



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 SELECT COMMITTEE ON END OF LIFE CHOICES IN THE ACT

The ACT branch of the Liberal Democratic Party welcomes this opportunity to comment on the above Consultation.

The ACT Liberal Democrats believe that adults have a right to end their own lives, with or without assistance, and to have access to information to help them do it. The ACT Liberal Democrats also believe in the inalienable right of individuals to end their lives painlessly, at a time of their choosing, and to be legally able to obtain information and assistance to do so with dignity.

The LDP is committed to enacting legislation to allow all adult Australians the right to assisted suicide where consent is given freely and confirmed.

The ACT Liberal Democrats note that:

- It has been nearly 25 years since the Northern Territory passed its laws relating to voluntary assisted dying. There has been political inertia until very recently.
- The risks of not introducing voluntary assisted dying far outweigh the possible risks of its introduction.
 - People are in unnecessary pain and suffering now, and existing evidence indicates models overseas have not been abused.
 - Slippery slope arguments opposing voluntary assisted dying are not been justified by the experience in jurisdictions where the choice exists.
- Limiting options for end of life choices is detrimental to human dignity. It forces people in pain and suffering to either:
 - take matters into their own hands; or
 - rely on doctors/ family who either act unlawfully or in an uncertain legal environment.
- Prohibition of assisted dying results in people ending their lives prematurely and in distressing ways while they can still exercise control over their own fate.
- There is very strong community support for allowing voluntary assisted dying.
- The model used in Switzerland should be the benchmark for any voluntary assisted dying scheme in the ACT. Adoption of a model along these lines would allow a patient-centred approach supporting self determination, while limiting the scope for abuse, and enabling strong enforcement if it occurs.
- The Victorian scheme does not provide an appropriate model for the ACT because:
 - it has a narrow scope of application when compared to the range of immense suffering possible across the human experience;

- its presumption against a patient-centred approach is unnecessarily paternalistic;
- it is unnecessarily bureaucratic, vesting power in the State to determine what must be endured and is possible to endure; and
- it has cumbersome timeframes that would prolong suffering, without hope, whether this is the patient's wishes or not. It runs the risk of many people dying from the condition before they can die under the freedom Victoria proposes to vest.

With these shortcomings, it is questionable whether the Victorian scheme will ever advance the dignity of any person currently experiencing chronic, irreversible suffering which may or may not result in death. Therefore, options for those who are in such circumstances will remain unregulated, legally uncertain or prohibited, just as they were before its enactment. As it is not yet active, there is no empirical evidence of its ability to achieve its purpose, nor is there much reason to rationally think it will.

The ACT as a progressive, mature and sophisticated jurisdiction has the willingness and capacity to develop the most appropriate voluntary assisted dying system in Australia.

If barriers to its legislative competence are removed, the Legislative Assembly will have the dignity of people's lives in its hands. Therefore, the ACT Legislative Assembly should ensure that any voluntary assisted dying scheme it introduces is not hampered by compromises and bureaucracy inherent in the recently passed Victorian legislation.

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 Liberal Democrats consider that options for end of life choices are currently very limited and detrimental to human dignity. In relation to voluntary assisted dying, in particular, people are essentially forced to either take matters into their own hands or to rely on doctors following the double effect doctrine¹ which typically involves the use of opioids to suppress respiration. It is also clear that Australian laws do not prevent voluntary assisted dying or unlawful medical practices.

The current approach does not respect individual autonomy (the right to self-determination) which demands that a competent and informed person has the right to choose how he or she dies and also has the right to ask for someone else to end his or her life, or to receive assistance to die². The right to be assisted is essential as for some illnesses or diseases people can be deprived of independence and must rely on others for basic care (such as bathing, feeding and toileting). Some people can also find it undignified to endure such circumstances.

The current arrangements are unfair. While great improvements have been made in palliative care, not all pain can be alleviated by medicine. The ACT should not discriminate against competent people who are experiencing unrelenting pain or suffering who are unable to freely end their lives just because they require assistance.

¹ see Legislative Council Legal and Social Issues Committee (2016) "Inquiry into end of life choices Final Report", Parliament of Victoria, page 101, https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf

² White B and Willmott L (2012) "How should Australia regulate voluntary euthanasia and assisted suicide? A background paper", Health Law Research Centre, Faculty of Law, QUT, November 2012 https://eprints.qut.edu.au/54757/1/How_Should_Australia_Regulate_Voluntary_Euthanasia_and_Assisted_Suicide_A21_White_and_Willmott.pdf. See pages 15-16.

The doctrine of double effect means that an act done with an intention of relieving pain is lawful (even if death is foreseen), but the same act done with an intention to kill is not lawful. While it is difficult to distinguish legal and moral distinctions based solely on a doctor's intention, it is clear that lives are already being ended unlawfully in Australia. Research studies surveying physician behaviour have concluded that Australian law has not prevented doctors from practising euthanasia or making medical end-of-life decisions explicitly intended to hasten the patient's death without the patient's request.

Various studies have found that between 4 and 7 per cent of Australian physicians reported administering, prescribing or supplying drugs with the explicit intention of hastening the end of life on the explicit request of a patient. However, it also appears that many doctors have not acted at the direct unambiguous request of the patient. In a 1999 survey of surgeons 36.2 per cent reported that, for the purpose of relieving a patient's suffering, they have given drugs in doses that they perceived to be greater than those required to relieve symptoms with the intention of hastening death. More than half of these reported that they had never received an unambiguous request for a lethal dose of medication. About one third of deaths involving a medical end-of-life decision occurred through the alleviation of pain with opioids in doses large enough that there was a probable life-shortening effect. More details are provided in **Annex 1**.

Some expert commentators³ have pointed out that as these practices are unlawful, they are also unregulated. Without appropriate—even light touch—regulation there is great uncertainty over what constitutes good practice, identifying which patients it is acceptable for doctors to assist to die, as well as what practices are acceptable, and whether doctors are really making decisions in line with patient's wishes.

The ACT Liberal Democrats also consider that the ongoing occurrence of unlawful practices in defiance of the law brings the law into disrepute.

Prohibition of assisted dying means that some people end their lives prematurely and in distressing ways.

In evidence to the Victorian Legal and Social Issues Committee Inquiry into End of Life Choices, the Coroner's Court of Victoria provided many horrific examples of how people were taking their own lives prior to the legalisation of voluntary assisted dying. These people are often the frail, elderly and vulnerable and many are dying alone and in pain. The Court noted that they are often dying earlier than they desire because they believe they must act alone, before they are no longer capable, and so that their loved ones are not implicated in their death⁴. Further detail on the Court's evidence is in **Annex 2**.

The Coroner's Court examined more than 200 cases of suicide by people experiencing irreversible decline in physical health linked either to disease or to injury⁵.

Of the **physical illness** cases, half were associated with cancer diagnoses and in most cases, the deceased had reached a point where they felt that their treatment was detracting from their quality of

³ See White and Willmott (2012) *supra* note 2, page 16.

⁴ Parliament of Victoria Legal and Social Issues Committee, 2016 *Inquiry into End of Life Choices, Final Report*, Chapter 8 "Victoria should legalise assisted dying", page 206.

https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/EOL_Report/LSIC_58-05_Text_WEB.pdf

⁵ Standing Committee on Legal and Social Issues, Inquiry into end-of-life choices, Melbourne, 7 October 2015, Transcript, Ms Caitlin English, Coroner; Mr John Olle, Coroner; and Dr Jeremy Dwyer, Manager, Coroners Prevention Unit, Coroners Court of Victoria. Pages 4-5.

https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/ELC_Transcripts/SCLSI_-_Coroners_Court_-_FINAL_-_End-of-life_choices_7_October_2015.pdf

life. Another significant group of cases (30 per cent) were people who did not actually have a terminal illness but suffered a range of different physical illnesses (such as a combination of diabetes, stroke, hypertension and heart disease) from which they were no longer able to recover. These individuals had been engaged in treatment for a long time, were not getting any better and the drugs were not doing them any good. They had come to a realisation that their physical health was not going to improve. The remainder were people with advanced incurable conditions (such as cerebral palsy) or with illness-related pain disorders. These people had been in treatment for a very long time and they were not getting relief from opioids or other pain treatment.

The **physical injury** group included people who had sustained an injury usually either from a motor vehicle collision or from a workplace injury. These people had been in treatment for up to 15 or 20 years, and the treatment had not slowed the decline in their quality of life. In most of these cases the suicide ultimately is related to a medication overdose. These cases demonstrated that these people were determined to end their life, making a strategy of prevention irrelevant. For a number of cases the patient would be unlikely to qualify for palliative care. For example, someone suffering from diabetes/hypertension/heart disease would not ordinarily be a palliative care candidate. Such people may have lived with diabetes and hypertension for years but then their eyesight started to fail, they lost their drivers licence and they then realized that things were never going to get any better. However, such a trigger is not a criterion for going into palliative care.

The Court also provided evidence on the method of suicide – with nearly three quarters of suicides being from poisoning, hanging or by firearm (Table 1 refers).

Table 1. Suicide methods among suicides of people experiencing irreversible physical deterioration caused by disease and injury, Victoria 2009-2013

Suicide method	Disease			Injury			Combined		
	number			number			share within cohort (%)		
Poisoning	54			20			29%	37%	31%
Hanging	45			19			24%	35%	27%
Firearm	29			5			16%	9%	14%
Threat to breathing	18			1			10%	2%	8%
Motor vehicle exhaust	7			6			4%	11%	5%
Rail	7			1			4%	2%	3%
Jump from height	7			0			4%	0%	3%
Sharp object	4			1			2%	2%	2%
Other methods	15			1			8%	2%	7%
All methods	186			54			100%	100%	100%
	<i>per cent</i>								
share of combined total	78%			23%			100%		

Source: Coroners Court of Victoria – further submission to the Inquiry into End of Life Choices, 20 May 2016, Submission 1037,

https://www.parliament.vic.gov.au/images/stories/committees/lsc/Submissions/Submission_1037_-_Coroners_Court_of_Victoria_further_submission.pdf

However, the figures presented in Table 1 hardly do justice to the powerful descriptions in the Coroners Court’s testimony detailing the distressing ways many Victorians chose to end their lives. These unnecessarily dreadful methods can only leave tremendously adverse impacts on the individuals in pain

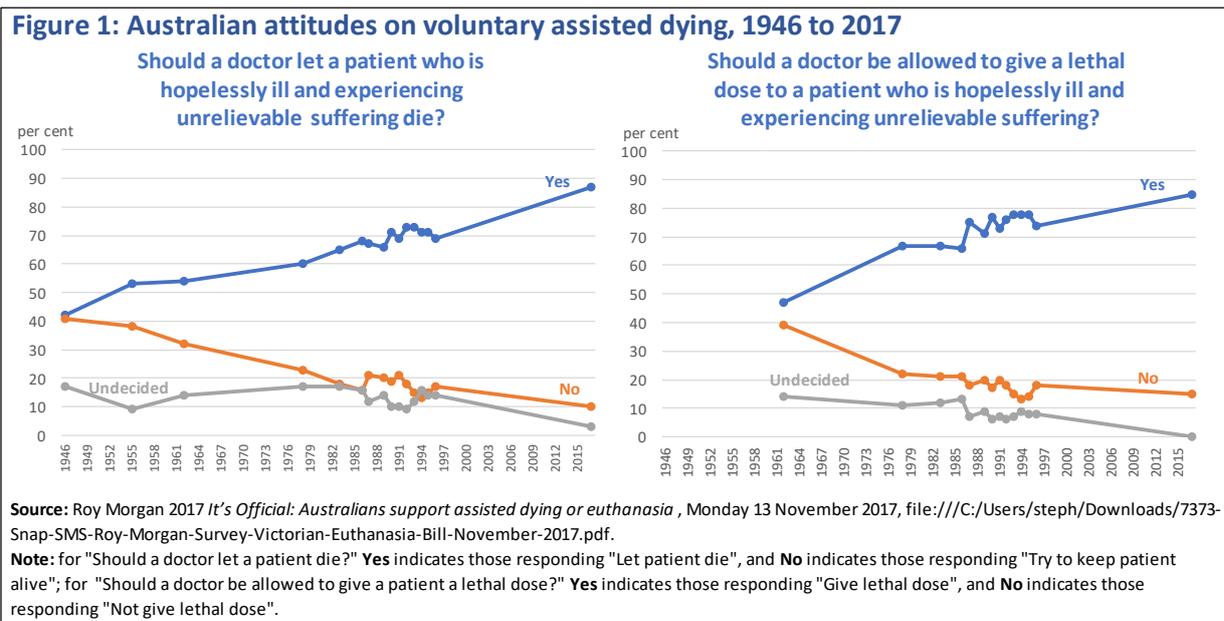
and suffering, as well as on their families and the wider community, including emergency response workers.

People should be free to make better decisions about their end of life choices. The ACT Liberal Democrats consider that a lack of resources for palliative care is not necessarily the problem or limiting factor.

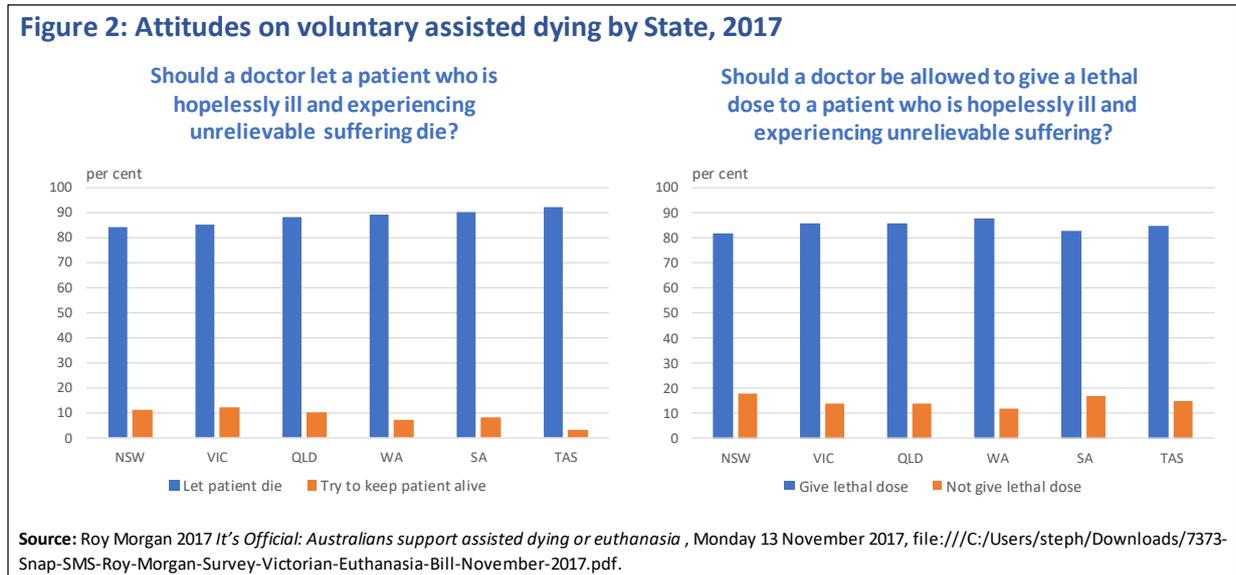
ACT community views on the desirability of voluntary assisted dying being legislated in the ACT

The ACT Liberal Democrats believe that adults have a right to end their own lives, with or without assistance, and to have access to information to help them do it. The ACT Liberal Democrats also believe in the inalienable right of individuals to end their lives painlessly, at a time of their choosing, and to be legally able to obtain information and assistance to do so with dignity.

While definitive opinion polling of the attitudes of Canberrans is not available, about eight or nine out of every ten Australians support doctors being able to let a patient who is hopelessly ill and experiencing unrelievable suffering die. Similar numbers support doctors being allowed to give a lethal dose to a patient who is hopelessly ill and experiencing unrelievable suffering (Figure 1 refers).



The ACT Liberal Democrats consider that it is unlikely that the people of the ACT would be any less supportive of voluntary assisted dying than their fellow Australians. Research indicates that support for assisted dying is strong in all States (Figure 2 refers).



Moreover, the people of the ACT generally have higher levels of education and demonstrate socially progressive attitudes compared to the rest of Australia, as was evident in the ACT recording the highest yes vote in Australian Marriage Law Postal Survey⁶.

Dying With Dignity Victoria, in its submission the Victorian inquiry into end of life choices, presented evidence from a Newspoll survey in 2012, and suggested politicians *'have more to fear from not supporting VAD [voluntary assisted dying] than they have from supporting it'*⁷.

It suggested voters supportive of the change were heavily influenced by candidate positions, despite their own historical voting record, which may be construed as allegiance. For all parties, according to the Newspoll data, for every vote lost because of support for euthanasia, a candidate gained four votes.

The Territory Chief Ministers' agreement on joint matters, including removing barriers to legislate on euthanasia⁸ has received a degree of publicity. This will allow Canberrans to offer their views to local representatives about the potential need and desire for change.

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

The ACT Liberal Democrats consider that the risks of not introducing voluntary assisted dying far outweigh the possible risks of its introduction. Our comments in relation to current practices highlighted how the prohibition of assisted dying is resulting in individuals end their lives prematurely

⁶ Australian Bureau of Statistics (2017) "Australian Marriage Law Postal Survey, 1800.0" <http://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/1800.0Main+Features382017?OpenDocument>

⁷ Dying With Dignity Victoria (2015) "Legislating for Choice", submission to Legislative Council of Victoria Legal and Social Issues Committee inquiry into end of life choices https://www.parliament.vic.gov.au/images/stories/committees/lsc/Submissions/Submission_625_-_Dying_with_Dignity_Victoria.pdf page 41

⁸ See ACT-NT Strategic Collaboration Agreement, February 2018.

and in distressing ways, as well as how doctors and patients are operating in unlawful and unregulated ways.

While greater certainty and appropriate safeguards are needed for a system of voluntary assisted dying, the ACT Liberal Democrats consider that the ACT needs to manage risks in a light touch and as simple manner, as possible. To do otherwise results in people experiencing pain and suffering who will not have their end of life choices respected.

Accordingly, the ACT Liberal Democrats believe that adults have the right to legally access assisted suicide provided there are appropriate safety mechanisms to ensure consent is given freely and confirmed. No one should be compelled to assist in the practice outside their conscience.

There may be concerns from palliative care providers (and their donors) that the introduction of a voluntary assisted dying system could cause confusion in the community about the role of palliative care in prolonging the lives of patients in as comfortable manner as possible. The ACT Liberal Democrats consider that such fears are misplaced, as a voluntary assisted dying system can be kept separate from palliative care and involve only the patient, their family and the doctors concerned.

It is not clear that more permissive systems have led to slippery slopes. Research into one of the voluntary organisations in Switzerland (EXIT Deutsche Schweiz) noted that reporting rates appeared to be 100 per cent despite increasing numbers of assisted suicides⁹. Another source noted that there are approximately 62,000 deaths in Switzerland each year and that academic studies suggest that between 0.3 per cent and 0.4 per cent of these are assisted suicides. This figure increases to 0.5 per cent of all deaths if suicide tourism is included¹⁰.

There does not appear to be much evidence of a slippery slope in other jurisdictions. One study into assisted dying in the Netherlands and Oregon found no evidence of heightened risk among vulnerable groups such as older people, women, the uninsured, people with low educational status, the poor, the physically disabled or chronically ill, minors, people with psychiatric illnesses including depression, and people from racial or ethnic minorities¹¹.

Another study that reviewed the systems in the Netherlands, Belgium, Oregon and Switzerland found that the legal criteria that apply to an individual's request for assisted dying are well respected, that individuals who receive assisted dying do so on the basis of valid requests; and third parties who assist individuals to die do not act unlawfully¹².

⁹ Schuklenk U, van Delden J, Downie J, McLean S, Upshur R and Weinstock D (2011) "End-of-Life Decision-Making in Canada: The Report by the Royal Society of Canada Expert Panel on End-of-Life Decision-Making", *Bioethics*. 2011 Nov; 25 (Suppl 1): 1–4. doi: 10.1111/j.1467-8519.2011.01939.x <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3265521/> page 82

¹⁰ The Commission on Assisted Dying (2011) "The current legal status of assisted dying is inadequate and incoherent...", Demos, London https://www.demos.co.uk/files/476_CoAD_FinalReport_158x240_I_web_single-NEW_.pdf?1328113363 page 259.

¹¹ Battin M, van der Heide A, Ganzini L, van der Wal G, and Onwuteaka-Philipsen B (2007) "Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in "vulnerable" groups". *Journal of Medical Ethics* 2007; 33:591–597. doi: 10.1136/jme.2007.022335 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2652799/pdf/591.pdf>

¹² Lewis P and Black I (2013) "Adherence to the request criterion in jurisdictions where assisted dying is lawful? A review of the criteria and evidence in the Netherlands, Belgium, Oregon, and Switzerland." *J Law Med Ethics*. 2013 Winter;41(4):885-98, doi: 10.1111/jlme.12098 <http://journals.sagepub.com/doi/abs/10.1111/jlme.12098>

The ACT Liberal Democrats consider that the introduction of an extended probate period could help alleviate concerns related to abuse of the elderly for financial gain. Such a scheme would involve delaying the access of beneficiaries to the deceased's estate for a suitable period. This period would apply only to those involved in the voluntary assisted dying scheme and could include exemptions that allowed for special circumstances. Many families who have witnessed the pain and suffering of a loved one despite the best efforts of palliative care would forego the immediate benefits, in order to relieve the pain of a family member, where it was requested. Such a measure would neutralise opposition on grounds of 'selfish' motives and ensure the scheme has a patient centred approach.

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

The research into models should absolutely not rest on the two Australian examples enacted in NT and Victoria.

There are significant differences in how schemes for voluntary assisted dying operate across the world and the benefits and risks of each should be understood and weighed. International schemes with a history of operation provide more valid examples of possible models than local models that have not been implemented. Accordingly, placing emphasis on the Victorian scheme is unwarranted, as it is not active and offers no evidence based approach for comparison.

Voluntary assisted dying is legalised in the following jurisdictions outside of Australia:

- Switzerland
- Netherlands
- Belgium
- Luxembourg
- Canada
- USA jurisdictions including
 - Montana
 - Oregon
 - Washington
 - Vermont

The ACT Liberal Democrats consider that any system should be as simple as possible, as too cumbersome an approach runs the risk of prolonging pain and suffering and could have unintended consequences, such as medical practitioners choosing to opt out.

The ACT Liberal Democrats consider that reform of end of life choices in the ACT should be benchmarked against the system used in Switzerland as this is the model that allows the widest personal freedom. While it has been argued that Switzerland was able to develop a permissive regime because assisted suicide, under certain conditions, was not criminalized in the first place there is no reason why a liberal regime cannot be introduced in the ACT.

The most significant aspect of the Swiss model¹³ is that provided the person assisting another to die is not motivated by selfish motives an offence has not been committed. This means that assistance can be provided by friends and relatives. Other features of the model include:

¹³ For details of the Swiss model see Schuklenk U, van Delden J, Downie J, McLean S, Upshur R and Weinstock D (2011) "End-of-Life Decision-Making in Canada: The Report by the Royal Society of Canada Expert Panel on End-of-

- no requirement that doctors are involved in the suicide.
 - the vast majority of assisted suicides which take place in Switzerland are not directly supervised by doctors;
 - assisting a suicide is often undertaken by one of the four voluntary organisations that exist in Switzerland; and
 - doctors are sometimes asked by their patients to assist in their death and the Swiss Academy of Medical Sciences has issued guidelines which declare that while physician-assisted suicide is not part of a doctor's task, the consideration of the patient's wishes is fundamental for the doctor patient relationship;
- limiting the circumstances where assisted suicide is considered to be a crime. In particular, in Switzerland assisted suicide is a crime only when four elements can be shown:
 - a suicide was committed or attempted;
 - a third party encouraged or helped in the suicide;
 - the third party acted on selfish grounds; and
 - the third party acted deliberately;
- having a system of reporting and investigation of all suicides;
- no requirement that the individual be terminally ill to be eligible for assisted suicide; and
- no residency requirement.

Therefore, it is open to Australians with the means to travel to Switzerland, who wish to 'go gently' or die with dignity by accessing voluntary assisted dying. At least 27 Australians have been assisted to die in Switzerland. Being able to exercise this choice in Australia would bring immeasurable benefits in terms of reduced stress and costs to the individuals and families concerned¹⁴.

The right to a dignified death should not hinge upon one's financial means to access it overseas. This ought to be abhorrent to any progressive thinker.

One aspect of the Swiss model is that, as the relevant article is part of the Penal code, it does not create a right to assisted suicide (rather, it recognizes the liberty to request assisted suicide and leaves it to each third party—whether a health-care professional or not—to accept such a request). Again, there is no reason why a new legislative scheme could not create such a right.

The Victorian approach includes a number of deficiencies that undermine its principal purpose of meeting the needs of those making free end of life choices. In addition to the unnecessary residency requirement:

- it has a narrow scope of application when compared to the range of immense suffering possible across the human experience.
- its presumption is against a patient-centred approach so it is unnecessarily paternalistic;
- it is unnecessarily bureaucratic, vesting power in the State to determine what must be endured and is possible to endure; and
- it has cumbersome timeframes that would prolong suffering, without hope, whether this is the patient's wishes or not. It runs the risk of many people dying from the condition, before they can under the freedom Victoria proposes to vest.

Life Decision-Making", *Bioethics*. 2011 Nov; 25 (Suppl 1): 1–4. doi: 10.1111/j.1467-8519.2011.01939.x <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3265521/> pages 81-82. See also White and Wilmott (2012) *supra* note 2, pages 12-13.

¹⁴ Between 2003 and 2017 Dignitas assisted 27 Australians to end their lives in Switzerland. This represented 1 per cent of such suicides in Switzerland. See Dignitas "Accompaniments to suicide per year and residence" http://dignitas.ch/index.php?option=com_content&view=article&id=32&lang=en

With these shortcomings, it is questionable whether the Victorian scheme will ever advance the dignity of any person currently experiencing chronic, irreversible suffering the natural history of which may or may not result in death. Therefore, options for those who are in such circumstances will remain unregulated, legally uncertain or prohibited, just as they were before its enactment. As it is not yet active, there is no empirical evidence of its ability to achieve its purpose, nor is there much reason to think it will.

We consider that the ACT has the maturity and sophistication to introduce a liberal and compassionate voluntary assisted dying scheme.

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

The *Euthanasia Laws Act 1997* was introduced by the Federal Parliament because the Northern Territory introduced and passed laws authorising euthanasia. The power of veto by the Commonwealth is possible because of the Territory power (section 122) in the Australian Constitution. While the Commonwealth can exercise this power of veto, any law passed by the Territory, including those which relate to the subject into the future, may not endure.

The current path can only be changed by:

- consent of the Commonwealth Parliament to remove the Act vetoing the law;
- referendum to remove the Territory power; or
- the ACT becoming a State.

The latter option is very unlikely. The middle path is historically unlikely to carry. Therefore, parliamentary consent, based on broad consensus across political divides is necessary.

Presently, two draft pieces of legislation are intended for introduction in the Federal Parliament - LDP Senator David Leyonhjelm's private Member's bill "Restoring Territory Rights (Assisted Suicide Legislation)"¹⁵ and Senators Di Natale and Gallagher's "Restoring Territory Rights (Dying with Dignity) Bill 2016"¹⁶.

Both bills prescribe the same substantive repeals to reach the outcome of authorising the Territory to pass laws regarding euthanasia.

Despite overwhelming community support, reform of the law governing voluntary assisted dying or euthanasia has been difficult. Between 1993 and the successful passage of legislation in Victoria there have been 52 attempts at legislating in Australian Parliaments. Not counting the two Federal private Member's bills currently extant, researchers have found only one Bill has been successful and only six

¹⁵ "Restoring Territory Rights (Assisted Suicide Legislation) Bill 2015 No. , 2015 (Senator Leyonhjelm) A Bill for an Act to amend certain Acts relating to the territories, and for other purposes"

http://parlinfo.aph.gov.au/parlInfo/download/legislation/bills/s1030_first-senate/toc_pdf/1523420.pdf;fileType=application%2Fpdf

¹⁶ "Restoring Territory Rights (Dying with Dignity) Bill 2016 No. , 2016 (Senators Di Natale and Gallagher) A Bill for an Act to amend certain territory legislation to restore legislative powers concerning euthanasia and to repeal the Euthanasia Laws Act 1997, and for related purposes"

http://parlinfo.aph.gov.au/parlInfo/download/legislation/bills/s1034_first-senate/toc_pdf/1603920.pdf;fileType=application%2Fpdf

others were 'close to passing'. These seven Bills represent only 14 per cent of all attempts from 1993 to 2015¹⁷.

In its current hyper partisan state, the Federal Parliament should welcome the introduction of a bill by a neutral third party. This issue is too important to be politicised for the benefit of one side or the other. This approach frees all Members of the Federal Parliament to vote based on conscience as there is no political advantage by binding any side to a position. Senator Leyonhjelm's bill which was first introduced in 2015, will be reintroduced in its previous form in 2018.

At the time of writing, it is not known whether Senator Gallagher will be found eligible to remain in the Senate. It is also unknown whether her replacement will be an advocate of voluntary assisted dying to lend Labor support to the private Member's bill as was planned for the alternative bill. It is not expected that Senator Seselja – the other ACT senator – would support the bill.

Senator Leyonhjelm's private Member's bill is specifically targeted at repealing the *Euthanasia Laws Act 1997*, its objects are:

- (a) to reduce Commonwealth interference with the laws of the Australian Capital Territory and the Northern Territory; and
- (b) to facilitate competitive federalism in law-making; and
- (c) to recognise the right of the Australian Capital Territory and the Northern Territory to legislate for assisted suicide within their jurisdictions; and
- (d) to repeal the *Euthanasia Laws Act 1997* the enactment of which was inimical to the objects stated in paragraphs (a) to (c).

The Territory should be given the best chance of successful reform in end of life choices through the Federal Parliament considering draft legislation targeted at repeal of the *Euthanasia Laws Act*. This would also create synergies by combining the efforts of Senators and members supportive of sensible reform to voluntary assisted dying in the ACT. By expressly recognising the benefits of competitive federalism, the ACT would be free to diverge from the Victorian model's shortcomings and create a path for evidence based analysis of actual policy outcomes.

The ACT Liberal Democrats also note news reports that the Canberra Liberals have indicated that the party would not lobby to overturn the *Euthanasia Laws Act* and that voluntary euthanasia was a conscience issue for them¹⁸.

It would be unfortunate to miss this opportunity for reform due to—possibly misplaced—concerns about overly-broad objectives relating to the rights of territories. This runs the risk of extending the pain and suffering of individuals and families.

The time to act is now.

¹⁷ Willmott L, White B, Stackpoole C, Purser K and McGee A (2016) "(Failed) Voluntary Euthanasia Law Reform in Australia: Two Decades of Trends, Models and Politics", *UNSW Law Journal* Volume 39(1)

<https://eprints.qut.edu.au/95429/1/Failed%20Voluntary%20Euthanasia%20Law%20Reform%20UNSWLJ.pdf>

¹⁸ Le Lievre K (2018) "ACT joins forces with NT to call for voluntary euthanasia reform", *The Canberra Times* February 25 2018. <http://www.canberratimes.com.au/act-news/act-joins-forces-with-nt-to-call-forvoluntary-euthanasia-reform-20180223-h0wkla.html>

Conclusion

Legalising voluntary assisted dying is not incompatible with maintaining the best standards of palliative care. History demonstrates the strength of the human instinct to survive. It is powerful and unconscious. This is the most logical argument against those who oppose voluntary assisted dying.

For many people right now, euthanasia policy is not a theoretical, philosophical or ethical issue – it does not exist in a vacuum; their lives have become defined by the illness or the injury diminishing their quality of life. The broad and instinctive support in the community reflects the comfort that is obtained by knowing the choice would be available, when they choose that ‘all is hope is lost’ and the conditions under which they live are unbearable.

It is the ability to wrest back control, where dignity is found. This holds true whether the action of dying is taken.

This is why the ACT Liberal Democrats believe that adults have a right to:

- end their own lives, with or without assistance, and
- have access to information to help them do it.

Access to voluntary assisted dying must not be hampered by compromises and bureaucracy as is inherent in the recent Victorian legislation. It must also adequately safeguard express intention and consent.

The ACT as a progressive, mature and sophisticated jurisdiction has the willingness and capacity to develop the most appropriate voluntary assisted dying system in Australia – one that can achieve the outcome of relieving immense suffering and offering dignity to those who wish to exercise free choice and self determination.

Unlawful medical practice

A number of research studies have concluded that Australian law has not prevented doctors from practising euthanasia or making medical end-of-life decisions explicitly intended to hasten the patient's death without the patient's request.

One study concluded that Australian law had not prevented doctors from practising euthanasia or making medical end-of-life decisions explicitly intended to hasten the patient's death without the patient's request. The proportion of all Australian deaths that involved a medical end-of-life decision in 1995-1996 were:

- euthanasia, 1.8 per cent (including physician-assisted suicide, 0.1 per cent);
- ending of patient's life without patient's concurrent explicit request, 3.5 per cent;
- withholding or withdrawing of potentially life-prolonging treatment, 28.6 per cent;
- alleviation of pain with opioids in doses large enough that there was a probable life-shortening effect, 30.9 per cent.

In 30 per cent of all Australian deaths, a medical end-of-life decision was made with the explicit intention of ending the patient's life, of which 4 per cent were in response to a direct request from the patient¹⁹.

Another study found that more than a third of surgeons surveyed in 1999 reported giving drugs with an intention to hasten death, often in the absence of an explicit request. In many instances, this may involve the use of an infusion of analgesics or sedatives. These actions may be difficult to distinguish from accepted palliative care, except on the basis of the doctor's self-reported intention. This study found that 36.2 per cent of respondents reported that, for the purpose of relieving a patient's suffering, they have given drugs in doses that they perceived to be greater than those required to relieve symptoms with the intention of hastening death. More than half of these reported that they had never received an unambiguous request for a lethal dose of medication. Of all respondents, only 5.3 per cent reported that they had given a lethal injection, or had provided the means to commit suicide, in response to an unambiguous request²⁰.

A study in 2007 found 43 per cent of doctors who had treated at least one terminally ill patient had been asked at least once to hasten death by administering drugs. The study also found that 35 per cent of these doctors reported administering drugs with the intention of hastening death at least once²¹.

A 2008 survey that compared doctors' attitudes and experiences in six European countries and Australia found that 7 per cent of physicians in Australia reported administering, prescribing or supplying drugs with the explicit intention of hastening the end of life on the explicit request of a patient²².

¹⁹ Kuhse H, Singer P, Baume P, Clark M, and Rickard M (1997) "End-of-life decisions in Australian medical practice". *Med J Aust.* 1997 Feb 17;166(4):191-6. <https://www.ncbi.nlm.nih.gov/pubmed/9066548?dopt=Abstract>

²⁰ Douglas C, Kerridge I, Rainbird K, McPhee J, Hancock L, Spigelman A (2001) "The intention to hasten death: a survey of attitudes and practices of surgeons in Australia". *Med J Aust.* 2001 Nov 19;175(10):511-5. <https://www.ncbi.nlm.nih.gov/pubmed/11795535>

²¹ Dr Neil Orford, Medical Director Intensive Care Unit, Barwon Health, Transcript of evidence, 29 July 2015, p. 721. cited in Parliament of Victoria Legal and Social Issues Committee, 2016 *Inquiry into End of Life Choices, Final Report*, Chapter 8 "Victoria should legalise assisted dying", Chapter 6 The existing legal framework governing end of life in Victoria, page 183

https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/EOL_Report/LSIC_58-05_Text_WEB.pdf

²² Löfmark R, Nilstun T, Cartwright C, Fischer S, van der Heide A, Mortier F, Norup M, Simonato L, Onwuteaka-Philipsen B, and the EURELD Consortium (2008) "Physicians' experiences with end-of-life decision-making: Survey in 6 European countries and Australia", *BMC Medicine* 2008 6:4 <https://doi.org/10.1186/1741-7015-6-4>

The Coroner's Court of Victoria evidence

In evidence to the Victorian Legal and Social Issues Committee Inquiry into End of Life Choices, the Coroner's Court of Victoria provided many horrific examples of how people were taking their own lives before the legalisation of voluntary assisted dying. These people are often the frail, elderly and vulnerable. Many died alone and in pain.

The Court noted that they are often dying earlier than they desire because they believe they must act alone, before they are no longer capable, and so that their loved ones are not implicated in their death²³.

During their evidence before the Inquiry, the Coroner's Court noted it had examined around 200 cases of suicide by people experiencing irreversible decline in physical health. Of these about 80 per cent were suicides where the irreversible decline was linked to disease, and about 20 per cent were suicides linked to injury²⁴.

Of the **physical illness** cases:

- About half were associated with cancer diagnoses, particularly the return of cancer after successful first treatment, the metastasising of cancer, and particular types of cancer such as pancreatic cancer. In most of these cases, the deceased has reached a point where they felt that treatment was detracting from their quality of life.
- Around 30 per cent were people who did not actually have a terminal illness. They suffered a range of different physical illnesses from which they were no longer able to recover. Examples included someone suffering heart disease, prostate issues and lumbar spinal osteoarthritis; or combination of diabetes, stroke, hypertension and heart disease. They engaged in treatment for a long time, did not get any better and the drugs did not do them any good. They came to a realisation that their physical health was not going to improve.
- About 15 per cent were people with well advanced incurable conditions, such as:
 - cerebral palsy
 - Parkinson's
 - multiple sclerosis
 - muscular dystrophy.
- About 5 per cent were people with illness-related pain disorders. Usually they had been in treatment for a very long time and they did not get relief through opioids or other pain treatment such as direct spinal stimulation. For people in these circumstances, every day was distressing.

The **physical injury** group included people who sustained a physical injury usually either from a motor vehicle collision or from a workplace injury. They were often in treatment for up to 15 or 20 years, and

²³ Parliament of Victoria Legal and Social Issues Committee, 2016 *Inquiry into End of Life Choices, Final Report*, Chapter 8 "Victoria should legalise assisted dying", page 206.

https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/EOL_Report/LSIC_58-05_Text_WEB.pdf

²⁴ Standing Committee on Legal and Social Issues, Inquiry into end-of-life choices, Melbourne, 7 October 2015, Transcript, Ms Caitlin English, Coroner; Mr John Olle, Coroner; and Dr Jeremy Dwyer, Manager, Coroners Prevention Unit, Coroners Court of Victoria. Pages 4-5.

https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/ELC_Transcripts/SCLSI_-_Coroners_Court_-_FINAL_-_End-of-life_choices_7_October_2015.pdf

the treatment was unable to slow the decline in their quality of life. In most of these cases the suicide method favoured related to a medication overdose. These people were taking medications for a long time, were getting worse and often suffered from the side effects of their medications. They ultimately made the decision to end their lives.

The transcript evidence from the Coroners Court also indicated that:

- these cases demonstrated that these people were determined to end their life, so a strategy of prevention was not relevant;
- for a number of cases the patient would be unlikely to qualify for palliative care. For example:
 - someone suffering from diabetes/hypertension/heart disease would not ordinarily be a palliative care candidate. Such people may have lived with diabetes and hypertension for years. Then their eyesight started to fail and they lost their drivers licence and they come to the realisation that things are never going to get any better. However, such a trigger is not a criterion for going into palliative care; while
 - in other instances there is no medical event – such as a fall – that could mean that a person ends up in hospital and then goes down a palliative care track. Moreover, the suicide cases often include people with a level of independence; and
- despite their suffering, the then legal status isolated them, and required them to die alone, and in some cases with physical violence by their own hand, to ensure family members were spared legal consequences or liability.

Further detail

The Coroner's Court of Victoria also provided evidence that between 2009 and 2013 there were 240 suicides in Victoria of people who were experiencing irreversible decline in physical health. These included 186 suicides where the irreversible decline was linked to disease, and 54 deaths where it was linked to injury²⁵. These represented over 8 per cent of all suicides in Victoria at this time.

Among the suicides related to disease, most deceased were suffering from multiple diseases, the most frequent of which included:

- Cancer in approximately 50 per cent.
- Diabetes in approximately 10 per cent.
- Arthritis in approximately 10 per cent.
- Cardiovascular disease in approximately 8 per cent.
- Parkinson's disease in approximately 5 per cent
- Huntington's disease in approximately 4 per cent.

Examples of combinations of diseases included Hepatitis C, neuropathy, anaemia and osteoporosis; Hypotension, osteoarthritis and lumbosacral spondylolysis; Diabetes, hypertension and glaucoma; and Chronic obstructive airways disease and congestive cardiac failure.

Among the injury-related suicides, motor vehicle collisions accounted for approximately 50 per cent of cases and workplace injuries approximately 25 per cent of cases.

²⁵ Coroner's Court of Victoria – further submission to the Inquiry into End of Life Choices, 20 May 2016, Submission 1037, https://www.parliament.vic.gov.au/images/stories/committees/lsc/Submissions/Submission_1037_-_Coroners_Court_of_Victoria_further_submission.pdf