HealthCare Consumers

Secretary, Select Committee on End of Life Choices in the ACT,
Legislative Assembly for the ACT
GPO Box 1020
CANBERRA ACT 2601
Email: LACommitteeEOLC@parliament.act.gov.au

Re: ACT Legislative Assembly Select Committee Inquiry into “End of Life Choices in the ACT”

The Health Care Consumers’ Association (HCCA) was incorporated in 1978 and is both a health promotion agency and the peak consumer advocacy organisation in the Canberra region. HCCA provides a voice for consumers on health issues and provides opportunities for health care consumers to participate in all levels of health service planning, policy development and decision making.

HCCA involves consumers through:
- consumer representation and consumer and community consultations;
- training in health rights and navigating the health system;
- community forums and information sessions about health services; and
- research into consumer experience of human services.

HCCA is a member based organisation. We consulted with our members through the HCCA Health Policy Advisory Committee and two focus groups held in February 2018, along with comments and experiences received in response to a request we made to our members for input.

Thank you for the opportunity to put forward a consumer view on this important topic and share our consideration of the issues around end of life choices, as they pertain to those accessing health care in the ACT.

Yours sincerely

Kathryn Dwan
Manager, Research & Policy

23 March 2018

HCCA Submission to the ACT Legislative Assembly: Select Committee Inquiry into End of Life Choices in the ACT

Submitted 23 March 2018

Contact: Darlene Cox
Executive Director
02 6230 7800

Executive Summary

Living is messy and so is dying. Despite our best efforts, we can rarely control the circumstances around death. This inquiry has opened an ongoing conversation about death and dying, but also quality of life, health care and palliative care. HCCA considers this to be a useful opportunity to make known consumer views and needs around end-of-life choices. Understandably, there are a wide range of consumer views, although most would agree that information about, and access to, a full range of **palliative care services** would allow more people in the ACT to receive high quality, safe and person-centred palliative care and end-of-life care in the place of their choice.

Consumers' preferred terminology is the **"termination of life on request"**. Therefore, throughout this submission we will refer to termination of life on request rather than "voluntary assisted dying". The rationale is provided under the sixth term of reference.

HCCA supports **consumer rights to be in charge of their end-of-life choices**. Those **choices depend upon individual circumstances** and the availability of good quality information that includes palliative care, whether provided in one's home or in a dedicated palliative care facility.

Improving **health literacy** and promoting effective and supported use of **Advanced Care Planning** provides opportunities for consumers to consider the issues for themselves, and to articulate their own wishes for future health care.

HCCA is aware that health professionals continue to make life or death decisions on behalf of consumers without appropriate consultation. For some, this reflects, in part, a culture of **ageism** making it difficult for older consumers to feel empowered, proactive and an equal partner in their care.

Significant legislative changes would need to be made at the Commonwealth level to enable the ACT to enact its own legislation for the termination of life on request. If legislated it would expand the end-of-life choices available for consumers in the ACT. This process of legislative change, even if achievable, would take considerable time to set in place. However, it would provide an opportunity for the ACT to monitor the implementation and effect of the Victorian legislation and better resource local palliative care services.

Regardless of what happens with ACT legislation HCCA suggests that there is real value in the ACT developing a **Charter for care of adult patients at the end of life**.[i] Such a charter would set out a commitment to provide the highest quality of care and support for people who are nearing the end of their life and help people live as well as we can for as long as we can. This Charter would start ensuring that both consumers and health professionals have a clear understanding about the expectations for end-of-life choices in the ACT.

Recommendations

Due to the prevailing Commonwealth legislation (Euthanasia Laws Act 1997), this Inquiry is the start of a conversation about end-of-life choices that has no straight lines or easy resolution. HCCA proposes the following recommendations be considered in relation to end-of-life-choices in the ACT:

1. Consumers want to be the ultimate decision makers about their end-of life care.
2. Consumer decisions depend upon the context, and the focus should always be on an individual's choices and their specific circumstances.
3. Consumers need access to a complete range of information about end-of-life choices.
4. Consumers want access to good quality palliative care services, either at home or in a dedicated facility. NB Currently demand for services is more than can be supplied for consumers in the ACT.
5. Health literacy improves communication. For this reason, steps should be taken to improve the health literacy of consumers, carers and health professionals.
6. Advanced Care Planning (ACP) needs to be encouraged and promoted to consumers, and used appropriately by health professionals to enable individual plans for end-of-life care.
7. The ACT needs a public campaign to affirm the value and contributions to our society of older people and people with disabilities.
8. The ACT should develop a charter for end-of-life care and choices in the ACT.

Responses to the Terms of Reference (TOR)

TOR 1 – 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;

The ACT Government, health care consumers and health professionals have an opportunity to work together to overcome systemic barriers that currently prevent the medical community from consistently assisting people to exercise their preferences in managing the end of their life. Specifically, ACT Health care consumers would welcome:

1) **An expansion of home-based palliative care services, to meet current and future demand,**
2) **Dedicated palliative care areas in all ACT hospitals,**
3) **More overnight respite opportunities, to better support people caring for a loved one receiving palliative care at home,**
4) **Training for relevant clinical staff in ACT hospitals in the palliative approach and shared decision-making,** and
5) **An expansion of hospice care**, including exploring the establishment of a second hospice, and identifying hospice models that would meet the needs of people who cannot receive care at home, but who require palliative in-patient care over an extended period of time.

These changes would allow more people in the ACT to receive high quality, safe and person-centred palliative care and end-of-life care in the place of their choice.

These recommendations are made on the basis of research HCCA undertook in 2017 with consumers and carers who have used ACT palliative care services. Health care consumers and members of the ACT Health Palliative Care Clinicial Network provided input to refine these recommendations and prioritised their importance and feasibility. The recommendations above are the five recommendations that were considered most important, and feasible, by consumers and clincians who participated in this process. The full report, *Consumer and Carer Experiences and Expectations of Home-Based Palliative Care in the ACT* is attached at Appendix.

People in the ACT value our publicly-funded specialist palliative care services very highly.[1] In large part, consumers value these services because they provide care that, more often than not, assists us to exercise the following preferences:

- To receive care in our **preferred location**;
- To be the principal **involved in decision-making about the goals of treatment and our care plan**;

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[1] These include the Clare Holland House hospice managed by Calvary Health Care ACT, the Calvary Health Care Home-Based Palliative Care Service and the specialist palliative care nursing staff and doctors working from The Canberra Hospital and Calvary Public Hospital.

- To receive **care that responds not only to our medical circumstances but also to our practical, emotional and psychosocial support needs** as well as those of our carers/ loved ones, including by considering our culture and unique personal circumstances; and
- To receive care in which **health professionals consistently communicate clearly, in a timely way and with sensitivity** about our circumstances.

There is strong support among health care consumers for palliative care services, but consumers also know and require that access to palliative care, and consumer experiences of palliative care, can be improved significantly in the ACT. Consumers told us:

> *She had palliative care in the home along with help from family and felt very looked after – it was a very dignified death.*
>
> *I think everybody who wants to go somewhere like Clare Holland House should be able to do that, it's the next best thing to dying at home… I was comforted in my heart that that was the best that could be offered [in end-of-life care].*
>
> *As a family member, [my experience of palliative care] gave me a sense of being comforted emotionally as well as physically.*
>
> *A society that rations end-of-life care has got its priorities wrong – the point is that end of life is one expereince that everybody's going to get – why not make it a good one.*

Our consultations with consumers also indicate strong support for the ACT government to work towards termination of life on request legislation.

There is evidence to suggest that resources for palliative care increase in places where termination of life on request has been introduced, because safeguards in such legislation "mandate… the improvement and rapid development of palliative care services"[ii]. With termination of life on request legislation now in place in Victoria, it seems probable that similar legislation will be introduced in more Australian jurisdictions over time. To make good use of the delay involved in the anticipated eventual change to the Euthanasia Laws Act 1997 (Commonwealth) the ACT has an opportunity to invest in palliative care services *ahead* of this probable change; and to ensure that people who receive end-of-life care here routinely experience high quality, safe and person-centred palliative care, ideally in the location of their choice – *now,* as well as providing time for robust community discussion.

TOR 2 - ACT community views on the desirability of voluntary assisted dying being legislated in the ACT;

Feedback from the two HCCA consumer focus groups was generally in favour of termination of life on request, while recognising that the issue is still contentious, and there are a wide range of consumer views on these issues, some of which are contradictory. Some comments were:

- Australia is a secular society and legislating for termination of life on request is consistent with this reality.
- There was strong support for self-determination, that is, the right to make choices for oneself regardless of one's circumstances. For instance, an individual may be depressed but that doesn't mean we aren't capable of thinking clearly about our choices.
- It would allow people self-deliverance from unbearable pain and suffering, both physical and mental.
- It would enable the person to choose a legitimate path with dignity, rather than having to take extraordinary steps (and often counter-productive methods) to end their life. Sadly, unsuccessful suicide attempts may leave the individual in a worse condition, while other methods (eg. choice to abstain from food and starve to death) can be traumatising for family/friends/carers.
- It may relieve the stress for family/carers because the responsibility for the end-of-life choice is assumed by the individual, rather than others feeling pressure to take part in, or even observe, an act that is currently illegal and/or they personally do not agree with.
- The termination of life on request should only be available to competent adults. HCCA acknowledges that this excludes certain groups, particularly children and some people with severe disabilities.
- The role of religion and spirituality is important. For example, there may be consequences of a successful suicide, such as if there are religious restrictions for a burial service can be provided when a person has suicided.
- Many did NOT want the legislation to specify a timeframe in which death was expected and therefore end-of-life treatment would be sanctioned. The means for predicting end-of-life timeframes are inexact and unreliable. The choice for termination of life on request should be able available to people enduring unbearable pain and/or suffering, whenever they have had enough of living.

TOR 3 - risks to individuals and the community associated with voluntary assisted dying and whether and how these can be managed;

Poor communication among consumers, carers and health professionals is a major risk. This could relate to a range of aspects associated with termination of life on request, namely the key rights of patients and consumers when seeking or receiving healthcare services (Australian Charter of Healthcare Rights[iii]). In particular, there could be poor communication around the rights of “access” and “respect”. Examples might be where a consumer is not made aware that termination of life on request, or even a range of palliative care services, are options that can be accessed in a range of end-of-life choices, or where a consumer has in place an Advanced Care Plan that is not respected.

The issue of poor communication leads into another risk identified by consumers - **inadequate or inaccurate information**. There was concern that those who might choose termination of life on request may not be given enough information (or inaccurate information) about the process, and as such might not be able to make a fully informed decision. There may be consumers who are inadequately informed about the options available to them, meaning that without sufficient information they are unable to fully consider their options, including termination of life on request.

Consumers also told us that they need the **flexibility to change their mind at any point** in time, if that is their choice. Consumers don’t want to be disempowered.

There was concern from consumers about the possible **lack of sensitivity to cultural and religious traditions** in relation to termination of life on request. Health professionals, in particular, need to be aware of the divergence of views on these issues, and that while there may be legislation for termination of life on request, people’s cultural and religious preferences may otherwise limit their end-of-life choices.

These risks around communication, information and cultural/religious sensitivity may be managed via training, education and awareness campaigns to improve health literacy amongst consumers across our community, as well as supporting skill development for health professionals in these areas.

Some concern was expressed by consumers that ageism and a **lack of social value** placed on older people might lead to people feeling pressured to choose termination of life on request inappropriately. There was also concern that pressure to choose termination of life on request inappropriately could potentially extend to those with disabilities or those who feel they are a burden on their families.

TOR 4 - the applicability of voluntary assisted dying schemes operating in other jurisdictions to the ACT, particularly the Victorian scheme;

Most consumers felt that the Victorian *Voluntary Assisted Dying Act (2017)* had strong checks and balances. However, a small number felt that these checks were unnecessarily strong, and that the time taken to meet all the requirements under the legislation could unduly extend suffering. In fact, a focus on managing risks may result in losing sight of the individual. Conversely, one consumer felt that the conservative approach adopted by Victoria was designed to assuage community anxieties and therefore served a purpose.

In our focus groups, a number of consumers felt that the Canadian model[iv] known as "Medical Assistance in Dying", has more of a consumer focus, with fewer hurdles to clear than the Victorian model. The Canadian model doesn't require that a person be expected to die within 12 months, so it isn't limited by a timeframe; and it retains a greater focus on the suffering of the individual.

TOR 5 - the impact of Federal legislation on the ACT determining its own policy on voluntary assisted dying and the process for achieving change; and

Without changes in Federal legislation, the current law provides that the ACT is unable to enact laws about termination of life. Many of the consumers we consulted seek a change in Federal legislation that would allow the ACT to make its own laws on this issue.

TOR 6 - any other relevant matter.

Terminology

In our consultations with consumers the issue of terminology was important. **"Termination of life on request"** was the term preferred by consumers. It was seen as empowering and encompassed the notion of refusing medication in order to die of natural causes. The term "Voluntary Assisted Dying" places the consumer in the less powerful position of asking for *assistance* to die, rather than *requesting* a service they want.

In general, consumers are in favour of unambiguous language (i.e. death and dying). However, cultural and religious sensitivities need to be respected. For instance, in some cultures it is not appropriate to speak of death and dying. Consumers in our focus groups also felt that to use the term 'suicide' has too many negative associations, and noted that suicide is not condoned in some religions.

Advance Care Planning

Advanced Care Planning[v] can be a powerful tool for consumers to ensure we are able to receive care that is consistent with a person's goals, values, beliefs and preferences. It prepares the person and others to plan for future health care, for a time when the person may no longer be able to communicate those decisions.. Termination of life on request, if legislated in the ACT, could be nominated by consumers as a part of their Advanced Care Plan (ACP).

Consumers told us the following about ACPs:

- These are important documents that open conversations about an individual's care preferences with their family and medical staff.
- It's important to keep this conversation ongoing in case things change and one are no longer able to communicate your wishes.
- It is advisable to have multiple easily accessible copies of your Advanced Care Plan, including one for the paramedics.
- People need to choose an advocate or enduring power of attorney very carefully. They need to be someone who respects the individual's views and won't impose their own.
- Having an Advanced Care Plan helps ensure your wishes are not dismissed.

> *At 92 she should get to make that decision. It shouldn't be a medical choice. It should be the individual's choice.*

ACPs are not foolproof! There can be well-intentioned adherence to the ACP which can undermine the person's intent. Or misinterpretation or miscommunication of the ACP if the details under which it is enacted are not clear.

HCCA are finalising contract negotiations for an ACP project that focuses on supporting multicultural communities, while recognizing that there are varying cultural constructs around discussing health and death that impact on these communities and working through these issues.

Conversations about death and dying

Talking about death and dying can be difficult. Both consumers and health professionals need to have more respectful and honest conversations regarding end-of-life choices, death and dying. We all need to be as realistic as possible so that consumers, their families, friends and carers, as well as health professionals, can work together through the choices available for end-of-life care. Ultimately, it is the consumers' right to determine their health care, but we need to be supported with sufficient information to empower us to make these decisions.

Concluding Remarks

We look forward to seeing how our feedback and comments shape the ongoing work on End-of-life Choices in the ACT. Please do not hesitate to contact us if you wish to discuss our submission further. We would be happy to clarify any aspect of our response.

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[i] https://www.health.qld.gov.au/clinical-practice/engagement/clinical-senate?a=163356

[ii] Tallis, R and Saunders, J. The Assisted Dying for The Terminally Ill Bill, 2004. *Clinical Medicine,* 2004. Volume 6, Number 4, pages 534 to 40. See page 537 for discussion.

[iii] https://www.safetyandquality.gov.au/national-priorities/charter-of-healthcare-rights/

[iv] http://eol.law.dal.ca/

[v] https://www.advancecareplanning.org.au/