



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 ACT Legislative Assembly Select Committee on End of Life Choices in the ACT: Term Of Reference 3

Dear Committee Secretary;

I am grateful to the Select Committee in End of Life Choices in the ACT for the opportunity of making this submission. This submission addresses Term of Reference 3: “risks to individuals and the community associated with voluntary assisted dying and whether and how these can be managed” (TOR 3). In addressing this TOR 3 this submission considers

the following:

1. Definitions
2. The history of voluntary assisted dying in Australia
3. Voluntary assisted dying is not pain relief

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4. Some observations on human dignity
5. The Irrevocable Nature of Death
6. Risks to Minority and Vulnerable Groups
7. Adverse experiences of voluntary assisted dying
8. Undesirable change within the health professions and in community attitudes to their role
9. The slippery slope of logic and reason.

Much of this submission draws on material contained in my paper "Such is Life": Euthanasia and capital punishment in Australia: consistency or contradiction?," which was published in *Solidarity* in 2016.² The Committee is referred to that paper for further development of the key arguments presented here and for references to the sources relied upon.

1. Definitions

The TOR do not define "voluntary assisted dying." In this submission the expression will be used to refer both:

- the provision of substances by one person to another at the request of the first person with the intention that that person will ingest those substances at some future time to bring about that person's death (Assisted Suicide); and
- the deliberate and intentional bringing about of the death of a person at their request by the actions of another person by a cause other than as a natural consequence of the cessation of treatment of an existing terminal medical condition at the patient's request leading to the patient's death from the natural consequences of that condition following cessation of treatment (Voluntary Euthanasia).

2. The history of voluntary assisted dying in Australia

Voluntary assisted dying has always been illegal in most parts of the world. It is now lawful in a small number of US States and European countries. In Australia, in legislation which has yet to become operative, it was legalised last year in Victoria. Apart from a brief period in the Northern Territory voluntary assisted dying has

² Michael Quinlan, (2016) "'Such is Life': Euthanasia and capital punishment in Australia: consistency or contradiction?," *Solidarity: The Journal of Catholic Social Thought and Secular Ethics*: Vol. 6 : Iss. 1 , Article 6. Available at: <https://researchonline.nd.edu.au/solidarity/vol6/iss1/6>

always been illegal in Australia. Voluntary Euthanasia was legal in the Northern Territory for less than 9 months (1 July 1996 to 25 March 1997) during the operation of the *Rights of the Terminally Ill Act 1995* (NT) (the *NT Act*) prior to the Commonwealth Parliament overriding its operation by amendments to the *Northern Territory (Self Government) Act 1978* (NT).

3. Voluntary assisted dying is not pain relief

Much support for voluntary assisted dying is driven by compassion and reaction to arguments such as those made by Bob Dent. Mr Dent was the first person to die in Australia under the Northern Territory legislation. For the five years before his death he suffered from prostate cancer in what he described as "a rollercoaster of pain". Mr Dent put a strong, emotional case for voluntary euthanasia in his final letter writing: "If I were to keep a pet animal in the same condition I am in, I would be prosecuted. If you disagree with voluntary euthanasia, then don't use it, but don't deny the right to me to use it."

No one should have to endure pain but the response to pain should be pain relief not death. The ability to control pain is substantially better in contemporary society than it has historically been so for this to be a basis for voluntary assisted dying today when it has not been accepted for the vast bulk of human history as a justification is difficult to reconcile. Professor Margaret Somerville, Dr Brian Pollard and others have noted that pain control has been available to deal with pain across a wide spectrum of diseases for decades but that most doctors are poorly educated in the area. In her book *Death Talk* Somerville tells the story of her own father's death. She was telephoned and told that her father was in his final days. On arrival she found him in great pain and incoherent. She insisted on his being seen by a pain specialist. Following a change to his pain relief his lucidity returned and he lived almost pain free for a further nine months. He told her that he wanted to live as long as he could but not with such terrible pain. Mr Dent should not have endured five years in "a rollercoaster of pain." If he did it evidences a need for better pain treatment.

The focus on pain and suffering as a justification for the introducing voluntary assisted dying is misplaced for empirical reasons. Dutch research has found that only 5% of those seeking euthanasia did so because they were in pain whereas in 57 % of cases a perceived “loss of dignity” was the reason.³In their study of terminally ill cancer patients, Ruijs et al found that the presence or absence of unbearable symptoms or unbearable suffering in patients was not a significant indicator of an explicit request for voluntary assisted dying. The motives for seeking voluntary assisted dying which were most frequently mentioned were instead existential concerns such as a perceived “loss of control, loss of autonomy, loss of dignity, not wanting to be a burden to others and fear of the future.”⁴ These existential concerns are concerns which are not isolated to those who are terminally ill and close to death but are also found in others in the general community including those experiencing a suicidal ideation or suffering from depressive illnesses. For example, some common causes of suicidal ideation in the general community include “feeling or appearing to feel trapped or hopeless”, “feeling intolerable emotional pain,” “increased isolation”, “talking about being a burden to others” and “talking about suicide or dying, expressing regret about being alive or ever having been born.”⁵ Such conditions are treatable. We do not treat existential fears in the general population by assisting suicide or euthanasia so why that should be considered an appropriate response to their existence in the terminally ill is unclear. It is also unclear how if indeed the ACT were to embrace voluntary assisted dying as an appropriate treatment for suicidal ideation in the terminally ill it could logically seek to discourage suicide in the general population for such reasons.

One method of treating these sorts of issues in the terminally ill which has proved

³ Harvey Max Chochinov, *Dignity Therapy* (OUP, 2012) 5

very successful is 'dignity therapy.' Below is a summary of Dr Chochinov's dignity therapy approach and of the findings of his research into the outcomes of applying the approach :

... Terminally ill inpatients and those receiving home-based palliative-care services were asked to complete pre- and post-intervention measures of sense of dignity, depression, suffering, and hopelessness; sense of purpose, sense of meaning, desire for death, will to live, and suicidality; and a post intervention satisfaction survey.

Ninety-one per cent of participants reported being satisfied with dignity therapy; 76 per cent reported a heightened sense of dignity; 68 per cent reported an increased sense of purpose; 67 per cent reported a heightened sense of meaning; 47 per cent reported an increased will to live; and 81 per cent reported that it had been or would be of help to their family. Post-intervention measures of suffering showed significant improvement and reduced depressive symptoms.

Finding dignity therapy helpful to their family correlated with life feeling more meaningful and having a sense of purpose, accompanied by a lessened sense of suffering and increased will to live. ...⁶

Focussing on methods of addressing the underlying concerns of those who seek voluntary assisted dying be they improved pain management, poor quality nursing home conditions or assistance in addressing loneliness, feelings of hopelessness or of being a burden on others are all available actions which the ACT might take which do not involve embracing voluntary assisted suicide.

4. Some observations on human dignity

Australia has a strong commitment to respecting human dignity. In Australia we recognise that human beings are important and valuable because they are human beings, that each is a distinct and unique individual and that each person is entitled to respect and has an inherent dignity by virtue of their

⁴ Cees DM Ruijs, Gerrit van der Wal, Ad JFM Kerkhof, and Bregje D Onwuteaka-Philipsen "Unbearable suffering and requests for euthanasia prospectively studied in end-of-life cancer patients in primary care," (2014) 13 *BMC Palliative Care* 62

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4292985/>

⁵ Christian Nordqvist "What are suicidal thoughts?" *Medical News Today* 13 February 2018 <https://www.medicalnewstoday.com/kc/suicidal-thoughts-ideation-193026>

⁶ Harvey Max Chochinov, *Dignity Therapy* (OUP, 2012) as quoted by Margaret Somerville, "Margaret Somerville: Dr Harvey's must-read book unpacks what dignity means" *Catholic Weekly* 8 June 2017 <https://www.catholicweekly.com.au/margaret-somerville-dr-harveys-must-read-book-unpacks-what-dignity-means/>

humanity. This is behind the introduction of anti-discrimination legislation at Commonwealth, State and Territory levels aiming to eradicate discrimination on a range of grounds including age, disability, race and sex. It is also behind Australia's commitment to health care and assistance to the aged and infirm. Through legislation and commitments of this kind we recognise that human beings are not less worthy, less valued or less dignified because they happen to live with a disability, or they are aging or they have particular physical characteristics. Legislation and assistance of this type make a statement about the sort of society we are. Such legislation and assistance make it clear that as Australians we do not believe that people cease to have dignity or to deserve our respect because they become incoherent, are the victims of mental illness, Alzheimer's disease, Lou Gehrig's disease, because they are born with Down syndrome or because they are ill, disabled or impaired for any other reason. Proponents of the introduction of voluntary assisted dying to facilitate "dying with dignity" perhaps unwittingly undermine the wonderful improvements in the respect for all people whatever their physical or mental circumstances might be at a given point of time. There is nothing undignified about the disabled, the terminally ill or the dying.

5. The Irrevocable Nature of Death

Proponents of voluntary assisted dying sometimes argue for a "right to die". As Mr Dent put it "If you disagree with voluntary euthanasia, then don't use it, but don't deny the **right** to me to use it." This assumes that an individual opting for euthanasia has given full and informed consent when lucid, rational and free of pain and depression. It also assumes euthanasia laws only affect the individuals who make such a choice. The evidence shows otherwise. Human beings do not live in isolation. Enacting voluntary assisted dying is not simply a matter of respecting a person's personal autonomy. A decision to voluntarily end one's life by accessing voluntary assisted dying impacts on many people including: the person's family, the person's friends and colleagues, those who have had responsibility for the treatment and care of the person, all of those with whom the person usually interacts including service providers and neighbours and significantly those who are called upon to provide the substances for the person to take or who are called upon to administer same.

Where voluntary assisted dying is legislated the State set limits on when it will and will not be permissible. As very few people would support the view that States should support the wishes of anyone in society who wishes to commit suicide by providing them with Assisted Suicide or Voluntary Euthanasia because, in a variety of ways, States generally seek to discourage suicide in the general population, when States do introduce voluntary assisted death they want to ensure that only those who fit the relevant criteria which is selected – such as the incurably ill – have their lives brought to an end in this way. The irrevocable nature of death suggests that voluntary assisted dying should remain prohibited if even a very small risk existed that a person might be assisted to suicide or be euthanised in error or outside the set criteria. This could occur where an error is made in applying the criteria is satisfied, where there has been a misdiagnosis, inadequate information of treatment or palliative care options or where the person seeking voluntary assisted dying is suffering from untreated pain, lacks the mental capacity to consent, suffers from an untreated illness, particularly a mental illness such as depression or when overborne or pressured by another. It could also occur if patients were euthanised without their consent. No State has ever enacted safeguards in relation to voluntary assisted dying which involve anything resembling the rigour of the processes which were applied in capital cases in Australia. Yet this rigour was not enough to defeat the potency of the irrevocable argument when it was mounted against capital punishment in Australia. Even though there were no definitive instances of innocent prisoners being executed in Australia, the risk that an innocent person may be put to death by the State was a very powerful argument for the eradication of capital punishment. The experience of voluntary euthanasia in Australia, unlike the history of capital punishment in Australia, evidences the risks of voluntary assisted dying. Two out of the seven patients who sought euthanasia in the Northern Territory were given inadequate information of their true medical condition and of their treatment options. Unlike the criminal justice system, with its system of judicial appeals, under the *NT Act*, if a doctor found that the patient did not meet the criteria for euthanasia, the patient could approach an unlimited number of other doctors until one could be found who would give the required opinion. This situation arose during the brief operation of the *NT Act*. In one case when there was no consensus among oncologists that the patient's condition satisfied the requirements, after an appeal on national television, an orthopaedic surgeon, who had no expertise in her condition,

provided the required certification and the patient was euthanised. In another case a patient was jaundiced and suffering from a bowel obstruction but was not advised of the palliative care and medical treatment available

Psychiatric illnesses and depression raise issues about a patient's mental capacity to provide informed consent. There is a close association between depression and a wish to die. Treatment often sees that wish disappear. Of the seven patients, who euthanasia under the *NT Act*, four showed symptoms of depression. Even where euthanasia legislation mandates a psychiatric assessment depressed patients remain at risk. Part of the problem is that depressed patients who have determined to seek euthanasia and see any mandated psychiatric assessment as an impediment to obtaining that outcome, are unlikely to disclose their full histories to a psychiatrist. During the operation of the *NT Act* one candidate, who was alienated from one child and had endured the death of another, withheld that information from the psychiatrist charged with her assessment. She was subsequently euthanised. People in pain want that pain to stop. Death can seem desirable when in pain. Many candidates for voluntary assisted dying change their mind when provided with pain relief and palliative care or when given access to dignity therapy.⁷ Adequate training of physicians in pain management and access to such services remain issues in Australia. A failure to appropriately control a patient's pain or to provide access to palliative care can result in requests for Assisted Suicide or euthanasia which cannot properly be termed voluntary. Just as the best legal system cannot completely eliminate the risk of an innocent person being executed, no voluntary assisted dying regime can completely eliminate risks like misdiagnosis – it is too late to discover than error on autopsy.

In his article *Legalizing euthanasia or assisted suicide: the illusion of safeguards and controls* published in *Current Oncology* Dr Jose Pereira noted that: in 2005 in the Netherlands 1 in 5 people euthanised had not given explicit consent and that a recent study in the Flemish part of Belgium revealed that 32% of the euthanasia cases studied occurred in the absence of request or consent because the patients were comatose (70%), had dementia (21%), because the physician decided it was

⁷ see "About Dignity Therapy" <http://www.dignitytherapy.com/about-dignity-therapy/>

“clearly in the patient’s best interest”(17%) or because the physician has determined that discussing it with the patient would be harmful to the patient (8%). Whilst it might be argued that the ACT would introduce better safeguards and monitoring of compliance there is no reason to believe that would be so. Reports conducted by the House of Lords Select Committee on Medical Ethics (1994), the New York State Task Force on Life and the Law (1994), the Tasmanian Parliamentary Community Development Committee (1998) and the South Australian Parliamentary Social Development Committee (1999) all concluded (three unanimously) that no law legalising euthanasia could ever be made free of the likelihood that the lives of people who did not wish to die would be endangered.

6.Risks to Minority and Vulnerable Groups

Voluntary assisted dying impacts disproportionately on the vulnerable, those suffering from mental illness, the elderly, the poor and indigenous Australians. People in these categories are more likely to consider themselves to be a burden to their families or to society as a whole. As elder abuse is already a major problem in our society voluntary assisted dying could lead to the ultimate in elder abuse – persuading family members to seek this “assistance.” There is also evidence that vulnerable groups are more likely to be euthanised. Having reviewed the operation of the *NT Act* Kissane concluded that “the gatekeeper roles designed by [the *NT Act*] failed to protect depressed, isolated and demoralized patients.” Kissane found that of the 7 people who sought to be euthanised, under the *NT Act*, 3 were socially isolated and 4 had displayed symptoms of depression. The real impact on the vulnerable of voluntary assisted dying is not just that some of them will die through this procedure when properly treated they would not have died but that the vulnerable may be discouraged from seeking needed medical attention and that the expansion of palliative care may be slowed or the under resourcing worsened which will most impact on the vulnerable. Many indigenous organisations have expressed concerns about the impact of euthanasia on Aboriginal health.

7. Adverse experiences of voluntary assisted dying

Whilst proponents of voluntary assisted dying euthanasia seem to assume a guarantee of a “good death” painlessly drifting off into a never ending sleep they fail to explain how voluntary assisted dying euthanasia could be free from the

complications which bedevil capital punishment by lethal injection. We hear little about horrible euthanasia deaths but unlike capital punishment by lethal injection, euthanasia does not normally occur in the presence of journalists and opponents of the process. Doctors and family members, who are involved in the decision making process of the person who has accessed euthanasia, are likely to support that decision. They are not likely to come forward to identify problems with the procedures. However, such evidence as there is suggests that complications are common. They include difficulties in finding a vein to inject the lethal injection, problems with the intravenous catheter, difficulties administering an oral drug, spasms, sudden, involuntary jerking of muscles, skin turning blue, nausea, vomiting, hiccups, perspiration, extreme gasping, patients waking up from a drug induced coma and death taking longer (up to 7 days) than expected. Forty years of capital punishment by lethal injection and the international experience of voluntary assisted dying suggest that complications may be inevitable. The idea that patients may be provided with substances intended to result in their death with the intention that they consume those lethal substances at a time and place of their choosing is a chilling idea for those who have read of some of the unintended and horrendous experiences of those who have sought euthanasia overseas.

8. Undesirable change within the health professions and in community attitudes to their role

Where health professional are involved in capital punishment in the United States their role can be confusing because they are normally in a position of trust and a fiduciary relationship with their patients and they normally treat, cure and save rather than end, lives. For this reason many argue that health professionals should not be involved in capital punishment. Even more confusion of roles can arise in relation to voluntary assisted dying. To date in Australia medical professionals have not been trained in the administering or calibration of lethal doses of substances – they are rather trained to avoid taking actions to intentionally cause death. If voluntary assisted dying were introduced it would be necessary to provide adequate training to those who might administer or supply. The fact that Australia does not provide universal adequate pain care management to those in pain suggests that it is unlikely that a perfect level of training would be likely to be achieved in the administering or supply of substances required for voluntary assisted dying. It would

be necessary either to have a trained speciality of persons performing this role or to seek to provide training across all health professionals. To date health professionals have not joined a profession intended to cause death. Many current practitioners may object on religious or conscience grounds to being required to participate in voluntary assisted dying. In practice many health professionals performing this role are euthanasia advocates and may have an actual or perceived conflict of interest. This is particularly so given that, a doctor has a fiduciary relationship of trust with their patient. Such a doctor may have been involved in assisting the patient to choose euthanasia and facilitated that objective. For example, Dr Nitschke paid for the fees of one of the psychiatrists who signed off on the availability of euthanasia for one of his patients during the brief operation of the *NT Act*. A change in the role of health professionals from being involved solely in the practice of healing to also being involved in the practice of voluntary assisted dying not only changes their role but it also changes the attitude of those who might seek their services particularly if they are from cultural or socio-economic groups who are reticent to seek medical assistance when needed in any event. There is at least anecdotal evidence of members of the Northern Territory's Aboriginal peoples ceasing to access necessary medical assistance, leaving hospitals and refusing immunisations during the operation of the *NT Act* out of fear of euthanasia.

9. The slippery slope of logic and reason

As States do not wish to condone or support assisted suicide or voluntary euthanasia across the general community limits are sought to be put on access to voluntary assisted dying. These limits may, for example, refer to terminally ill patients with some identified anticipated lifespan. Whatever criteria are set logic and reason pose this insurmountable problem to that criteria remaining fixed. This problem arises because whatever criteria is chosen must be a matter of subjective opinion and that criteria is inevitably going to face challenge by those who wish to access voluntary assisted dying but who fall, in the initial challenges at least, just outside the set criteria. For example if the criteria requires sufficient medical support for a diagnosis of likely death resulting from a diagnosed terminal illness within three months what of the person with a diagnoses of three months and one week or four months or five months or a year. There is no logical foundation on which whichever period is set as the criteria can logically rest. If the objective of the introduction of

voluntary assisted dying is to enable those in pain or who consider that their life is not worth living because they have a terminal illness, on what foundation of logic does the State continue, in a voluntary assisted dying world, refuse access to death by this means to those who profess to be in pain – physical or mental – but fall outside whatever criteria is set? As there can be no robust logical foundation on which a limited set of criteria is set, it is inevitable over time that in practice or in law, or in both, those criteria will not remain fixed.

Conclusion

Improvements need to be made in Australia and in the ACT in the availability of pain relief and the treatment of pain and in the care of the disabled, aged and infirm so that they are aware that they are loved by their community and that they share in the human dignity of all of human beings no matter what their physical or psychological disabilities and medical condition might be at any point in time. Focussing on improving access to better pain management, access to dignity therapy and palliative care and improving the quality and lived experience of the elderly in nursing homes and living in their own home are all positive steps that could and should be taken to demonstrate the continuing respect we have as Australians for our aging population and our sick and infirm. Voluntary assisted dying is not the answer.