSPM has been aware of the six-hour online education for VAD and its more medico-legal focus on the process of VAD.

The care for people who want VAD requires more than the current online training. It should be holistic and must be underpinned by a genuine and enduring relationship with the person. This is an important safeguard to avoid reliance on potentially simplistic assessments/reviews. If practitioners are to provide this end-of-life care option, then they should be the leading physicians for these patients and their families into the bereavement phase. If this holistic care needs to be provided by a VAD team, then this should be facilitated by the legislation and the level of resourcing made available for implementation. The reliance on palliative care teams should not be permitted, on the grounds of the conflation mentioned earlier. VAD practitioners can be supported via direct or indirect consultations with specialist palliative care services, but there must be a clear delineation of roles during the end-of-life care and after death.

ANZSPM therefore puts forward that those persons delivering VAD will require a high level of competency in communicating with patients that may extend beyond current training, to include a knowledge of:

- Health system pathways and the role of other professional groups in counselling for and delivering VAD, including when working with vulnerable populations
- Exploring the reasons for a VAD request with patients who may be depressive and/or dealing with difficult family circumstances, live in isolation, or have multiple comorbidities
- Practising clinical neutrality
- Detecting signs of coercion and reduced capacity.

In addition, there are many people within the health system who need to be made aware of the nature of palliative care and the potential positive outcomes for patients. This should be done as part of formal training and continuing education programs, including any training provided to those accredited to deliver VAD.

Educating the public will also be a priority. Within the Australian community, there is a generally poor understanding of the legislation and the alternatives to VAD that are available for dealing with their specific circumstances. Community education should also take account of the needs and circumstances of different cultural groups and vulnerable populations.

CONFLICT AND BEREAVEMENT SUPPORT

ANZSPM affirms RACP advice that support, counselling and mediation services must be available for individuals, families and the health professionals involved. This should include all persons who have been exposed to conversations, care and distress that are against their beliefs. Support in the bereavement phase is not well-delivered within the current health system. The introduction of VAD will place additional pressures on the system and the people within it, and if not dealt with, will lead to long term health and economic impact. In particular, these pressures must be considered as a 'new need' separate from palliative care which by its nature does not involve the same considerations, and it must be delivered by the new VAD providers including the proposed system navigator workforce.

MONITORING, EVALUATION AND EVIDENCE-BASED PRACTICE

ANZSPM recommends that implementation planning should include monitoring and evaluation of the patient, family and health professional experience. This will need to be expertly crafted and transparently reported to address these dangers and positively inform future practice. It is also important that rigorous and independent data collection occurs to ensure safe and robust evidence-based practice. Monitoring and evaluation should be overseen by an independent Review Board that considers issues arising from the first discussion (not the first request, because many misunderstandings and issues arise before the first request) and extend to include the bereavement of caregivers and family.

In summary, a rigorous monitoring and evaluation framework for Queensland's VAD implementation should be established and maintained by an independent monitoring body and should include measures of:

- Effective communication of arrangements for health practitioners and institutions when conscientious objection is exercised
- Quality of governance including nature and extent of changes made to institutional governance, at the level of each institution, as a result of the legislation's implementation
- Patient and caregiver experience, including indicators of coercion and the levels of regard for the medical profession during decision-making and including death and bereavement.

In the interests of ensuring reporting accuracy and the availability of research data, the current prohibition on listing VAD as a cause of death on a patient's death certificate must be re-examined.

COMPLAINTS HANDLING

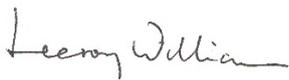
In the interests of patient and caregiver safety, an independent complaints body separate to the Review Board should be established for the reporting and monitoring of poor practice. Information collected should be publicly available, including for use in prospective research into VAD.

CONCLUDING COMMENTS

ANZSPM puts the case that provision of voluntary assisted dying services is not part of medicine and that the Queensland legislation and the implementation pathways developed for its implementation should acknowledge this. VAD is a major change in medical practice (contrary to the Hippocratic tradition) and at odds with any other drug intervention we offer. Although the intention may be claimed to be the same (to relieve suffering), the lethal dose prescribed or administered is not within the bounds of medical practice. The service should therefore be provided as a non-medical treatment even in instances where clinicians are involved. That is, the clinician clearly distinguishes between their VAD activities and their medical practice.

Several of our members have had direct experience with the implementation of similar legislation in Victoria and New Zealand, and you may wish to speak with them to discuss any matters that relate to implementation. In particular, ANZSPM members could assist in developing a robust understanding of the inter-relationship between the VAD Bill and existing palliative care and advance care directives in Queensland.

Yours sincerely,



Professor Leeroy William

President



Janice Besch

Chief Executive Officer