



LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON END OF LIFE CHOICES IN THE ACT

Ms Bec Cody MLA (Chair), Mrs Vicki Dunne MLA (Deputy Chair), Ms Tara Cheyne MLA,
Mrs Elizabeth Kikkert MLA, Ms Caroline Le Couteur MLA.

Submission Cover Sheet

End of Life Choices in the ACT

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ACT Right to Life Association Inc

22 March 2018

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

Dear Mr Snedden

Please find attached a submission from the ACT Right to life Association Inc to the Select Committee on End of Life Choices in the ACT which has been prepared by Mr Denis Strangman AM, a Life Member and Member of Council of the Association. This submission is made on behalf of the Association.

You will note that the submission has two Appendices marked "Confidential". If possible we wish that information to remain confidential because it is known to Mr Strangman through his connection with the individuals named and is not public knowledge. The remaining content of our submission can be made public without qualification.

Should the Committee wish, we are prepared to appear in person before the Committee. Our representatives would include myself and Mr Strangman and others who may be relevant because of their experience and knowledge. I may be contacted on (02) [REDACTED] for that purpose.

Yours sincerely

(Mrs) Bev Cains
President
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Submission by Denis Strangman AM, on behalf of the ACT Right to Life Association Inc, to the ACT Legislative Assembly Inquiry into end of life choices in the ACT.

Background about the author: Denis Strangman AM is a Life Member and member of the Council of ACTRTLA Inc. He was made a Member of the Order of Australia in 2015 for his work in brain tumour support and advocacy, both in Australia and internationally, following the death of his wife in 2001 from a Glioblastoma brain tumour. He has had extensive experience in cancer and palliative care matters in the ACT during the past seventeen years, including being a past member of the Committee that developed a palliative care strategy plan for the ACT and a member of the Quality Committee at Clare Holland House. He is also a past member of the Board of Palliative Care ACT. He remains active in brain tumour support and is also a current Advisor to the Victorian-based STEP Care Phase 2 study which is intended to test the effectiveness of the early introduction to palliative care of those with certain advanced and terminal cancers, including glioblastoma brain tumours.

Definition issues

The use of “end of life choices” in the Committee’s title disguises the fact that the Inquiry is primarily about euthanasia and assisted suicide. This is reinforced by the four references to “voluntary assisted dying” in the Committee’s terms of reference and its mention of the Victorian legislation as a reference point.

“Voluntary assisted dying” is not a neutral term, it is the terminology of choice by those who are pushing for the introduction of euthanasia and assisted suicide, which was the objective of the Victorian legislation which is held up specifically in the Committee’s terms of reference as a potential guide for similar legislation in the ACT.

The ACT Right to Life Association supports life from conception to natural death and has done so since its inauguration 46 years ago. As far as we know, we are the longest-established NGO in the ACT to have consistently opposed euthanasia and assisted suicide.

We believe that given the facts and knowledge about the dangers of euthanasia and assisted suicide and its operation in countries such as Belgium, Canada and the Netherlands, and in US States such as Oregon, a majority of the population would oppose their introduction in the ACT.

Unreliability of public opinion polls

The unreliability of public opinion polls on euthanasia and assisted suicide have been amply demonstrated. This is a link to a particularly useful commentary by anti-euthanasia advocate Dr Peter Saunders in the UK:

<http://pjsaunders.blogspot.com.au/2012/12/why-opinion-polls-supporting-euthanasia.html>

The result of a poll can depend very much on how the question is phrased and the state of knowledge of the full implications of euthanasia and assisted suicide on the part of the person being asked.

Canadian anti-euthanasia advocate Alex Schadenberg has illustrated this point by suggesting five alternative questions a polling organisation could ask:

- * Are you concerned that if assisted suicide is legalized that some vulnerable people will be pressured into asking for assisted suicide?
- * Are you concerned that elderly people, who are already experiencing elder abuse, will be pressured into asking for assisted suicide?
- * Are you concerned that people who live with depression would not be adequately protected from assisted suicide, if legalized?
- * If palliative care was available for every person who needed it, do you believe that there would be less demand for assisted suicide?
- * Do you think that society should be improving the availability and quality of palliative care and the care of people with disabilities or chronic conditions or should we be legalizing assisted suicide? ¹

Current dying situation

As is the case elsewhere, at least 50% of deaths are “clinically expected deaths” ²; in other words, they are not the result of some traumatic or accidental event, and at least 70% of people have expressed a wish to die at home. ³ However, a proportion of those who are dying are admitted to hospital, an aged care facility or nursing home, or to Clare Holland House (CHH).

This could be because their carers or family are unable to care for them at home or there has been a rapid deterioration in their health situation. Caring for a dying person at home can be a challenging experience, even for someone with a medical background, and one would not wish to insist that a dying person’s preferences in this regard be carried out if they do not have an adequate support team in the home setting. ⁴

Since its transfer from the grounds of the former Canberra Hospital to Barton Clare Holland House has established itself as a place of holistic palliative care along the

¹ See: <http://alexschadenberg.blogspot.com.au/2012/12/do-americans-want-to-legalize-assisted.html>

² See Scott I., Mitchell G., Reymond E., Daly M., 2013, ‘Difficult but necessary conversations - the case for advance care planning’, *Medical Journal of Australia*, 199 (10), pp. 662 – 666, cited in *Dying at home: Preferences and the role of unpaid carers A discussion paper on supporting carers for in-home, end-of-life care* May 2014, Carers Australia. Available at: http://www.carersaustralia.com.au/storage/Dying%20at%20home_Final2.pdf

³ See page 22 of *Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services*. Productivity Commission Draft Report, June 2017. Available at <http://www.pc.gov.au/inquiries/completed/human-services/reforms/draft/human-services-reforms-draft.pdf>

⁴ The author has been involved with the death of his older sister in 2014 in Canberra as a patient under the home-based palliative care service, and with his older brother in NSW in 2016 as a patient in a nursing home who was transferred to a public hospital.

lines first promulgated by Dame Cecily Saunders, the founder of modern-day palliative care and the hospice movement.⁵

Euthanasia and palliative care

Because it is a palliative care facility for those who are dying Clare Holland House does not practice euthanasia or facilitate assisted suicide. It operates according to the definition of palliative care as stated by the World Health Organisation (WHO), which includes these two key points:

- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death⁶

As much as this Parliamentary Committee might wish to influence *how we die* it cannot change the irrefutable fact that we must all die at some stage.

*In our opinion euthanasia is incompatible with the practice of good palliative care. Despite what is claimed about euthanasia and palliative care being complementary to each other the introduction of euthanasia would destroy the community's favourable understanding of end of life care both in Canberra Hospitals and at Clare Holland House and would marginalise the provision of palliative care services.*⁷

It is our experience as residents of the ACT that people know that not only does Clare Holland House practice palliative care, it also undertakes its work of caring for the dying under the guiding values and mission of Calvary Health Care (CHC) and the Little Company of Mary (LCM).

In other words, people know that it is highly improbable that there will be anything illegal or unethical done to them at Clare Holland House or in the hospitals run by CHC. This is a reputation that has been carefully fostered during the 39 years that the Little Company of Mary has been operating in the ACT.

This reputation has been underpinned by the very favourable experiences of families who have had a loved one die at Clare Holland House. This is confirmed by the death and funeral notices appearing in the Canberra Times, which often carry tributes to the staff and the care received at Clare Holland House.⁸

I recall as a former Board Member of Palliative Care ACT that Board meetings regularly included a list of donations and messages received at the Hospice. The

⁵ See: https://en.wikipedia.org/wiki/Cicely_Saunders

⁶ See: <http://www.who.int/cancer/palliative/definition/en/>

⁷ The author understands that in the *Journal of Bioethical Inquiry* (Mortier, T., Leiva, R., Cohen-Almagor, R. et al. *Bioethical Inquiry* (2015) 12: 177. <https://doi.org/10.1007/s11673-015-9635-7>) the authors claim that in Belgium during 2012-2013 “almost 40 percent of the patients who received euthanasia did not see a palliative care specialist nor interacted with a palliative care team”. Original not available to author because of paywall.

⁸ Here is an extract from the Obituary for Leo Burggraaff (a fellow Parishoner) placed in the Canberra Times on 10 February, 2018: “Heartfelt thanks to Dr Fiona McDonald and the teams at Palliative Care in the Home and Clare Holland House ... Memorial donations welcomed to Palliative Care ACT.” This is typical of the references to Clare Holland House.

Notice Board in the staff tea room at the Hospice, where we held our meetings in that period, would often be full of grateful messages from family members.

The introduction of euthanasia and assisted suicide would irretrievably damage this reputation, which has been built up over many years of selfless service and would lead to a fearfulness in the community about the care of the dying in the ACT.

This fearfulness would also extend to the care of people in the various ACT hospitals, including that provided by the Palliative and Supportive Care unit at The Canberra Hospital (THC), that provided by the home-based palliative care program linked with the Hospice, and that provided in nursing and aged care institutions.

Not only would the introduction of euthanasia and assisted suicide into the Territory affect the reputation of existing facilities it would also throw the administration of palliative care into chaos. Health professionals are quite clear on what is permissible and what is not in relation to the medical care of those who are dying. *It is likely that there would be an exodus of experienced health professionals from palliative care should euthanasia and assisted suicide be foisted on the ACT healthcare system. This has apparently happened in Belgium.*

Professor Benoit Beusekinck, a consultant oncologist in Belgium, was quoted in January 2018 as claiming that after more than 15 years of legal euthanasia in Belgium “palliative care units are ... at risk of becoming ‘houses of euthanasia’, which is the opposite of what they were meant to be ... Some Belgian palliative care units that have opened their doors to patients requesting euthanasia have seen nurses and social workers leaving the unit because they were disappointed that they could no longer offer palliative care to their patients in an appropriate way.”⁹

The author visited Brussels in September 2013 to talk specifically with local people who had experience of the implementation of euthanasia in the hospital system. I spoke with a Chaplain attached to a major hospital that practised euthanasia on its patients. He gave me the example of a patient selected for euthanasia at a nominated time and day.

He approached the patient and asked if there was anything he could help him with. The patient said there was – he had an adult daughter from whom he had been estranged for many years and would the Chaplain be able to track her down? The Chaplain managed to locate the daughter with some difficulty and she came to the hospital for a very much appreciated meeting but the nominated time at which the patient was to be killed was put back by this meeting. Later the Chaplain was castigated by the Hospital administration for interfering in the process and sabotaging the pre-arranged time for the killing. This is an example of how euthanasia and its utilitarian approach can affect the operation of a health facility and its staff.

Euthanasia would be a challenge to the ACT Health system

⁹ “Palliative care nurses quit ‘houses of euthanasia’. Catholic Herald (UK), 18 January 2018. Available at: <http://www.catholicherald.co.uk/news/2018/01/18/palliative-care-nurses-quit-houses-of-euthanasia/>

In practical terms the introduction of euthanasia and assisted suicide would also represent a challenge to a health system that is already under strain.

The author has been a volunteer carer peer support worker for the past six years at Ward 2N (the mental health ward at Calvary Public Hospital at Bruce) and last year received an award as the “ACT Mental Health Carer of the Year” from Minister Rattenbury.

One thing that emerges from involvement in the ACT mental health area is the knowledge that qualified psychiatrists are in very short supply both in private and public practice.¹⁰ In the carers’ circles that I move in carers and family members often talk about the problem of trying to access a qualified psychiatrist to look after their loved one. An article in the Canberra Times of 21 March 2018 states that the ACT had 49.6 psychiatric services per 10,000 people in 2015-2016 – the second lowest in the country behind the NT – which was down on 56.4 in 2008-2009.¹¹

The few remaining psychiatrists in the ACT could be tied up by a requirement similar to that in Section 18(1) of the Victorian legislation to be consulted should there be any doubt about an applicant’s decision-making capacity due to “a past or current mental illness”. This could detract from their ability to provide specialist services particularly to mental health patients in the ACT.

Inappropriateness of the Victorian model

Term of Reference 4 specifically mentions the Victorian scheme and its possible relevance to a scheme for the ACT.¹²

In addition to the observation made above about the likely imposition on psychiatrists, the first point to note is that *the Victorian scheme is untested*. Unless proclaimed earlier, it does not come into operation until 19 June 2019 and will not be reviewed until five years hence.¹³

The Victorian legislation consists of 143 Sections within 130 pages. There were over 400 amendments moved in the marathon debate in both Chambers of the Victorian Parliament but only 39 of those amendments were adopted.

The legislation and Government actions (or inactions) remain deficient in many aspects – the opportunity was not taken to improve the funding for palliative care services in Victoria; there are doubts about safeguards; ‘doctor shopping’ is still possible; the residential requirements are still loose and open to misuse; the ‘appropriate drug’ has not been researched; and there are no extra safeguards for vulnerable, elderly residents in nursing homes.

Cross-border abuse

¹⁰ See Appendix 1 (Confidential addendum to this submission).

¹¹ See: <http://www.canberratimes.com.au/act-news/huge-demand-for-acute-mental-health-services-while-beds-decline-stats-show-20180313-h0xem8>

¹² The Victorian legislation is “Voluntary Assisted Dying Act 2017”, No 61 of 2017.

¹³ 2019 is mentioned in Section 2 (2) of the Act.

We wish to concentrate on one likely deficiency in particular – the potential for abuse relating to residency requirements. Section 9 (1) (b) (i) and (ii) of the Victorian legislation requires the applicant to “be ordinarily resident in Victoria” and “at the time of making a first request have been ordinarily resident in Victoria for at least 12 months”.

As most people are aware the ACT Health service does not only look after patients who live in the ACT but provides services to people who usually reside in the NSW Greater Southern Area Health Service (GSAHS), which includes Queanbeyan, Cooma, Goulburn, Bega, etc.¹⁴ There are complicated inter-State reimbursement arrangements in place.

With the recent defeat of euthanasia legislation in the NSW Parliament¹⁵ there is the potential for some NSW residents to seek access to any euthanasia and assisted suicide program that might be introduced in the ACT.

There is already some anecdotal evidence of manipulation of residency requirements in regard to Government services in the ACT. Former residents of the ACT who have sold up and retired to the Coast have been known to offer a son or daughter’s Canberra address as their “ordinary residence” in order to access certain services. It has been claimed that some young people who ordinarily reside in neighbouring towns have sought a car licence in the ACT by giving a relative’s ACT address as their “ordinary residence” in the belief that it might be easier for them to obtain a licence in the ACT.

The identification of Canberra as the place to go to access legally-endorsed euthanasia and assisted suicide would greatly tarnish this City’s reputation.

Suicide, suicide prevention, assisted suicide, and suicide contagion

ACT Health has contributed only a limited effort to suicide prevention in the ACT and more could be done. For example, there is no Suicide Prevention Plan in existence in the ACT. The author can recall strong efforts being made to develop strategy plans in relation to cancer and also palliative care in the ACT but a similar effort has not been made in relation to suicide prevention.

The situation in regard to what might be described as “conventional suicide” can be described by reference to an inadequate study of suicide in the ACT (**See Confidential Appendix 2**). The description “conventional suicide” has been used for want of an alternative description but there is nothing routine or “conventional” about such suicides – all suicides are a tragedy.

There has been some discussion about the effect of the introduction of euthanasia and assisted suicide on conventional suicide rates. The author was a member of a working party that developed clinical practice guidelines for glioblastoma brain tumours several years ago and is reasonably familiar with the levels of evidence to support an assertion. No one would claim that the level of evidence supporting a correlation between euthanasia and assisted suicide and “conventional suicide” falls

¹⁴ See: https://en.wikipedia.org/wiki/Greater_Southern_Area_Health_Service

¹⁵ See: <https://www.parliament.nsw.gov.au/bills/Pages/bill-details.aspx?pk=3422>

into what might be described as Level 1 evidence but the experiences in Belgium and Oregon cannot be dismissed out of hand.¹⁶

The correlation is also underpinned by the precautionary work undertaken by groups such as MINDFRAME in relation to media reporting of suicide.¹⁷ Mindframe describes itself as providing “access to up-to-date, evidence-based information to support the reporting, portrayal and communication about suicide and mental illness”.¹⁸

Mindframe has been largely responsible for the introduction and continuation of the messages at the end of media articles (including television) to the effect that “If this program has raised issues for you, please contact BEYOND BLUE, LIFELINE, SANE, etc etc.”

Obviously, there is a belief that community reporting and discussion about “conventional suicide” can have a deleterious effect on some people.

A person with lived experience of suicide described to the author how her teenage daughters were susceptible to adverse reactions when suicide awareness programs were conducted at their schools. Their father had suicided and there was a need to handle the subject very carefully.

Why would there be an exercise of caution in relation to media reporting and education presentations? The obvious answer is that there is a strong suspicion of a correlation between examples of suicide in the community and impressionable people following suit.

Some people describe this as “suicide contagion”, as can happen when a well known celebrity suicides. Researchers in the USA found that in the five months following the 2014 death of actor Robin Williams suicides were 10% more frequent than suicide trends would predict.¹⁹

This precautionary approach also underlined the furore caused by the Netflix series “13 Reasons Why” which featured a high school student who died by suicide.²⁰ People were concerned about the possible contagion effect of this Series.

If there is concern about the flow-on effects of reporting about “conventional suicide” surely there should also be concern about the impact of advocates who campaign for

¹⁶ A key article about this subject appeared in the *Southern Medical Journal*. See: <https://sma.org/southern-medical-journal/article/how-does-legalization-of-physician-assisted-suicide-affect-rates-of-suicide/> The subject was discussed further between Neil Francis and Professor Margaret Somerville here: <http://www.abc.net.au/religion/articles/2017/05/19/4671796.htm>

¹⁷ See: <http://www.canberratimes.com.au/act-news/huge-demand-for-acute-mental-health-services-while-beds-decline-stats-show-20180313-h0xem8>

¹⁸ Acknowledgement is made to the fact that mental health may not be the only cause of suicide and that some suicides might be caused by marriage breakdown, job loss, etc.

¹⁹ See: <https://www.goodtherapy.org/blog/suicide-rates-increased-following-death-of-robin-williams-0219181>. The source reference is: Fink, D. S., Santaella-Tenorio, J., & Keyes, K. M. (2018, February 7). Increase in suicides the months after the death of Robin Williams in the U.S. *PLOS ONE*, 13(2). doi:10.1371/journal.pone.0191405

²⁰ See this article in “Scientific American” by a former Inspector of Mental Health Services in Ireland: <https://www.scientificamerican.com/article/13-reasons-why-and-suicide-contagion1/>

easier access to and State-endorsed “assisted suicide”, particularly if they already have a high public profile.

ACT Right to Life is not advocating the censorship of these advocates but points out that (1) As an organisation it (ACTRTL) is not responsible for initiating this public discussion, and (2) it believes it has a moral duty to engage in this debate when it emerges so that the public may obtain a balanced viewpoint. We also believe that a strongly-expressed argument in defence of life, and in opposition to assisted suicide and euthanasia, might sway a person from contemplating suicide.

The acceptance of assisted suicide and euthanasia as a legitimate practice in our community, our laws, and our health system, must surely lead to a situation where life is devalued and susceptible people might erroneously believe they are undertaking something which is in line with community attitudes.

The flow-on effect of easier availability of euthanasia and assisted suicide could also have implications in regard to the propensity for elder abuse and the adoption of a utilitarian approach to expensive healthcare where the view obtains traction that it is more cost-effective for the State to enable a person to suicide rather than invest in resources-heavy healthcare.

One way of campaigning in defence of life would be for a State or Territory government to pledge itself as supporting “Zero Suicide”.²¹ It is acknowledged that the adoption of the Zero Road Accident campaign by the NSW Government has reduced the opportunity to campaign with this approach.

Much more could be done in regard to suicide prevention and “postvention”²² and the Territory government needs to “get real” about these public policy subjects.

Destruction of hope

Pro-euthanasia advocates often state that they need access to euthanasia and assisted suicide facilities “just in case”. What they mean is that they do not necessarily require immediate access to a lethal drug but wish to have it as a “back up” for all eventualities.

The problems with this approach are that: (1) if it is a lethal drug there is the danger of it falling into the wrong hands; and (2) the *existence* and State-endorsement of euthanasia and assisted suicide can have a destructive effect on those who believe in hope while coping with a life-limiting illness.

I have to say that I was a latecomer to an understanding of the role of “hope” in the brain tumour journey and all cancer journeys. My UK colleague, when we were

²¹ The Zero suicide concept was introduced into the Henry Ford health services in Detroit USA in the 2000s and has been hailed as a success. See: <https://www.theguardian.com/society/2015/feb/18/detroit-suicide-taboo-depression-screening-mental-health-henry-ford> The author suggested the scheme to the Canberra Health Network (a local Primary Health Network in the area) but they were insistent that its principles were already being followed. The concept can also be applied to a region or a City.

²² See: <https://en.wikipedia.org/wiki/Postvention> “A postvention is an [intervention](#) conducted after a [suicide](#), largely taking the form of support for the bereaved (family, friends, professionals and peers). Family and friends of the suicide victim may be at increased risk of suicide themselves.”

preparing our first jointly-authored publication in 2008²³, was very keen to refer to “hope” and contacted Dr Jerome Groopman from Harvard, to obtain his permission to republish in our book a definition of hope that he had included in his publication “*The Anatomy of Hope*”.²⁴ I was not so understanding at the time and agreed reluctantly.

Dr Groopman wrote in his excellent definition:

“Hope is the elevating feeling we experience when we see – in the mind’s eye – a path to a better future. Hope acknowledges the significant obstacles and deep pitfalls along that path. True hope has no room for delusion. Clear-eyed, hope gives us the courage to confront our circumstances and the capacity to surmount them”.

For many people the adoption of “true” and “realistic” hope is the means by which they are sustained in their journey. It would be very dispiriting to them to know that a fellow resident in a hospital or a nursing home has abjured hope and proposes to make use of State-sanctioned euthanasia or assisted suicide, and, indeed has a “back up” supply of poison in a cupboard in their room, to give effect to those plans. This would be an unwelcome development should the ACT support the introduction of euthanasia and assisted suicide.

²³ The First Walk Around the World for Brain Tumours: and the International Brain Tumour Awareness Week Paperback – June, 2008 by [Kathy Oliver](#) (Author), [Denis Strangman](#) (Author)

²⁴ See: https://en.wikipedia.org/wiki/Anatomy_of_Hope

