LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON VOLUNTARY ASSISTED DYING BILL
Ms Suzanne Orr MLA (Chair), Ms Leanne Castley (Deputy Chair),
Mr Andrew Braddock MLA, Mr Ed Cocks MLA, Dr Marisa Paterson MLA

Submission Cover Sheet

Inquiry into the Voluntary Assisted Dying Bill 2023

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ACT Ministerial Advisory Council for Multiculturalism (MACM)

Submission to the Voluntary Assisted Dying Bill 2023 Enquiry - conducted by the Legislative Assembly Committee Inquiry.

To whom it may concern, please find herein a submission to the 2023 Voluntary Assisted Dying Bill 2023 Enquiry on behalf of the ACT Ministerial Advisory Council for Multiculturalism.

About the ACT MACM:

The Ministerial Advisory Council for Multiculturalism is a significant community advisory group which represents people from culturally and linguistically diverse backgrounds who call Canberra home. The Council started their three-year term on 1 September 2023, and is granted a mandate by the Multiculturalism Act 2023, the Charter for Multiculturalism, and the Minister for Multicultural Affairs, Tara Cheyne MLA.

As a legislated group, the Council provides advice to the Minister for Multicultural Affairs on the aspirations, needs and concerns of Canberra's culturally diverse communities. They provide expertise and community engagement to direct the needs and priorities of the ACT Government to ensure Canberra remains a city where everyone can belong and participate.

The Council is a group with 11 members, who are culturally diverse, representative of the community and well-regarded by new and long-time Canberrans. These members are: Ms Izabela Barakovska, Dr Shanti Reddy, Mr Arun Bharatula, Ms Chin Wong, Mr Efe Momoh, Ms Ivapene Seiuli, Ms Lew Ching Yip, Ms Sukriti Kapoor, Dr Sultan Lubna Alam, Mr Timothy Sunwoo, and Ms Zakia Patel.

The MACM welcomes this opportunity from the ACT Legislative Assembly Committee Inquiry and emphasises that these are the views of the Council, and not of the ACT Government or ACT Public Service.

This submission is guided by the document, 'Summary of the ACT's framework for voluntary assisted dying.'

Contribution to the review:
The MACM met and discussed the Voluntary Assisted Dying (VAD) Bill 2023 with consideration to how the bill and its implementation would be interpreted, utilised, supported or challenged by the highly diverse multicultural community of the ACT and region.

Below, we have offered some views in response to the **VAD Framework**, to guide policymakers and legislators to consider the ways that multicultural people would engage with, or seek to engage with, the process of VAD.

1. The VAD process

Overall, the MACM agrees that the step-by-step process of the framework is reflective of legislation across other Australian jurisdictions and offers a regulated and considered process for when there is a need and desire for VAD. At minimum, this bill needs to allow for the same access and standard of care across all jurisdictions that currently allow for VAD. The VAD ACT bill must balance the needs of the community.

It should consider complex and co-locational patients who may fall under the categories of border-communities, inter-state medical care, or temporary residents.

Cultural elements: For many cultures, entering and leaving the world is incredibly important and often associated with traditions or procedures — cultural, spiritual, and religious. Working together with the person choosing VAD to ensure that any wishes they have for how they end their life are considered will be an important part of the process.

Scope: when considering the scope and eligibility of the VAD process, we have taken into account diverse community views given the highly sensitive nature of the topic, however, MACM members agree there is a need for VAD service in the ACT for those who qualify on the advice of medical practitioners. This needs to be a fully regulated process, with clearly articulated criteria to qualify, supported by strong clinical expertise, and safe access to assessment and service for those who need it and have exhausted other care options.

There is a strong sentiment for VAD to be offered only with serious considerations to the quality of life experienced by a person with a medical condition on advice of expert clinical guidance. Also, that the pathway of this service balances the right to an individual to choose and encourages the pursuit of clinical care and treatment where it is reasonable and available.

During our community consultation, we have received feedback to include the following additional services in the proposed VAD Bill, subject to meeting the essential medical prerequisites noted in the draft Bill.

- People with dementia (via vigorous advanced care planning processes)
- Young people (under 18) (with Gillick competence determination)
- People who choose to go through palliative care. People undertaking palliative care should not be excluded from accessing VAD — the two should be complementary.

Furthermore, the inclusion of a ‘cooling off period’ — window between the final approval and medication administered — should be based on a national standard, noting the

heaviness of the decision for some, and should not be drawn out for an extensive period of time.

2. **Language and self-advocacy**

There is a great emphasis to this Bill on the ability of an individual to self-advocate for their needs within the medical system. When considering the experience of multicultural individuals and families and institutions – medical, legal, political or other – there can be many barriers to effective and informed communication. When one is unable to communicate with medical professionals or people responsible for their care in their dominant language, or potentially at all, there opens up potential for miscommunication, misrepresentation, or criminal behaviour.

Where possible, MACM urges that the process and professionals involved with the VAD process implore the support of professional translators, alongside or in the place of, family translation, to ensure that the person choosing VAD is most clear on their right of choice and responsibilities. Given the highly interconnected and communicative nature of many multicultural communities, professionals should also consider where possible to consult with an individual on whether a translator is or is not a member of their cultural or local community, despite shared language. This would offer the choice of privacy for the individual and family.

Furthermore, the use of a professional translator enhances the protections of an individual engaging in VAD from interference from other parties (partners, family members etc.) who may apply for a person to choose this end-of-life process or not choose it.

3. **Clinicians and facilities**

Multicultural communities often have a different perspective on end of life. There is some hesitancy in seeking palliative care services, partly because of practical issues such as type of food and other amenities which are not tailored to meet expectations. It is highly desirable to encourage them to seek palliative care services in the first instance.

In addressing the eligibility criteria for VAD, it is imperative to consider the multicultural dimensions of our society. The sensitive intersection of palliative care and the process for requesting and assessing this service must be navigated with the utmost respect for cultural and religious diversity.

A significant portion of our multicultural medical community finds themselves at a crossroads, balancing personal beliefs and professional responsibilities in the face of this highly sensitive matter. The MACM recognises these challenges and strongly supports provisions that allow health professionals the option to abstain from participating in the process, should it conflict with their personal or religious convictions. Similarly, there is a

need for care facilities, especially those run by religious groups, to have the same option to decide whether they provide the VAD service.

There should be provision for seeking independent carers and practitioners, not just relying on family carers as they may not encourage pursuing VAD option, given the religious beliefs.

4. Intergenerational / Collectivist Decision Making

The highly interconnected nature of many multicultural communities, which can include collectivist decision making in a family or community and/or intergenerational living, means that there can be times where an individual chooses to engage in decision making with others in their life.

This more multilateral style of decision making requires that we consider the following:

- That the family or individual is not being pressured or influenced into pursuing VAD,
- That an individual is not pressured or forced out of their decision to pursue VAD where approval has been given from medical professionals, but also,
- That consideration to the collectivist decision making more common in multicultural communities, that there is great consideration for the way regulations around VAD might punish individuals or families who disagree with or seek to discourage an individual who has chosen VAD. Noting that family decision making in what can be a heightened emotional context must be considered very carefully with respect to what actions and / or consequences are or are not legislated.

5. Building trust

As related to other points in this submission, trust is an inherent part of the engagement with the healthcare system for any matter - particularly, as it is usually when a person is feeling vulnerable or is in ill-health. Where possible, a consistency in the people involved with an individual's end-of-life process can offer great comfort and support to the person and their community of support, as it facilitates a greater opportunity to build a relationship and trust. Building trust should be reflected as a key part of the process.

6. Declaration of death

The framework outlines that the Register of Births, Deaths and Marriages will record both the cause and manner of death - that the cause of death will be the relevant condition, with the manner of death recorded as ‘voluntary assisted dying’, and the death certificate only recording the relevant condition.

Where an individual wishes to uphold privacy in their choice to undertake VAD - for choices which in the multicultural community may include that of pressures of family, community

and faith - it is valuable to consider the impacts of the public record of VAD. It is important that this be communicated to the individual as part of the VAD process, particularly if their wishes for confidentiality conflict with this process.

Furthermore, clarification on whether this impacts the life insurance of an individual should be made clear as part of the administrative process of VAD in the decision-making phase.

7. Costs associated with VAD

MACM would seek clarification on the costs of VAD - both, in relation to the public health care system, and on the person choosing the VAD. Given the mixed views in the community - due to diverse cultural, religious and spiritual beliefs - on VAD, it may not be appropriate for VAD to be wholly funded by taxpayer budgets or the public healthcare system. Noting however, that as with treatment offered for other illnesses related to drug use, smoking or alcohol, which may also have mixed support from multicultural communities, that an individual's financial circumstances should not be a barrier to receiving care or services, irrespective of cause.

Furthermore, given the addition of this service to the ACT healthcare system, MACM suggests that this activity be fully resourced, including staff and the system to administer the VAD process from start to end. It is essential to ensure that addition of VAD service should not add further pressure to a health system which is already stretched.

8. Community and family education

In acknowledging concerns of the multicultural community that the VAD bill may encourage suicide or suicidal thoughts, particularly in vulnerable members of the community, MACM encourages clear education and awareness of the intention, eligibility and impact of the process be made available in multilingual and multimodal formats. It would be valuable to include as many major and minority languages as possible in a kind of introduction to VAD, to be consistent with the efforts and offerings of community education by other states and territories. It is key for this information to be ACT specific, to account for differences in the process, procedures and regulations.

This education piece is an opportunity to highlight that there are clear guidelines, regulations and eligibility criteria around the VAD process, and it is for those who are experiencing a significantly reduced quality of life due to relevant and diagnosed medical condition/s (terminally ill condition). This could take form in a handbook for community (and health professionals), but also in-person information sessions to support open conversation, building awareness, and supporting a ‘single source of truth’ regarding VAD. Ultimately, this will help individuals and healthcare practitioners make informed decisions.

This also lends itself to noting the overall heightened sensitivities around the VAD bill with respect to some of the highly diverse religious beliefs and family frameworks within the

multicultural community, and the need to consider how this may impact an individual or family experiencing or being relationally impacted by the choice of VAD.

For any further community engagement on VAD or other matters- especially on more sensitive policy making such as this - MACM would also like to encourage the inclusion of multicultural specific roundtable discussions as part of the consultation process. This will ensure that the ACT's multicultural community of highly diverse opinions, ideas, needs and lived experiences, have more opportunities to engage with the decision-making process.

Thank you for this opportunity to contribute a submission to shape the implementation of the ACT Voluntary Assisted Dying Bill.

Yours sincerely, on behalf of the Ministerial Advisory Council for Multiculturalism,

Ms Izabela Barakovska (Chair)

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03/12/2023