



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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Select Committee on End of Life Choices in the ACT

Inquiry into End of Life Choices in the ACT

I attach my views and wishes concerning all the terms of reference for this important and timely inquiry.

I strongly urge the ACT Government to investigate thoroughly how it can enable ACT residents to take responsibility, if they wish, for when they want to die, to have access to assistance that may help them carry out their wishes in a non-judgemental, non-punitive way, and without onerous procedures or long delays that would add to any distress or suffering experienced by the individuals concerned.

The reasons for this – personal, social, economic – are all included in my submission.

My views on end of life matters have been consistent and have strengthened over many years, and could be summarised in my published response below (SMH 6/3/15) to the Federal Government’s comments on the 2015 Intergenerational Report:

Governments are in no position to advance veiled whinges about dire budgetary impacts and economic challenges of an ageing population while they fail to allow us practical and compassionate options for end-of-life decision making. Just give us the ability and means to avoid, if we wish, the channelling of thousands of our own hard-earned dollars and those of other taxpayers to the burgeoning medical, pharmaceutical and aged care sectors that can be required even now to enable us to eke out an increasingly poor quality and stressful existence before the inevitable happens.

Sue Dyer Downer (ACT)

I believe the ACT Government should lead this country in progressive social change that provides residents, and possibly others, with options for voluntary- assisted dying (VAD) and /or other supports and options for voluntary euthanasia. The ACT certainly would not be leading the world - other developed countries have done that - but the ACT should aim to significantly improve on the medicalised and limited arrangements that have been legislated for in Victoria.

I wish the Committee well in its investigations and deliberations.

Thank you.

Yours faithfully

Sue Dyer



Downer ACT 2602

12 March 2018

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TOR 1

Current practices utilised in the medical community to assist a person to exercise their preference in managing the end of life, including palliative care.

- My strong impression is that the medical community focuses on a medicalised approach ie pain relief where possible, palliative care, and following an individual's Advance Care Plan directives re stopping treatment, drugs, etc. This of course relates to those suffering terminal illness or other conditions that will eventually kill them, directly or indirectly.
- They address dealing with end of life suffering, about pain relief, and palliative care, even when more and more evidence suggests this is not necessarily an adequate and effective response for many with terminal illnesses.
- The medical community does not offer advice and support for those who may wish to end their life when they have other medical conditions (eg chronic and debilitating conditions affecting quality of life significantly but not necessarily terminal for some years to come, or even at all, or do not wish to experience social and/or economic circumstances which may be exacerbated by financially and psychologically draining medical and/or other daily life conditions.
- My experience is that
 - those who put effort and thinking into their will, estate plan, Enduring Power of Attorney (EPA), memorandum of wishes, and Advance Care Plan, have no wish to waste their savings on institutional care and the pharmaceutical and medical sectors whose charges continue to rise and will eat into savings significantly
 - those who do not mind using savings for these purposes may, when finding themselves totally reliant on the public purse, do not wish to experience lengthy care and treatment options that are increasingly inadequately resourced and open to abuse (TOR3, third dot point, about the federal inquiry into the *'Quality of care in residential aged care facilities in Australia'* also refers)
 - overall, my views on current practices which are driven largely by the medical and pharmaceutical sectors, are outlined in the text of a letter to the editor in my covering note to this inquiry, about government not being in a position to deny voluntary euthanasia options when increasing costs of health and aged care face all generations
 - rising costs are a real concern, and will not disappear and it is unreasonable to expect governments to meet every cost.
- The community needs become more aware that it is impossible and unrealistic to expect that governments can guarantee financially that anyone can access all the resources needed and support to live out their life well and comfortably in worsening circumstances, for as long as it takes. Rising costs to the individual and the deficiencies and inability of the public and private sectors to provide support currently continue to cause considerable concern - see Attachment A for examples of this in the media over only one weekend.
- Many Australians are waking up to the numerous and growing costs (financial and non-financial) and associated deficiencies in living a long life, even without chronic or terminal illnesses.
- Governments should therefore give people real choices about saving their own and taxpayers' funds and allow them to end their life when they wish in guaranteed, non-violent and non-

stressful ways, including methods utilising medical supervision if this is what is preferred by the individual.

- My impression is that the current informal medical approaches for enabling individuals to exercise their end of life choices focus on situations involving terminal illnesses only, by increasing drug intakes or withdrawing treatments. The individual is largely passive in these circumstances and it is difficult to advance end of life in non-grim ways. Choosing to starve yourself to death is one option, as undertaken by a friend's mother after a stroke (given the poor long term outlook and associated dependencies), but no-one should have to contemplate let alone carry this out. Other more humane options should be readily available.

There seems to be no way of bringing on earlier death if an individual wishes eg at the beginning of an Alzheimer's diagnosis or other dementias or diseases which will inevitably kill (in the case of Alzheimer's, the body after the mind).

- Given the current practices and constraints, the only other action individuals can take is to arrange death by violent and probably very distressing means, or seek information and assistance from an organisation like Exit International about less violent means, or seek to use expensive end of life arrangements overseas
 - all of these other options are unacceptable for reasons of humaneness (ie animals receive a better end to their lives than many humans), financial cost or lack of equity of access to the various options, or the capability to search them out.

TOR 2

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

- Enabling Voluntary Assisted Dying (VAD) should be a prime ACT Government objective in its current term
 - logical acceptance of this would be more likely here because of the ACT's demographics and the more highly educated and socially aware population and willingness to give freedom of choice to others (the same sex marriage survey results refer).
 - VAD should be available, not just for the terminally ill – any legislation should go much further than the limited medical model being set up for Victoria
 - an approach that focuses more broadly on human rights should be adopted so that those without terminal illness should also have access to safe means of ending their life if they wish (for personal, social, economic or health reasons including debilitating chronic health conditions that cause total dependence on others at high psychological and/or financial cost)
 - in addition those with terminal illnesses should not have to endure living until say six months of life is predicted to be left to them (as in Victoria). Animals in these situations do not have this requirement forced upon them.
- Individuals are expected by all governments to take responsibility for most aspects of their lives for decades
 - being able to exercise end of life choices in a compassionate and non-violent way at a time of their choosing is another responsibility which individuals should not be prevented from exercising by any government, territory or federal.
- It is not the business of churches, religious or other non-government organisations and institutions to determine if, when, and how an individual exercises end of life choices
 - they should focus only on those do not wish to exercise such a right or responsibility.
- Individuals who make their views well known, eg in writing, in Advance Care Plans, etc should have the means to end their lives peacefully; if they are in a situation where they suddenly can't direct or exercise this wish themselves, then others should have the right to ensure that their wishes are met with the least delay and bother possible, and without punishment.
- Quality of life decisions and the desire not to be partially or fully dependent on others should be accepted as reasons validating an individual's wish to end their life. For example, persons who have suffered major strokes and have a poor inability to understand what is happening to them, cannot respond well to others, have little hope of improvement and are highly dependent on others should have access to VAD, particularly if written instructions have been given for this
 - VAD should be legal if an individual considers that their mental or physical health situation or outlook is unendurable for social, economic or health reasons, including inability to manage life in a comfortable manner or independently, without financial stress or risk of abuse

- The individual's self-assessment should be paramount ie if they wish to end life before they become less mobile, more incontinent, more forgetful and confused, more fearful, isolated, unable to engage with their environment and others, are dependent on others for everything that is required to be done in their daily life, and/or if they have a diagnosis of a condition (mental or physical) that will probably lead to their death eventually.
- An individual should be able to determine when a life well lived is unlikely to continue and if they do not wish to experience the changes and all the dependencies and mind and body impositions that are likely to accompany this.
- It should be recognised that many do not want to be forced to live a long life regardless of its quality and costs (for themselves and taxpayers).
- It should be recognised that many do not wish to become partially or fully dependent on others – whether family or employed carers (in the home or residential care) – the costs, risks of abuse and increasing inability of an individual to rectify deficiencies
 - in addition, many 'baby boomers' do not have children who might be able to assist with their care (though this should not be expected either by individuals of government – the burden it places on others can be massive and destructive to their health). Employing advocates to ensure quality care, and others to monitor and attend to day-to-day matters that are never covered by residential care charges, can be exorbitant.
- The governmental mantra of the benefits of 'ageing in and receiving care in place' (including the home) is still fraught with risks, stress, and possible financial ruin at a stage in life when individuals are likely to have less and less ability and energy to problem solve, organise and monitor care arrangements (and their deficiencies) – unless others are on hand to monitor (often on a daily basis), negotiate, liaise and act to improve the quality of care, especially as an individual's own functioning and abilities decrease.
- NDIS, already under financial pressure from the demand for its services from those under 65, is not available for those over 65 – meeting the costs of any disability and early intervention needs is increasingly having to be borne by governments or the individual. This, like the purchase of certain drugs, can be financially destructive not just of individuals but also of their family if they have one.
- VAD and legal recognition of voluntary euthanasia in general should be available to those who receive a diagnosis of a condition that will eventually kill them and who do not wish to see out the condition for an indeterminate time
 - for example, besides many cancers and other diseases, various dementias, including Alzheimer's, will kill, sometimes very slowly but surely. Fast or slow, the cruel changes in mental and physical functioning and behaviours should be able to be avoided, if an individual so wishes, through VAD or other means of voluntary euthanasia before awareness and abilities are badly compromised
 - poor means of communication, loss of understanding and awareness of needs and surroundings, incontinence, aggressive and abusive, fearful or petulant behaviours towards others should not have to be contemplated by an individual, let alone endured. (Plus enduring the risks arising from such conditions and

circumstances – see TOR 3). Such conditions increasingly require dependency on others whose abilities to provide support may be deficient for a range of good reasons. Quality of life is not achievable with many conditions at any age. Living – just – may be, but not quality. Distress, fear and accompanying anti-social behaviours will only increase and worsen the individual's existence and sometimes the responses of others

- researchers, pharmaceutical companies and support organisations will continue to put out optimistic, skewed views about life before death in these circumstances. No-one describes the truth in the media. Given the numbers affected and resources required but not available to provide safe, quality of life for all with such conditions, those who wish to by-pass the often horrendous dying process should be allowed and assisted to do so at an early stage of diagnosis.
- Likewise, those without terminal diseases or conditions should be able to call a halt to living before they become full-time burdens on others, the state or their own estate.
 - those who wish to donate, say, much of their estate to national cultural institutions (and make a difference to many lives in the future) should be able to halt expenditure on a plethora of essential personal support mechanisms, so that their donations are maximised for others to enjoy – this requires access to VAD or other means of achieving a guaranteed and peaceful death.
- More and more advertisements are now appearing for purchase of a large range of home-based services which those without part or full-time support by family or others (ie 'free of charge') will increasingly have to spend large amounts of money on, eg:
 - independent nursing
 - transition to aged care research and services
 - downsizing
 - personal care
 - pharmaceutical services
 - respite for carers
 - companionship
 - linen services
 - household tasks
 - major cleaning
 - gardening
 - relocations
 - handyman jobs
 - advocacy for patient care, and so on.
- This support industry, all involving 'outside helpers', costs money, and rightly so, but individuals should be able to decide if they do or do not wish their estate to be frittered away, possibly over many years on services that are increasingly provided by profit-making companies and organisations
 - it needs to be recognised and accepted by governments, the medical profession, pharmaceutical industry, and researchers that many people, as they age, do not want to live increasingly futile lives, especially when the main antidote to this is expenditure of large amounts of money. The great majority do not have this available to them and

those who do may see it disappear very quickly: then what? No wonder many desire to plan and control their life and death as they wish

- if they wish to put their affairs in order and end their life, for whatever reason, at a time chosen by them, they should be allowed to do so (as they can now via suicide) but with a VAD or similar legislated framework in place they could access support and assistance to improve what they might have to experience to achieve death.
- Rejection of palliative care for those with terminal illness should be recognised as valid and achievable by VAD or similar. I have had friends who have not wanted to endure lengthy home-based palliative care, or have not wanted to accept the next stage of moving to a palliative care institution even for three or so weeks of extremely poor “living” in a highly drugged state. But currently people are forced to do this, while enduring a horrible and worsening state of “living”
 - those who wish to avoid any palliative care or only limited periods of it (at home or elsewhere) should be given the opportunity to quickly access VAD or other means of voluntary euthanasia. If unable to communicate this, others should be able to expedite the processes required, based on understanding of the individual’s prior expression of wishes, written, recorded or otherwise.
- The above comments are based on personal experience of watching friends and elderly relatives die lingering deaths, both in and out of formal care arrangements.
- I will not have a full-time advocate, monitor, and problem solver to try to minimise stress and discomforts that could arise during a long and distressing lead-up to death, through natural causes or onset of disease or disability.
- I therefore wish to seek the means to implement my end of life choices, and having some assistance available (for a fee of course) in recognition of my wishes is a highly desirable and comforting thought.

TOR 3

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

- There will always be risks to individuals under any VAD or similar arrangement but surely, based on experience elsewhere, these can be identified, addressed and avoided to a great extent.
- In the past year a battery of media coverage has reminded us bleakly of the many ongoing and seemingly intractable risks faced by those who are forced to keep “living”, to entrust their care and savings to others as they become less and less able to monitor and seek rectification of many abuses.

Some of these people may very well have sought VAD if available before becoming subject to abuses. In addition, the current federal government inquiry into abuses in the aged care sector, the recent damning report on the government-run Oakden aged care facility in South Australia and journalistic investigations and significant class actions concerning various aspects of aged care provider scandals (eg Aveo), all reveal risks that a growing number of Australians face as they are forced to make major changes to their lives. Throw in increasing frailty and complex health problems and an inability to ‘fight back’ and why are researchers still wondering about increasing incidence of suicide by older depressed men in nursing homes?

- the call for far better treatment of depression in older Australians generally refers to better pharmaceutical management as a sole solution. It does not address causes that might well be a poor quality of life, nutrition, isolation and situations many may wish to have avoided altogether at an earlier age. And unfortunately older women tend not to have strength or access to means that will guarantee successful suicide when few options realistically are available to secure this.
- Despite very regular calls by professionals for significant improvements in aged care, drug treatments for the elderly, action to lower rates of depression and suicide in older Australians (particularly older men), the difficulties of making rapid progress on these issues is highlighted by the need for a federal government inquiry into the *‘Quality of care in residential aged care facilities in Australia’*, with three terms of reference seeking to respond to recent financial scandals and clear mistreatment and abuse of residents, plus addressing the poor consumer protection for residents *‘who do not have family or friends or other representatives to help them exercise their choice and their right to care’*
 - negotiating and checking the minefield of care pathways, funding required and expecting the imposition of extra costs (eg see the recent ACAT case involving The Pines, Farrer), is not an attractive proposition to tackle let alone consider at a time of high vulnerability and would require substantial assistance on the part of others
 - many who are self-funded retirees would already face falling income and other significantly rising living costs (eg health insurance, GP visits in a place where bulk billing is hard to come by, power charges, other maintenance -of -health costs eg exercise classes, physiotherapy) and want a more peaceful existence
 - pre-care, an increasing number of older people already find it hard to monitor and deal with and contribute to day to day matters like body corporate issues and decision-making

- no wonder many wish to remain in their own home for as long as possible (despite ‘downsizing’ incentives for the minority who own very valuable homes and for whom it is easy to make a comfortable transition). Most hope and pray they may die peacefully at home, even though the statistics do not bear out that scenario happening for the vast majority
 - VAD or similar approaches would enable those of any age who do not wish to face or deal with risks of entering residential care/nursing homes, or to receive palliative care at home or in institutions, to carry out their own wishes.

- Risks from family member abuse of any VAD set up surely can be minimised, especially if an individual seeking VAD or similar has expressed their wishes clearly in the past. Abuse by some eg of older family members for financial gain, is not a reason to prevent others (eg without families or those whose families aren’t naturally predatory) having access to a legislated VAD set up, especially if they have given clear indications of wishes well beforehand (via an Advance Care Plan, EPA, other directives etc)
 - the ACT Government should strongly promote the excellent service available on the development of Advance Care Plans and run many practical workshops eg including through community networks such as senior citizens groups and U3A, to enable many more to describe their end of life choices.
This is one way of minimising risks of any abuse of end of life choices
 - individuals should be more educated about the responsibility they have to themselves, their families, their GP and the hospital sector by drawing up and maintaining their EPA, Advance Care Plan, and any other directives.

- Without VAD or similar the number of people – of all ages - attempting suicide via violent, grisly or illegal means is likely to grow. Botched attempts create huge and often ongoing costs to the individual, families, and the health sector. Others may be asked to help (to ensure success) and become liable for prosecution for doing so. A safe supportive framework for those who wish to access voluntary euthanasia, with a checking process, is far preferable
 - those who are more educated and financially well off and have the means to research and seek support, in Australia and overseas, will continue to be able to end their lives in ways that are totally unavailable to many more. This current inequitable situation will probably worsen as more and more find themselves in highly undesirable situations and discover they do not have the private and personal means to either improve their lives or to bring about death when they wish to.

- Risks associated with responding legislatively to other human rights or medically related situations have been managed by governments and individuals on a shared responsibility basis eg safe abortion provision - and the ACT has managed this well.

- Any VAD or similar arrangement for the ACT should not be so onerously prescriptive and limited that it causes most individuals who seek to implement their end of life choices to not qualify for recognition or support under the arrangement
 - this is the real risk of a VAD, that its focus and parameters will not be of any assistance to the many who wish to avail themselves of some help (eg advice, guidance, means) in implementing their end of life choices.

- There is also the high risk with a very limited scheme that many ACT residents with deteriorating quality of life will face experiencing worsening mental health as a consequence, particularly if they are not able to access VAD (or have no way of opting for far more expensive overseas assistance, or accessing grisly or illegal means of ending their lives locally).
- But focusing instead on addressing “the poor mental health in many older Australians” is no reason to avoid introducing VAD
 - yes, there is ‘poor mental health’ in many older Australians, particularly those in residential care, and this is unlikely to change. Just calling, with monotonous regularity, for brand new drugs, different drug mixes for depressed older people, and suggesting nursing homes ‘should be more like a hotel’, is not going to help, in highly practical and individual ways, those whose health and associated day-to-day circumstances continue to deteriorate and impact greatly on key quality of life indicators and who nevertheless do not want to ‘enter the fray’ of admission to and existence in residential care including nursing homes
 - also, it is well known that people with one or more serious illnesses are more likely to develop depression, but this should not become a barrier to those people (of any age) addressing the impacts of their prognosis and deciding what they wish to do.
- Any ACT resident, young or old, with failing mental and/or physical health, including non-terminal debilitating/chronic conditions and/or other deteriorating life circumstances (eg financial, social) should be able to access VAD or other forms of voluntary euthanasia if they wish and when they wish.

TOR 4

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

- Any ACT voluntary assisted dying (VAD) scheme should be far more encompassing than the Victorian approach of those who wish to access VAD or similar arrangements
 - it should not be restricted to those with terminal illness and, say, six months to live: many would wish to avoid this stage of their lives if they could
 - non-judgemental processes should be put in place to ensure a minimum number of 'hurdles' and delays are faced by those seeking VAD.

- A VAD scheme should recognise that those with failing mental health should still have the right to request VAD. Poor mental health will only worsen among sections of the community if VAD or similar options are not available for them to consider. Many, particularly older people or younger people with very poor life expectancies, would benefit from knowing that they have VAD or similar to call on if necessary. Such knowledge would be very comforting to many and improve their lives and mental outlook.

- A much more accessible scheme than Victoria's is needed to address the realities of many wanting practical end of life choices and the means to implement them
 - too many academic researchers (and the palliative care industry) keep pushing the view that older Australians need, for example, 'to be valued more' in order to reduce the high suicide rates among the older cohort, that many (ie wrongly) feel they do not want their care prolonged as it is an imposition on society and that it's their responsibility to 'bow out' of life (eg see ABC News article 31/5/17 re suicide rates in men over 85)
 - however, people are entitled to hold these beliefs which can be based on their own and others' circumstances and they also have the right to suicide. Access to VAD would make the decision and process far more civilised for those who wish to pursue an end to their life.

TOR 5

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

- The federal government should be lobbied strongly so that the ACT (and NT) can legislate on VAD or broader voluntary euthanasia arrangements if it wishes, for its own residents.
- There is a strong equity issue at stake here ie Victorian residents have access to a limited scheme now: currently only wealthy, well-educated ACT residents capable of pursuing other options have some hope of implementing their end of life choices. The same sex marriage survey results show a high level of liberal attitudes on social issues that affect choice for sections of our community. The ACT Government should take heart from this in its endeavours to address the repeal of the federal legislation ('Andrews' Bill')
 - no, we do not want another survey (ie an ACT one), just action to pursue this issue.
- The ACT Government's recent announcement about working with the NT Government to overturn the current federal legislation is to be applauded and both governments should quickly develop a plan, involving active public participation, to bring the current Coalition government to its senses
 - we are now in the lead-up to a federal election and freedom of the ACT to legislate on end of life matters should be made a paramount issue for electioneering and also for calling out our ACT federal politicians and election candidates to support the repeal of the legislation (if not achieved this year). If repeal is resisted by any politician inside or outside the ACT, much 'noise' should be made by the ACT and NT governments about human and legislative rights for their own citizens in the lead-up to the federal election.
- If calls for repeal go unheeded, some temporary arrangement should be put into effect eg by regulation, to enable a framework scheme to operate with or without some medical intervention/assistance
 - checking and implementation procedures should be put in place without risk of punishment of any involved.
- If a High Court case is required in trying to ensure that the rights of the ACT residents are recognised on this matter, I am sure many in the ACT would support this and even be willing to contribute donations to such a cause
 - the damage to any recalcitrant federal government involved in the process would be more costly to that government, in numerous ways. Hence the need to make the most of the pre federal election period.

There is little policy development happening in this country at the moment that is socially progressive and it would give hope to many here and in other states if the ACT (and NT) achieved the over-turn of the federal legislation and got to work on providing a liberal framework of voluntary euthanasia options.

TOR 6

Any other relevant matter

- If the Federal legislation is not repealed and/or the ACT Government does not act to improve support and options for individuals who wish to access VAD or other forms of voluntary euthanasia, I and others I know will still pursue whatever options we can access and afford and be prepared to go to court and possibly jail in our 80s and 90s if we ever assist others to die when they want to.
- However, I believe that VAD is a 'sleeper' issue which many in the ACT would come out and support strongly if there was an easy and sociable way of doing so
 - perhaps follow-up to the inquiry could include such mechanisms eg through any interested community groups, senior citizens groups, the U3A network, COTA, and possibly Alzheimer's Australia and others, as well as avenues that would reach younger and middle aged residents too.

Attachment A

A sample of cost issues

Mounting cost pressures and associated stress on individuals and governments regarding quality of life issues, particularly for those on limited incomes, are clear and indisputable: eg the following articles from just two days of newspapers received (10-11 March 2018) refer:

ACT fails AMA's health report due to long-term underfunding (Canberra Times 10/3/18)

Revised BUPA gap cover plan 'inadequate' (Canberra Times 10/3/18)

Outrage over 'unconscionable budget
(increase in retirement village fees taken to ACAT) (Canberra Times 10/3/18)

Painkiller price hike referred to consumer watchdog (Canberra Times 10/3/18)

Nation's ailing health now \$164bn burden (Canberra Times 10/3/18)

Unaffordable housing affects well-being (Sydney Morning Herald 10/3/18)
(a growing issue particularly for older women)

Elder Abuse (The Saturday Paper 10-16/3/18)

Advocate fights for rights of patients (Canberra Times 11/3/18)