



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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From: Marshall Perron
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Secretary,
Select Committee on End of Life Choices in the ACT,
Legislative Assembly for the ACT,
GPO Box 1020,
CANBERRA ACT 2601.

Dear Sir/Madam

Attached herewith a submission addressing the terms of reference of the committee on End of Life Choices in the ACT.

If the submission is found not to comply with the requirements for acceptance in any way please let me know.

I wish the committee well in its deliberations.

Yours faithfully

MARSHALL PERRON

[REDACTED]

BUDERIM QLD 4556

[REDACTED]

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A SUBMISSION TO THE SELECT COMMITTEE ON END OF LIFE CHOICES IN THE ACT

BY MARSHALL PERRON

15 JANUARY 2018

I welcome the opportunity to make this submission to the inquiry and commend the sponsors for their initiative.

PREAMBLE

Considering the broad ranging terms of reference, it is certain many submissions to the committee will state...

- That the vast majority of ACT resident adults want to have the option of assisted dying if their quality of life becomes unbearable.
- That even optimal palliative care cannot relieve suffering for everyone.
- That some doctors assist some patients with intractable suffering to die without safeguards or scrutiny.
- That the absence of a lawful right to access appropriate drugs to die at a time of choice compels many terminal or incurably ill to violent suicide.
- Those regimes where medical assistance to die is lawful are closely monitored and operate satisfactorily.

All of those statements are accurate. They demonstrate that with the recent exception of Victoria, Parliaments in Australia have fallen behind the needs and aspirations of an ageing community, many of whom feel abandoned by a society that fails to respect individual autonomy by refusing them the option to die peacefully with dignity at a time of their choosing.

COMMITTEE REFERENCE 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.

Modern medicine and improved living standards have resulted in an ageing population dying predominantly of degenerative disease. A few of those ailments result in protracted unbearable suffering that can be relieved only by the death of the person.

Medical advances mean death can, and is often, artificially prolonged beyond what is deemed necessary or wanted by many citizens.

Currently, ACT law does not protect doctors who act compassionately to relieve intractable suffering by accelerating death. The law prohibits frank discussion between patient and doctor about an intention to suicide; it encourages individuals to keep their plans to end their life secret from family to avoid them becoming an accessory. The law compels terminally or incurably ill people intent on taking their own lives to do so before they lose the physical or mental capacity. The length of life lost in such cases is a tragedy for the individual and all who loved them.

Laws permitting a competent adult the option of access to the means to a peaceful death would minimise unbearable suffering and reduce violent, lonely, premature suicide.

The provision of palliative care is an essential part of our advanced society. Australia has a world class service and its development and expansion should be encouraged in both the private and public sector.

While palliative care accommodates the needs of a majority of the dying, even the best resourced service cannot relieve the extreme suffering some endure. This fact is acknowledged universally by responsible organisations and professionals involved in the palliative care industry. To quote from the national peak body, Palliative Care Australia 1999 position paper on euthanasia...

PCA... Acknowledges that while pain and other symptoms can be helped, complete relief of suffering is not always possible, even with optimal palliative care. And...

Recognises and respects the fact that some people rationally and consistently request deliberate ending of life.

The palliative care response to intractable pain and suffering is terminal sedation, a medically controlled process that is utilized close to the end of life, commonly without the explicit consent of the patient. In order to avoid accusations of intending to hasten death, the delivery of sedatives and analgesics is slowly titrated upwards, which means that control of pain and suffering may take some days to achieve. As nutrition is with-held, it can take up to two weeks for the patient to die.

Terminal sedation is, in fact, slow euthanasia, once commenced, the death of the patient is certain and intended. It would be more humane to assist a patient with unbearable, unrelievable suffering (upon request) by the administration of drugs that cause death in minutes rather than starving to death over several days or weeks.

COMMITTEE REFERENCE 2.

ACT community views on the desirability of voluntary assisted dying being legislated in the ACT.

Opinion pollsters have surveyed Australian adults on the subject of voluntary euthanasia since the 1950's. The results show a progressive rise in support over the period to today where it stands at over 80%. Other polling by organisations like The Australia Institute and the ABC Vote Compass separately confirm that it is the clear desire of a massive majority of citizens to have the option of legalised voluntary assisted dying. Without doubt, any honest survey of the ACT community would return the same results.

COMMITTEE REFERENCE 3.

Risks to individuals and the community associated with voluntary assisted dying and whether and how these can be managed.

The committee has the advantage of relevant reports by credible organisations and individuals both in Australia and overseas.

I refer to the reports by the **Parliament of Victoria Legislative Council Legal and Social Issues Committee Inquiry into end of life choices** of June 2016 and the subsequent report of the **Ministerial Advisory Panel on Voluntary Assisted Dying of July 2017** these will be of relevance to this committee due to their comprehensive nature and the fact they have only recently been completed. *See further comment regarding the recently passed Victorian Voluntary Assisted Dying Bill 2017 below.*

Also relevant is two reports by the respected think tank **Australia 21** titled '**How Should Australia Regulate Voluntary Euthanasia and Assisted Suicide**', of Nov 2012 and '**The right to choose an Assisted Death: Time For legislation?**' Jan 2013. These reports are based on an assessment of relevant Australian data with input from a broad range of people considered experts in their field. The reports conclude that the current legal framework has failed, the law is incoherent or illogical, palliative care cannot address all suffering, some terminally ill patients are forced to choose an unsatisfactory death and that the Australian community wants change.

Australia 21 recommends...

“State governments should develop legislation now to permit and regulate voluntary euthanasia and assisted suicide in defined and limited circumstances.”

Internationally, the **Royal Society of Canada** released a report into **“End of Life Decision Making”** in Nov 2011. The society commissioned a panel of six Canadian and international experts on bioethics, clinical medicine, health law and policy, and philosophy, to prepare a report. Among the groups findings is...

“The evidence does not support claims that decriminalizing voluntary euthanasia and assisted suicide poses a threat to vulnerable people, or that decriminalization will lead us down a slippery slope from assisted suicide and voluntary euthanasia to non-voluntary or involuntary euthanasia. The evidence does not support claims that decriminalization will have a corrosive effect on access to or the development of palliative care.”

I also refer the committee to the **Quebec National Assembly Select Committee Dying with Dignity report**, March 2012.

This is arguably the most comprehensive report ever conducted into the subject and is a valuable reference source on the law and practice relating to treating patients approaching death, the role and limitation of palliative care, public attitudes and recommended reform. Having visited permissive jurisdictions in Europe the Committee concluded...

“After carefully studying foreign experiences, we can confidently say that allowing this practice (Medical aid in Dying) would not harm society’s most vulnerable because there are ways to define and structure it to avoid any risk of abuse.”

Collectively the above reports represent years of studied deliberation and community consultation by people eminent in their field. Many of their findings are directly relevant to the situation in Australia and should be considered by the committee in preparing its report.

COMMITTEE REFERENCE 4.

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

The committee will logically examine the new Victorian Voluntary Assisted Dying Act 2017 and I urge comparison with the NSW Voluntary Assisted Dying Bill 2016 which was narrowly defeated in November 2017.

The contrast between the two is stark. In my opinion the balance between accommodating the needs of suffering individuals and sensible safeguards against abuse is captured in the NSW Bill (although I would advocate some changes). The Victorian Act has unfortunately been drafted with a view to minute control of the process at every stage and that has made it overly bureaucratic and unnecessarily expensive.

A safe responsible assisted dying law can be drafted relatively simply to regulate the relationship between the eligible patient and the medical professionals. It does not have to contain 143 clauses and 8 forms as the Victorian Act does. Viewing the highly successful Oregon Death with Dignity Act is recommended to compare the opposite end of the spectrum regarding complexity of lawmaking.

Should this committee recommend a Bill to allow assisted dying in the ACT I urge members not to mirror the complexity in Victorian example. There are better models to draw from which will accommodate the needs of patients, protect doctors and the vulnerable and require minimal government expense.

COMMITTEE REFERENCE 5.

The impact of Federal legislation on the ACT determining its own policy on voluntary assisted dying and the process for achieving change.

The Federal Euthanasia Laws Act 1997 has effectively prevented the elected representatives to the ACT considering the passage legislation to permit any form of assisted dying. There is no doubt the ACT Legislative Assembly would have passed such a law many years ago had the authority to do so had not been removed. A Bill was introduced in the ACT before the Northern Territory Rights of the Terminally Ill Act was passed in 1995.

Now that an Australian state has passed a VAD law, any case to prohibit the Territories addressing the subject has disappeared. Hopefully one of the two Bills currently before the Senate to restore powers to the Territories will be debated and passed in the near future.

IN CONCLUSION

The call for a right to die that has gathered momentum over the past three decades is driven by a growing tendency to value quality of life over quantity for ourselves. While suffering in life cannot be wholly avoided, futile unbearable suffering near the end of life is quite naturally abhorred. It is perfectly rational to do all one can to minimise it.

In the absence of a lawful regime permitting access to drugs that provide a peaceful death, citizens who are determined to end their suffering choose violent, messy (although lawful) ways to die. This situation is unacceptable.

Claims that it is not possible to devise safeguards to protect the so called vulnerable are not based on fact. That statement misrepresents the comprehensive power parliament has to prescribe eligibility criteria and the conditions upon which assistance to die would be permitted. International experience has demonstrated that a responsible, safe regime to permit voluntary euthanasia is possible. If they can do it, so can we.

END.

About the author.

Marshall Perron was a member of the Northern Territory Legislative Assembly for 21 years from 1974, serving as a minister for much of that period and Chief Minister for 8 years. He was the architect and sponsor of the first voluntary euthanasia law, the *Rights of the Terminally Ill Act 1995 (Northern Territory)*.