



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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ACT Assembly Committee
Inquiry into end of life choices
Via email
LACommitteeEOLC@parliament.act.gov.au

Thank you for the opportunity to provide a submission on the end of life choices of ACT residents. ADACAS is Canberra's largest independent, individual advocacy service. Our client groups are people with disability, frail older people and their family carers. As independent advocates we take seriously our role in ensuring that our clients have their voice heard in matters that affect them. Being heard, and having your decisions respected with regard to end of life choices are fundamental human rights for all Canberrans.

ADACAS typically provides input to systemic inquiries on issues which have arisen within the individual case work that we undertake. Given that end of life choices are currently limited by legislation, we have not had advocacy cases which seek to ensure that a person can access assisted dying if that is their choice. The issue however, is an important one from a human rights perspective and we therefore provide comment based on the fundamental principles which underpin our work. We know that as life progresses many of us change our views about what quality of life means to us. The same is not also true for dying. Opportunities for conversations about dying and end of life choices are rare, particularly for people who are in the ADACAS client groups.

People with disability often experience systemic discrimination based on the values that society holds. These values may not be explicit but they lead to behaviours which indicate that the worth of the life of a person with disability is somehow less than the worth of the life of other people in the community. This discrimination is already felt by people with disability interacting with the service system and with the health system, where they may for instance not be considered suitable candidates for particular treatment options because they live with disability. In particular, denial of access to the service because of capacity assessments which routinely negate the right to actively participate in decisions about their own life, must change. The issue is magnified for people who also live with other differences, such as indigenous status, being of a different race or living with extreme poverty. For some people the sense of, or fear of, their life not being valued by others is sufficiently strong that it acts as a deterrent to accessing support services or seeking medical assistance. The legalisation of a process which enables voluntary assisted dying, if not done with appropriate safeguards, may act as a further deterrent to help seeking by people with disability because they fear that their life will not be valued and that others may decide on their behalf that an end of life choice be made.

In our experience people often experience a loss of decision making rights as they age. This can be because of ill health or declining cognitive capacity. It can also be because of elder abuse situations where trusted others usurp the rights of the older person for their own gain.

ADACAS is concerned that the right of all people to continue to be active decision makers in their own lives is enabled, including through changes to guardianship, enduring power of

attorney and other substitute decision making regimes. The availability of decision making support, either through the persons existing networks, or accessed from others in the community, is essential to ensuring that decision making rights are respected. Availability of support to engage in a decision about care at any life stage ensures that options are broadened and decision making is accessible to all. Ensuring available decision support, at minimum, meets obligations to uphold the rights of all in our community to equitable access to life, health and justice. Consistent with the UNCRPD it enables articles 5,6,7,9,10,11,12,12,14,15,17,25,26 & 29.

The Australian Law Reform Commission Capacity Inquiry identified that substitute decision making regimes are contrary to the United Nations convention on the rights of people with disability and should be replaced with supported decision making regimes. These new arrangements should ensure that the *will, preferences and rights* of the person are central to all decisions which are made about them. Where a person approaches end of life and it is more difficult for them to communicate their will, preferences and rights, it becomes even more important that significant investment is made in ensuring that they can participate in end of life decisions to the greatest extent possible and that their wishes are well informed, and well respected by those around them. Any safeguards which include measurement of capacity rather than required support, or are not explicit in addressing the inherent and insidious devaluing of the lives of those who require additional support within our community, are insufficient and must not be included in any end of life choices legislation.

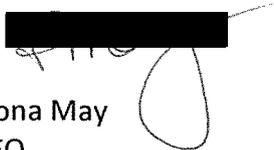
One strategy which may address this issue is ensuring that participation in voluntary assisted dying process can only occur once someone has opted in to the scheme. A requirement to opt in while you are well, including through making advance directives or care plans about end of life and palliative care, would ameliorate the risk that others devalue the lives of some of our most vulnerable citizens. Palliative Care Australia already has resources on talking about dying which could inform new mechanisms under new legislation. Access to appropriate support for decision making with the process of opting in to the scheme will make it more accessible for all.

If assisted dying is legislated in the ACT, it must be carefully safeguarded and information and support should be made available to those most vulnerable. Provision of decision support as required around the preparation of advanced care documents to maintain engagement with health and other services would improve access to health services for people whose capacity is questioned by others, and has potential to also support these individuals with end of life decision making. In the context of other advance care planning explicit inclusion of an opportunity to talk about what a good enough death looks like for the individual would be valuable.

Current medical practices do not offer universal access to support, when and where it is needed, for participation in care choices at any point of life. Putting aside the reality of inequitable access to services which promote and maintain health; reasonable action to mitigate risk around end of life choices remains challenging for those most vulnerable. Development of voluntary assisted dying legislation must include mechanisms which ensure that the lives of people with disability or older people are not devalued and that their own decisions are central to the decision making process.

We look forward to further opportunities to engage with Government as work on this reform progresses. If you would like to discuss any aspect of our submission please contact me by phone or at [REDACTED].

Yours sincerely

A handwritten signature in black ink, appearing to read 'Fiona May', is written over a black rectangular redaction box.

Fiona May
CEO

15 March 2018

