



LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON END OF LIFE CHOICES IN THE ACT

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Submission Cover Sheet

End of Life Choices in the ACT

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Submission to the Inquiry on End of Life Choices in the ACT

Canberra Multicultural Community Forum Inc. (CMCF) is pleased to take this opportunity to make a submission to the Committee Inquiry on End of Life Choices in the ACT; from the multicultural community's perspectives.

About CMCF

Canberra Multicultural Community Forum Inc is the recognised Peak body representing more than 110 ethnic and associated community organisations in the ACT and its surrounding areas. CMCF was established in December 2005 to have a unified voice and a single peak body to promote the common interests and articulate the purpose and direction of the multicultural community in the ACT. The Forum acts as the multicultural voice of ACT.

CMCF held a community conversation evening session on 30 January 2018 to hear and share the different views associated with the proposed committee inquiry into the choices and management of end of life from the multicultural community's perspectives.

CMCF welcomes the Inquiry into 'End of Life Choices' as an opportunity to explore issues of great importance to the multicultural community, reflecting on its cultural, faith and religious beliefs.

Please note that Canberra Multicultural Community Forum does not have a policy that supports "voluntary assisted dying". The multicultural communities in Canberra have a wide range of religious, cultural and personal views on this issue. Within individual communities there can be a wide range of views and beliefs. CMCF sees its role as presenting the breadth of views expressed during our community conversations.

The Terms of Reference established to inquire into end of life choices in the ACT are:

- (a) current practices utilised in the medical community to assist a person to exercise their preference in managing the end of their life, including palliative care;
- (b) ACT community views on the desirability of voluntary assisted dying being legislated in the ACT;
- (c) risks to individuals and the community associated with voluntary assisted dying and whether and how these can be managed;
- (d) the applicability of voluntary assisted dying schemes operating in other jurisdictions to the ACT, particularly the Victorian scheme;
- (e) the impact of Federal legislation on the ACT determining its own policy on voluntary assisted dying and the process for achieving change; and (f) any other relevant matter;

In this submission, CMCF will set out some of the key themes identified during the community conversations and recommendations for consideration by the Inquiry Committee.



Canberra Multicultural Community Forum (CMCF) Incorporated

Chair Chin K WONG

CMCF believes that the community needs to openly discuss death and dying to recognise that dying is a natural and expected life journey.

This submission was prepared by Volunteers from CMCF and contributes the views of the multicultural community. CMCF welcome this opportunity to contribute to this Inquiry and engage our members on this important topic of end of life choices.

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Yours sincerely

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Themes emerging from the community conversation that everyone can agree on.

1. Palliative Care – supporting the multicultural community

Currently multicultural community members are under represented both as Palliative Care Volunteers and as service users. CMCF recommends that more resources be made available for Palliative Care and for the ACT Government to develop a comprehensive, holistic, fully funded, culturally competent palliative care program specifically targeting the culturally and linguistically diverse multicultural communities, with options of being cared for at home, residential care or in special health care facilities during the end stage of life, and with a choice of secular care.

CMCF would welcome the opportunity to work with Palliative Care and train a group of multicultural volunteers and peer educators. Multicultural communities need a better understanding of palliative care to be more likely to use the excellent palliative care services available in the ACT.

The availability of secular palliative care for residential care in the ACT is important for a multi faith community. Also, if the legislation is enacted there must be palliative care provided by organizations who do not actively oppose end of life options.

2. Increasing Cultural Competency within the Health system.

Planning to address the needs and the participation of the multicultural communities must be incorporated at the very beginning of the discussion of this issue and other important issues within the health system.

There is concern about the current level of misunderstandings that can occur between healthcare providers and multicultural individuals and communities in a health setting. The level of overall health literacy was reported as very low in some multicultural communities. It was felt current health education was not working for some communities. This legislation would introduce a new level of complexity to an already complex system. To introduce Voluntary Assisted Dying into a health system requires a high level of trust in that system. Cultural competency and increasing multicultural communities' understanding of the health system is an important aspect of that.

- Promoting person centered care with individualized treatment and case management will assist the healthcare system to provide individualized care that meets the needs of individuals holistically from a family, cultural, religious and community point of view.
- CMCF recommends that a comprehensive education program be established for health care professionals about end of life choices and the legislation and its application to 'End of Life' care in the context of the needs of multicultural communities.
- Increase the level of cultural competency within the Health system through consultation with multicultural communities and ongoing PD with staff.
- Better access to health information overall is important. Including translated health materials

3. Broader Community Discussion and Consultation about End of Life

CMCF recommends that the ACT Government undertake wide community consultation to assess the views of communities about voluntary assisted dying and the current practices utilised in the medical community to assist a person to exercise their preference in managing the end of their life. This consultation should include the examination of futile treatment and the acceptance of death as a normal part of life.

Multicultural community members are underrepresented in using Advanced Care Planning and further outreach and education should be supported to address this. CMCF recommends the promotion of a national approach to advanced care planning legislation including the development of a common template for advanced care directives. Individual wishes set out in Advanced Care Plans should be implemented.

4. Support for the Multicultural strategy within the Victorian legislation

The following points are from the Victorian legislation and should be included if end of life choices legislation is adopted in the ACT:

Only accredited and independent health interpreters should be used in any end of life process. Resources are to be developed in plain English with accredited translations into community languages, including Auslan.

Support, counselling and referral to culturally competent palliative care is to be provided at the initial verbal request phase.

Without access to proper information in people's own language communities cannot be properly informed and able to make their own decisions.ⁱ The Victorian legislation had multicultural resources available during all stages of the process.

This is the broad discussion emerging from the community conversations around the Terms of reference

Statements or questions from participants

- ✚ “Does it have to be a medicalised process? Could it be done at home? As in some other countries.”
- ✚ “There should be choices for people to make their own decision about when they want to die so people who want to die are not tempted to do things alone and without proper support.”
- ✚ “If the person has the capacity to make the decision they should be able to do so.”
- ✚ “From the Jewish point of view life belongs to God. But every person has free will to make their own decisions.”
- ✚ “Dying is normal it's part of life. People should be able to choose how they leave that life.”

- + Participants also discussed communities who do not tell the loved one they are dying. It is felt it would be too much for the person to know and be stressful and worrying for them. ⁱⁱ

- + *Another participant discussed the difficulty in their community of being straightforward about anything. It was just not done. The participant gave an example of a family who had a beautiful young child who had a terrible accident. The community leaders were called in to intensive care to discuss how the family could be told that their child was dying and there was no hope of recovery. The participant said it was not possible to tell the family this information. There is a very firm belief in miracles and acts of God even in completely hopeless situations. This community would probably oppose legislation both for themselves their religious group and for other people in the community as well.*

- + The overall feeling was that there was generational difference with younger people better educated more likely to be supportive of this type of legislation but with a high level of concern from older community members who would see it as breaking tradition moving away from their community and religion and into a more western influenced lifestyle.

- + *A group of participants felt that their community would not support voluntary assisted dying and wanted to clarify if their church would bury someone who had participated in a voluntary assisted dying process. There were two areas of concern; that younger community members would be more supportive of and possibly participate in a voluntary assisted dying process for themselves. Being supportive of change would be challenging for older community members who would see that as young people moving away from their culture and religious beliefs into a more Western lifestyle. Choosing to participate in the process of Voluntary Assisted Dying would be against the beliefs and practices of the older generations and the more religious people in the community.*

Their church would possibly refuse to conduct the funeral and burial of the person. The second concern from the older generation was a fear that they could feel pressured to participate in a voluntary assisted dying process so that they were not a burden to the family either financially or at the care level. This cultural and religious community would oppose the legislation and would not find it acceptable for other people in the community either.

- + There was a comment that the Victorian legislation has many checks and balances which was reassuring. Some participants felt that less than six months to live was too short and should be less than 12 months to live to be able to qualify for the program.

- + There was discussion about the current law which prohibits anybody from assisting in a suicide of another person. Participants felt this law could be changed so that people did not have to die alone because of the risk of implicating someone else in their death.

- ✚ Some communities entrust the medical profession with great respect that could be jeopardised if assisted dying legislation were adopted. There are concerns about medically assisted dying in some communities. It could be interpreted as “killing” by the respected medical professional. It is not acceptable to be the person to assist their loved ones to exercise their preference for assisted dying.
- ✚ Concerns were raised about the operations of Claire Holland house and the religious basis of the service provided.
- ✚ The role of honesty about an individual’s condition varies within the multicultural community. Some families and communities will not discuss the fact that a person has a terminal illness and that information is kept from the person who is dying.
- ✚ Some communities have a very strong religious basis for their practices and beliefs that may include the concept of suffering in this life to have a better life in heaven or the next life.
- ✚ Some individuals and communities believe strongly in miracles and never give up hope.
- ✚ It was noted in some countries of origin and anecdotally in Australia some communities have a hidden high rate of suicide of older and sick community members who do not want to be a burden on their family. The implications for this legislation are unknown.
- ✚ It was reported there can be a level of frustration within multicultural communities. Individuals are actively seeking religious guidance on issues such as voluntary assisted dying or Advanced Care Planning. Some community members report approaching religious leaders for guidance or assistance and being frustrated at getting no response or no assistance and no understanding from the leaders of the religious organization about current issues that are coming up for individuals and communities within Australia and the ACT. CMCF would encourage specific education and engagement of religious communities and leaders.

Case studies

Case Study 1: *A recent suicide where the person went to Mexico to source drugs was very upsetting. Family and friends felt he had gone too soon and would have lived many more useful years. The person had a cognitive decline disease and could feel himself fading. He felt he had to do something before he lost his marbles completely and might not be able to do it for himself.*

He did not want to live as his Father had done with 15 years not knowing anyone and in a Nursing home incontinent, in nappies with no dignity, unable to feed himself, or watch TV or have any type of life. Friends felt if he was confident he could end his life when he chose he would have lived on. He knew about the Victorian Legislation but thought he would never qualify. He was already having trouble with decision making. He felt he would be declared incompetent then barred from a Voluntary Assisted Dying process. Even when it was his clear wish.

The police investigation after the death was intrusive and unhelpful because the circumstances were clear. The person had gone to great lengths to protect his family from being implicated in his death. The family was devastated by his decision but felt they could not stop him and felt it was tragic that he had to die so early and completely alone.

The friends and family want a system that can accommodate people who have a disease that will end their lives and want to end their lives but are not suffering from a terminal illness like Cancer that can have a 6 or 12-month end date. Cognitive decline can be terminal but usually progresses slowly. Many people are afraid of continuing to live in a body but without themselves present in their own mind. How can this circumstance fit into the proposal?²ⁱⁱⁱ

Case study 2 (this was reported as an example by a participant. It did not occur in the ACT)

In a Sydney hospital, the doctor said to the professional interpreter tell them they're going to die. The interpreter argued with the doctor saying it is not appropriate to tell the person like that. The doctor said you're just the interpreter -do what I say -tell them they're going to die. The patient who did not understand English was becoming more agitated and saying what are you saying why are you arguing with him? The doctor says to the Interpreter- we're busy -I don't have time- TELL him he is going to die! The Interpreter refused and said family needed to be told first and must be there for the conversation with the Patient. The Doctor was extremely angry at having his instructions refused. He was the professional and said "Do as your told- you're just the Interpreter."

This case studies illustrates the need for cultural competency within the health system, mutual respect and cooperation between the Professional Health Interpreter and the Medical Professional.

This process would hardly be acceptable in any context and demonstrates the pressures of poor practice, lack of time and lack of insight into patients' needs by a medical professional.



Footnotes

ⁱ Examples of excellent Victorian resources available in many languages.

<http://healthtranslations.vic.gov.au/bhcv2/bhcht.nsf/PresentDetail?Open&s=End of life and palliative care services>

<http://healthtranslations.vic.gov.au/bhcv2/bhcht.nsf/PresentDetail?Open&s=Victorias end of life and palliative care framework - consumer summary>

ⁱⁱ Particular communities are not specifically identified for beliefs or attitudes because the participants did not feel like they were representing their whole community. Most participants felt there was a wide range of views within their own communities. Some communities had concerns and questions. These are included in the discussion without being attributed to a particular community.

ⁱⁱⁱ The case studies are a true reflection of the intent of the conversations that generated them but have been changed so no individual or community can be identified in a “small town” like the ACT.