



LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON VOLUNTARY ASSISTED DYING BILL

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Submission Cover Sheet

Inquiry into the Voluntary Assisted Dying Bill 2023

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SUBMISSION TO INQUIRY ON VAD BILL 2023, 8 DECEMBER 2023

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Attachment A: Key background considerations and factors influencing this response

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Document references:

- **SFVAD** – Summary of the ACT’s framework for voluntary assisted dying (Source: ACT VAD website).
https://hdp-au-prod-app-act-yoursay-files.s3.ap-southeast-2.amazonaws.com/1416/9881/6193/Summary_of_ACT_VAD_Framework_.pdf
- **ES** – Explanatory Statement and Human Rights Compatibility Statement (Source: ACT Legislation Register *via* VAD website).
https://www.legislation.act.gov.au/b/db_68609/
- **Bill** – Voluntary Assisted Dying Bill 2023 (Source: ACT Legislation Register)
https://www.legislation.act.gov.au/b/db_68609/

I Introduction to this submission – approach and rationale.

1. The ACT government is commended for its work and leadership in getting VAD legislation and the accompanying documentation to this stage only a year after it was given the ‘green light’ by the Federal Parliament to address VAD policy and practice in the ACT.
2. Given that there are no specific terms of reference for this inquiry, this submission comments on matters in the plainer English ‘SFVAD’ and ‘ES’ documents, as opposed to quoting only sections of the bill itself. My comments
 - focus mainly on and around eligibility/access matters, and the implications of the bill for a wider range of individuals now and well into the future
 - follow the text in page order for both the SFVAD and the ES documents.
3. My comments are made with many others I know in mind, mainly older women who will not be making an input to this consultation for health, caring and other personal reasons. Nevertheless they hold strong personal and well-educated and informed views about why and how they would want more improved access to VAD when they consider that they are no longer able to *“enjoy a life with dignity”* and wish to *“die with dignity”* via *“choices... about the circumstances of their death”*¹.
4. I made submissions to the 2018 VAD inquiry, and the consultation on the VAD discussion paper earlier this year. I hope that the Select Committee members have been able to acquaint themselves with some of these past submissions for background and context purposes. I also hope that the whole Assembly can ensure, in strong and transparent ways, that this bill as presented is not made weaker, that VAD support is not made more cumbersome, or difficult to access and navigate, but rather that it can be improved even in some small ways - both currently – ie in 2024 -and in the future
 - those voluntarily looking for choice and access to VAD will be looking to all parties for a clear commitment to the build on and improve what has been able to be developed to date, to make VAD provision in the ACT more humane and compassionate for a wider range of individuals
 - hopefully not just the Committee's report but also the parties’ policy platforms on future VAD policy development will illustrate all parties’ willingness turn work together on this important area of ‘people policy’ without delay
 - more clarity and commitment to improvement of VAD support in the ACT will give more individuals hope, comfort, and relief - this is what many are looking for and wish to plan for over the coming years.
5. For future reference, it would be helpful if follow up public explanatory documentation on the ACT’s processes and starting the VAD ‘journey’, included numbering of headings and paragraphs, to assist quick and clear reference by individuals using the documentation in any correspondence or consultation with professionals and others about such documentation

¹ The quotes are from the **ES** and are repeated often across that document as lead-in to points on “Legitimate Purpose” explaining the purpose of introducing VAD: e.g. see ES p. 30, pt 2; p. 36, pt 2; p 38 pt 2; p. 42, pt 2.

- lack of this in the SFVAD and in much of the ES makes pinpointing of issues in this submission for eg, clarification, more difficult as referring to only page numbers and ‘third dot point’ becomes cumbersome across a large and detailed document.

II Review of the (final) VAD Act – suggested amendments (Bill S159, pp 110-111 refers)

1. Given the comments at I above, the reasons and explanations provided in the bill’s supporting documentation and the comments made below on these documents, I suggest that S159 (2) be amended as follows
 - 1st line “...must include, **but not necessarily be limited to** a review...”, or improved words that make this intent and coverage clear
 - include in (2), or a new (3), specific reference to “**widening other aspects of eligibility including relevant conditions**”
 - just mentioning “*eligibility*” would be insufficient, as it could enable a future ACT government to introduce more restrictive eligibility and access requirements
 - include at (2) consideration of need for the second review to occur sooner (eg at 3 not 5 years after the first - S159 (1)(b) refers
 - needs arising and developments elsewhere are likely to call for improvements sooner not later.
2. Other Review process fine tuning: in addition, in view of how many individuals’ well-being and quality of life will be severely impacted and cause unwanted suffering over, say, even the next five years (ACT demographics refer)
 - there should be commitment either inside or outside of the bill to structure and get the reviewing and research going well before the three year period rolls over
 - starting the review in 2028 is an inadequate approach, given that starting the process then means that it could be 2030 before all the policy development consultations, any legislative amendments and new process formulation can be finalised for implementation
 - waiting all these years for possible changes and action should be avoided, given the matters already listed for review. Addressing wider eligibility links directly to individuals who wish to seek VAD because of suffering and other personal circumstances that can contribute to what is chronologically “*the final part of a person's life where quality of life becomes unacceptable...*”.² is required for both compassionate, and individual rights reasons (ES p. 28 refers to the application of “*compassionate grounds*”)
 - also the bill, or some other parliamentary means, should ensure that between the start of the VAD Act and the first review, there is both commitment and the ability (hopefully, with tripartite support at the time), to amend any ‘matters arising’ from the Act’s operation: ie some things may need to be fine-tuned expeditiously as situations/issues/ gaps/experiences arise, in order to better provide and streamline a VAD service to those who wish to seek it.

² EN, p 12, para 2.

III Comments arising from the Summary of the ACT's framework for voluntary assisted dying (SFVAD)

A Overall requests

1. None of the *requirements* should be changed to make access harder to achieve than is proposed currently, for those who wish to use VAD.
2. Some improvements should be considered and adopted both now and while the Act is operational for review purposes (**II** above refers)
 - even if the Act is still founded at this stage on basically a medicalised approach, the consideration and interpretation of the individual's health/medical/well-being/quality of life and related situation at impacts should be made more noteworthy and paramount as reasons for requesting VAD
 - some of the content of the Explanatory Notes (EN) supports this broader scope but then appears 'watered down' and weakened by concern for the rights of those (a small number surely) who may be vulnerable to some sorts of exploitation or abuse in any VAD set-up (see also **IV E 1** below).
3. The bill and final Act should be promoted as a start on a much longer road to reform that recognises the needs of a broader cohort who wish for choice, control, and support, for their end of life decision making: ie the legislation should commit to look further than what is currently described in S159 (2) of the bill.
4. Overall the ACT should be aiming for a social and rights model for VAD. The size and population make up of this jurisdiction should assist and encourage the development and implementation of such a model.

B Eligibility requirements (SFVAD pp 1-2)

1. Attachment A contains some background considerations and observances that have influenced my responses to both the SFVAD and ES documentation. It aims to help the committee appreciate the comments below, particularly in relation to "*eligibility*" and "*relevant conditions*" and why future review of widening eligibility is suggested at **II** above. The Attachment refers to specific parts of the bill too.
2. One or more chronic "*diagnosed*" (p. 1) conditions would also be "*relevant*" (p. 1) since they too can and do contribute to significant progressive cognitive and physical decline and ultimately death via organ failure, serious accidents, cumulative frailties, and loss of engagement, that in turn lead to more of the same occurring
 - the chronic conditions associated with ageing in particular do create "*intolerable suffering*" from, for example, pain or other incapacity that is not treatable with pharmaceuticals sufficiently, or if it can be, leads to unwanted or poorly tolerated

side effects and other health and medical complications and unwanted bodily impacts

- such failure of functioning is also a medical situation that causes significant decline in quality of life that cannot be stopped or reversed
 - if the opinion of the person is that such physical and or cognitive conditions causes them to be “*suffering intolerably in relation to this condition*”, and they understand and wish to access VAD, then they should be able to do so
 - by this stage of their life many factors described in Attachment A would have been experienced far too much for the individual's liking and/or may be looming and wish to be avoided given the state they find themselves with very poor prognoses and a worsening outlook of decline.
3. ‘*Suffering Intolerably*’: agree that this should be “*in the opinion of the person*” as long as it is not argued about or diminished by others involved in the processes set down for VAD in the Act
- in addition no one with non-curable chronic conditions who is also suffering should be forced to take pharmaceuticals or seek high care or palliative care in order to try to do make end of life stages more tolerable - for many non-terminal conditions this is impossible to achieve. Those experiencing this know and live it 24/24.
4. Given the above points, it should be made clear that VAD can be sought and accessed successfully by an individual who decides to either stop, or not ever take up in the first place, one or more “*treatments*” (p. 1) for chronic conditions. They should not have to face debilitating bodily reactions and other unwanted daily impacts for conditions that that will ultimately lead to death , via interim loss of total independence, and seek other means of accelerating a wish to die, eg via starvation
- would a person who decides that they ‘have had enough’ and refuses more treatment or drugs for one or multiple chronic conditions (including high blood pressure, angina, heart complications) should be eligible to apply for access to VAD in view of the fact they would be on a trajectory for dying sooner and possibly in horrible ways, or by more health complications and painful pathways
 - refusal of treatments along with decision-making capacity would surely also meet the criterion about “*anticipation and expectation... based on medical evidence of suffering*” (p. 1). Persons resorting to this decision about treatment(s) and their outlook should have access to the VAD in a timely way before one or more conditions (ie without the requisite drugs) affect the key organ and renders the person unable to sufficiently exhibit “*decision making capacity*”.
5. Also, a person who has had a major stroke and may face another one leading to a totally passive dependent vegetative state instead of immediate death, may not wish to undertake rehabilitation and other treatments and also does not wish to suffer worse consequences of another stroke - such person should not have to starve themselves in order to avoid a worsening path to the inevitable.
6. Likewise, the “*anticipation and expectation of suffering*” (p. 1), should not just be based mainly or solely on medical advice - the individual’s experiences, life history, insights into their own functioning in their day-to-day living environment, should have primacy about

whether the impact of any “*condition*” is considered to be unacceptable and contrary to the person's expectations of well-being, personal dignity, quality of life, and independence.

7. A growing loss of independence and expected further loss of this should also be recognised as an acceptable cause of or major contributor to “*suffering intolerably*”.
8. Given the current focus on evidence of actual “*Decision-making capacity*” (p. 1), it is crucial that those wishing to access VAD can easily do so at a very early stage of any diagnosed condition since many terminal incurable neurological conditions can cause rapid and sudden decline in cognitive ability and therefore an inability to pursue VAD support
 - a person with such diagnosis should not have to wait until they are “*suffering intolerably*” to access and have VAD approved because they could quickly become ineligible according to the requirements described on p. 1
 - such situations also call for faster “*review*” attention to Active Care Plan considerations (S159(2) of the bill refers, also II above.
9. Meeting current and proposed requirements regardless of time of expected death (p. 2, first main para/dot point): interested ACT residents (and potentially eligible others) should be provided next year with a clear list of requirements that must be met.
10. If some or all of the above matters cannot or would not be accepted under the bill’s eligibility framework, then it is incumbent on the ACT government to make this clear to ACT and other potentially eligible constituencies and advise what they are supposed to do instead - besides resorting to a violent (and unpredictable outcomes) pathway to suicide, or a slow lingering death by starvation, or refusal of all treatments.
11. “*Exemption*” (p. 2 top main inset para): highly desirable, however some assessment should be made by the relevant ACT authorities (Health, Treasury, Justice) about whether more specific VAD and general health related resources and funding might be needed since some in nearby areas or even major centres like Wagga might choose to seek main terminal or other illness treatment in the ACT in order to avoid the strictures associated a far less supportive/accessible NSW VAD set up. The ACT/NSW government arrangements concerning the ACT's hospital and other health support for NSW residents may need to be revised up for this reason.

C Process for VAD request and assessment (pp 2-3)

1. **Telehealth consultations re VAD and accessibility** are likely to be required or preferred by many eligible individuals in the ACT in view of the difficulty in accessing even a GP appointment, or inability to travel to one, and therefore would require a visit from a practitioner instead (equally hard to obtain for many)
 - but according to the Commonwealth Criminal Code, accessing VAD advice by telehealth/video services is illegal
 - what is the ACT Government doing with other jurisdictions to ensure that the Criminal Code 1995 (S 474 29A) is amended in time for the commencement of VAD in the ACT - eg through one-on-one

representations, and via National Cabinet and national meetings of Attorneys General?

- it is imperative that this amendment be achieved before the next federal election.

2. “*Requesting*” VAD (p. 2, 2nd main dot point), raises some questions:

- what happens if a (first) request is not accepted - ie all requirements not met?
- it is not clear what “*unable to assess*”, (p. 26, sixth dot point under second main dot point) means - does it mean that the practitioner is unable to agree with the person’s opinion that they meet requirements, or is it that the practitioner does not have the skills or any other inability to interpret some associated documentation?
- what if a person who wishes to seek VAD has been dealing with a GP and/or other medical professionals who prefer to keep people alive at almost any cost or may consider that the person may still be around in 10 years’ time, regardless of the impacts of their progressive and inevitable physical and/or cognitive decline and suffering ?
- a person in the state required for contemplating and wanting to choose VAD should not have to initiate ‘doctor shopping’ expeditions - will the VAD support process provide such persons with a list of suitable practitioners to approach rather than rely on the ‘unwilling’ practitioner/GP to make a referral onto someone of the GP’s choosing unless the GP can and should access such a list in this situation?

D Accessing the substance (SFVAD pp 3-4)

1. It is not clear if a “*contact person*”, as described in the first sentence of the 6th main dot point, is still required to be appointed if the individual is able to handle the approved substance themselves.
2. When a “*contact person*” is required to assist with self-administration, will a list of suitable available people be made accessible if the person approved for VAD does not wish to involve anyone they know for this role, or does not have access (because of their age, lack of family etc) to someone they could nominate to fill the role appropriately?
3. The last dot point on SFVAD p. 3 should not be weakened or revised: ie ensure no eligible witnesses are required for self-administration of an approved substance.
4. This section would require considerable additional advice and direction when VAD decision-making via an Advanced Care Plan (ACP) is considered and, hopefully, enabled - (Bill S159 (2) refers)
 - further work on ACP and VAD is strongly supported, and resolution is encouraged sooner rather than later (see **II** above)
 - the growing incidence of neurological conditions as a chief cause of death (preceded by unwanted intolerable ‘living’ circumstances pre-death), in Australia, particularly for older women, makes “*Accessing the substance*” a key gender issue for VAD that should be openly acknowledged and committed to for resolution on a tripartite Assembly basis (see also **IV D points 3 and 4** below).

E Role of health professionals (SFVAD pp 4-6)

1. Final VAD guidance documentation for public use should make it very clear that GPs are eligible to be a coordinating or consulting practitioner (p. 4, 1st dot point ; p. 5, 2nd dot point)
 - looking simply at the table may suggest that only medical specialists can be involved: many seeking VAD would not be familiar with the more encompassing use and means of the word 'specialist' at the top of p. 5, and may not even be seeing any medical specialists as such for their condition(s).
2. Nurse practitioner involvement is very welcome and should be encouraged through considerable upskilling and resourcing support for VAD here
 - discussions should be able to be carried out by telehealth too for reasons outlined in C1 above, but can they be done so legally by 2025?
3. P. 3 – last dot point: if a health practitioner or provider is unable to assist with a VAD request, a 'neutral' list of suitable personnel should be available to the person seeking more information and access for VAD - such a list is discussed at **C2** above.
4. 'Objecting' personnel at all levels of the medical hierarchy should be mentioned in some way to get an idea of any pattern or pools of refusal - this should be done to help individuals who want VAD to access it in a timely way with the fewest stumbling blocks and bottlenecks; these people, and those who may be supporting them mentally and physically, already face enough hurdles in their day-to-day lives
 - the list suggestion at **3** above refers.

F Role of health services and facilities (SFVAD pp 6-7)

1. The scope, involvement, and contribution to implementing processes is encouraging but needs to be balanced by adequate resourcing and upskilling
 - too often it appears that the introduction of progressive reform or initiatives by the ACT government is not accompanied by adequate short and long-term resourcing, upskilling, and the ability to carry out sound data and other information collection and analysis in-house and over time - this area of policy development and research should not be done on an ad-hoc basis or left in the hands of consultants.
2. VAD in the ACT has the potential to be a very good example of how a holistic approach to service delivery can be developed and promoted actively and passively across a range of portfolios (not just Health) - ongoing review and reporting should address this too, and other areas of ACT service delivery may benefit from VAD experience and learnings.
3. **On-site VAD at a facility** (SFVAD, p. y, 1st 'hollow' dot point o): the facility should be expected to allow resident access to VAD health professionals except in highly exceptional circumstances (which would need to be determined)
 - not allowing access because it is "*not reasonably practical*" is not sufficiently supportive of a resident who may have no wish to face what "*transfer*" involves (see 4 below also)

- after all, these facilities are being supported in a range of direct and indirect ways by government/taxpayer funding: the choices of a resident about visitation should be paramount, be respected, and is a private matter between themselves and any visiting professionals.
4. **Transfer from a facility** (p. 7, 2nd ‘hollow’ dot point): the two sub points here should be reversed in priority and importance
 - given the state of most people's health, capacity and dependence once they enter a facility these days, let alone at the time of wanting to use VAD, transfer should be avoided as much as possible: it would also be an administrative and coordination burden on the individual and all others who may be involved at such a time
 - facilities should be expected to facilitate a person’s access to VAD on site and approach this in a professional, supported, and timely way (including provision of an appropriate place): after all they deal with dying and dead residents on a very regular basis, all year round
 - the first subpoint should therefore make clear that the bar is set high for objecting when a resident wants VAD professionals to visit and assist them.
 5. **Facility policy notification** (p. 7, 3rd main dot point): all internal and general documentation given out to prospective and existing facility residents should make VAD matters, facility policy and processes, etc very clear - it must be more than a footnote in small print
 - a government contact point for further information should also be included in facilities’ statements about VAD
 - this documentation should be checked and monitored by government for clarity and availability purposes.
 6. **Monitoring of facilities re VAD:** VAD requirements for, and expectations regarding facilities’ behaviour and responsiveness about VAD consultation delivery on site, should be formally monitored in an ongoing way
 - a hotline for reporting any difficulties encountered by residents should be established and this should be made known across all facilities too
 - unfortunately, many in facilities may still feel discriminated against or stuck out of reach of VAD, due to age, infirmity, inexperience at or fear of speaking up, or just not wanting to ‘cause a fuss’, and consequently they would suffer needlessly because of their accommodation situation
 - it is important that messages about VAD and a range of mechanisms be instituted to assist people in such situations.

G Oversight, reporting, compliance (SFVAD pp 7-8)

1. **The board** should also be proactive in reporting publicly on the Act’s progress, VAD uptake, issues arising, trends, people, issues emerging that are not covered by legislation or established processes, remediation of any gaps or difficulties faced by individuals seeking VAD, etc
 - issues to improve delivery that are unable to be addressed without a legislative amendment or reform should also be reported to government as they occur for

actioning and reported on annually - including progress made by government to respond to matters raised.

2. **“Enforcement agencies”** (p. 7, 2nd main dot point): this terminology here raises questions
 - who are these agencies? New or existing, or new parts of existing ones?
 - what ‘enforcement’ might occur, and how, in relation to individuals who start on the pathway to the VAD use? Given the current hurdle regarding telehealth, and the lack of revision of the Commonwealth Criminal Code (see C1 above), all references to enforcement regarding individuals who want to pursue VAD should be done in such a way that does not deter people from considering VAD, using the processes made available and taking more control of their end of life situation.

IV Comments arising from the Explanatory Statement (ES) document

A General Comments

1. The ES document is certainly helpful and hopefully will assist the production of clear information and guidance documentation for public use before and after 2025.
2. The document’s content and length has many queries and identified matters of interest for me but time and space for this submission has limited them to what follows.

B Background (pp 1-2)

1. My comments in III above and at Attachment A are totally ‘in sync’ with the p. 1 statement that **“eligible individuals should be able to make informed choices about the end of their lives”**
 - the issue is “eligibility” which is addressed in III above and should be further considered and committed to for humane and compassionate purposes at least in ways suggested in II and III C above.
2. *“End of life”* is not just about *“health”* and *“care”* - end of life decision-making, its impact and timing, are most meaningful to the individual making or having made a decision about VAD and includes many factors that might also end up being health and condition related (III C above also refers).
3. At this time, the bill is presented as basically a medical focused and linked service and process, but access should not be determined purely by medical factors and considerations - hopefully, there is some flexibility available in the proposed setup and that this can also be addressed and progressed further as a VAD priority in the next few years
 - more experience of ACT VAD will surely demonstrate that many more (especially older women), will want - for sound personal reasons - to exercise their free will and personal responsibility to themselves by looking to access VAD as “an additional

choice” (p. 1): but they will find the door closed and despair, given the bill’s current requirements

- as raised in **III B point 10** above, what then happens to these people? That too should be mentioned, including their views
- how many, for example, will be unable to access VAD, yet are 70 – 80 – 90 – 99 or 102 years of age, are frail and/or fully or mostly bedridden, most likely urinarily and faecally incontinent and fully dependent on others for care and on a drug regime - all of which is not wanted as a state of ‘life’ ? Such people are conveniently out of sight for years with no quality of life or dignity
- the views of these people should be able to be sought ad addressed in the first and subsequent VAD legislation and policy reviews. (**II** above refers).

4. Indeed, the ES document accepts that the **“Bill may exclude certain groups of people who are suffering from issues, such as extreme pain, loss of autonomy, indignity, and mental anguish”** (p. 22 point 4)

- for the purposes of future VAD development, and political commitment to the same, addressing those in these situations should receive primacy too because the individual’s viewpoint and value of their life should take priority over any political wish and belief in an *“inherent value of human life”* (p. 22), and *“the need to protect vulnerable people”* (p. 22 point 4)
 - there is no ‘inherent value’ in a life which is judged by a suffering individual to be very poor, with no prospect of reversal or improvement, and the only outlook being inevitable death by design or by accident
 - the value of ‘sanctity of human life’ (p. 22) should be assessed by the individual, according to their personal circumstances and outlook
 - ‘protecting vulnerable people’ is not an excuse to severely curtail others (likely a majority) from holding hope and a wish for VAD and the ability to pursue it if they wish
 - there are many other situations and reforms managed by governments where factors that may potentially create or exacerbate already existing “vulnerabilities” can be addressed - again the power should be shared with the individuals involved to enable end of life wishes to be respected by others (possibly adult education would assist this).

5. *“Palliative care”* references eg p. 2 para 1): palliative care should be treated and clarified as an option and a choice in all government-source documentation - living *“as comfortably as possible”* (p. 2) is not a prospect that many wish to experience especially if years of increasing pain, incapacity, organ failure, and associated dependence have been experienced

- no part of the VAD process should be seen to ‘push’ palliative care options onto an individual (p. 5 of SFVAD makes much of informing individuals about such care and treatments)
 - for many this is merely another unwanted, purposeless, and still institutionalised, ‘life extension’. See also Attachment A point 17

C Overview of the Bill (pp 2-4)

1. Experiencing ‘suffering and dying’ in unwanted ways is not restricted to those with a known, diagnosable, illness or condition, but at least the ES recognises this (see **IV B point 4** above).
2. P. 3 (e) -protection for health practitioners needs to be ensured by reform of the Criminal Code (see **III C point 1 and III G point 2** above).
3. P.3 - the Board does need to report widely and publicly on a range of matters (see **III G point 1** above).

D Consultation on the Proposed Approach (pp 4-5)

1. Hopefully the next stages of consultation (also across the years), will enable interested individuals and potential VAD applicants to participate as stakeholders in specific policy-focused roundtables: many older residents have views but do not have the means or ability to input a written submission or access Yoursay survey/input sites
 - prospective VAD users and carers et al are stakeholders too.
2. The need for ongoing consultative and monitoring approaches between 2025 and the 2028 review stage are also raised above (eg **III F point 6**) about enabling those facing VAD ‘difficulties’ in care facilities to be heard and followed up easily (use a hotline for this and other ongoing feedback? In the first instance no one should have to write to a minister about such matters.
3. ACT and “*unique needs*” (p. 5, 3rd main para), yes - the ACT has unique needs, and this includes a large and growing cohort of educated older and ageing females (unpartnered, never partnered, widows, divorcees), many of whom have good knowledge and awareness of political and administrative processes, policy making, policy gaps, governmental service delivery pluses and minuses. Generally they have also had far more experience of observing and/or caring in a myriad of ways for increasingly frail, chronically ill and dependent individuals as the latter’s’ lives ebb away - and in ways that few men (especially those in key decision-making positions) will experience to the same extent
 - this in turn informs many women's views about taking control of their end of life situations and their wish for VAD access at a time of their choice.
4. **VAD is a gender issue**, as this submission and Attachment A seek to highlight. Current and future ACT governments are encouraged to take on the challenge of meeting women's VAD wishes in far more flexible ways through consultation, leading to more progressive VAD policy making.

E Consistency with human rights (pp 5 – 45)

1. Far more consideration and credence should be given to addressing a person's right and ability, with support, to exercise free will and personal responsibility

- this is accepted **and** expected many other areas of personal and government endeavour
 - this is a key tenet and expectation in any advanced democracy; moreover reform and progressivism that potentially benefits a majority should not be hindered or ignored because of the particular wishes of a minority or concerns about some vulnerable persons - these matters can be addressed; see comment at **IV B point 4** above about addressing such risks.
2. *“No duty to live”* (p. 7 para 3): yes, *“the right to life does not impose on individuals a duty to live”*, so when an individual who has taken personal responsibility for decades to live and contribute decides that they are unable to live *“a life with dignity”*, with a level of quality, autonomy, and independence that matters to them, then they should be able to choose not to live and have access to nonviolent and reliable means to do so
 - the p. 7 (last para) statement *“the right to live is more than existence”*, and discussion there, about how dignity is needed to ensure a life not **“substantially diminished”**, totally reinforces and gives credence to many comments I have made above in this section, in **III** above and in Attachment A about the need for wider and more flexible access to VAD.
 3. *“Right to equality”* (p. 8 para 3) : while the bill does promote ***“the right to equality and non-discrimination”***, it is not ***“ensuring that an individual who wishes to access VAD has support to access it”***
 - eligibility limitations and gender issues refer and are discussed throughout this submission, eg at **IIIB, IVD point 3**, and Attachment A, II
 - if an individual who wishes to access VAD and is knocked back, they are discriminated against for not meeting quite strict medical-based requirements.
 4. *“Fluctuating decision-making capacity”* (p. 9, para 1): this is a very important feature that **should not be watered down**, given the prevalence of incurable neurological conditions in older women particularly, and the ability of many conditions to cause the brain to act unpredictably while reasonable cognition still exists.
 5. Removal of specific timeframes (p. 9): another key and important feature that **should not be watered down in any way**. Personal choice about, and timing of, use of VAD post-diagnosis will provide individuals with significant relief and a sense of control over an increasingly uncontrollable body and general life affecting condition or conditions
 - yet it is important that responsiveness to requests for VAD access is prompt, since some conditions can create sudden declines that would then negatively impact decision-making capacity and hence may rule the person ineligible according to the bill’s requirements.
 6. However on p. 11 (second main para), it is made clear that ACT VAD will only be available to ***“those who are in the advanced stage of illness...”*** or in the ***“final part of life”*** where ***“the quality of life becomes unacceptable”***
 - these statements appear to contradict, to quite an extent, previous comments about being able to prepare for VAD post diagnosis - prospective VAD users should be able to decide when they have entered a final part of their life, and their condition and

overall situation is advanced and intolerable enough to be considered a significant and ongoing barrier to quality of life and personal dignity and autonomy

- no one should have to face the prospect of years of clear and consistent bodily and quality of life decline because of what a GP or specialist may have said at an earlier stage, post diagnosis (see comment also at **III C point 2** above)
- **“advanced”** should not mean having to endure an existence to a stage of horrible debilitating incapacity or pain dependency, or fear-inducing, cognitive loss and loss of inhibitions and awareness of societal norms and behavioural control, before VAD support can be sought, approved and used.
Will this bill ensure flexibility in how “advanced” is interpreted and considered by the individual and practitioners and assessed overall?
- for the current bill’s purposes, constant decline (ie progression), should be a key determinant along with whether the impacts of the progression are acceptable or not to the diagnosed individual, rather than waiting for the **“advanced”** stage to somehow be identified.

7. *“Treatment (if available) is no longer effective”* (p.12, para 2): this implies treatment should have to be pursued “if available” - such treatment, including pharmaceuticals, is well known not to be curative, and may only stabilise some aspect of a condition or slow its acceleration in some people
 - individuals with diagnoses that meet the bill’s requirements or who experience medical incidents with poor outcomes and who want to access VAD should be able to eschew a treatment regime or stop one when they wish to opt for VAD instead, without out waiting for worsening impacts of the natural progression of the condition disease or organ damage that already exists
 - will such individuals gain access to VAD support?
 - **III B points 3-5** and **IV point 5** above on suffering, and **Attachment A, I, point 1**, also discuss and raise issues concerning a person’s refusal or cessation of treatments and the implications of this for accessing prompt VAD support.
8. *“Right to freedom of thought... religion...”* etc (p. 13, para 2 on): what is paramount is that the person should not have to endure the ‘run around’ from practitioner to the practitioner or facility to facility
 - see comment on this at **III F points 3-6** above.
9. *“ACAT hearings”* (p 12, last para): this option/pursuit needs to be avoided as much as possible all along the VAD support pathway
 - ACAT processes and preparation is hard enough for able-bodied, well, and cognitively sound people to pursue: most looking for VAD would need to employ – at some cost – an agent to manage and assist this?
 - avoiding ACAT hearings (appeals) as much as possible for people in end of life situations means some that flexibility about eligibility requirements is needed as well as giving primacy to the views and experiences of the person seeking VAD
 - and again, what happens to those who are able to pursue an ACAT hearing and lose?
III B point 10 IV B point 3, and IV E point 3 above also raise this issue of inability to access VAD and the need for follow-up.

10. *“Rights limited”* (p. 10): the prime consideration, as much as possible, should be an individual's wishes, and flexibility in interpretation of any requirements: unfortunately, the current bill is more predicated on protecting the medical profession, which in turn negatively impacts VAD support and coverage at this time
- hopefully, this can be addressed and revised more over the next five years
 - a VAD set-up that is driven primarily by an individual's assessment of their situation and a desire for VAD and which puts onus of responsibility for self-administration etc on an individual, or a responsible *“contact”* assistance person, would give far more ACT residents greater hope and relief as they face what they know will otherwise be an intolerable and unwanted future
 - primarily it is important and essential that an individual can **“access a dignified end of life on their own terms”** (p. 15 last point).
11. *“Right of children...”* etc (pp 17-20): yes, restrict VAD access to adults for the time being but review it as planned.
12. *“Reviewing”* (p. 20, para 6): yes, VAD is a **“fast developing policy area”** and ongoing review, revision, improvement, and reporting is essential and needs to be well resourced
- review issues arising and suggestions are discussed above at **II; III A point 2; III B points 1 & 8; III F, point 2; IV D point 2; and at Attachment A, II, points 9-10.**
13. *“Eligible condition”* (p. 21 point 3): it is not clear what this is - a **“relevant condition”** is referred to in the SFVAD, p. 1 and in the bill as *“the relevant conditions”* (S11 1 (b))
- presumably, it refers to the situation that the individual is in that meets all eligibility requirements described in S10 and S11 of the bill ?
 - although the bill says *“condition means a disease, illness or other medical condition”* (S11 (4)).
14. *“Decision making” and ACPs”* (pp 24-25): an individual who has lost decision-making capacity (p. 24, point 3) yet has clearly set down their VAD wishes in their ACP is to be denied access to VAD in order to ‘protect’, them at least as an interim measure, until reviewing occurs and changes may be made
- this does not recognise a person’s decision-making about a choice they wish to have implemented, so tackling this (S 159 (2) of the bill refers), is necessary
 - after all a dead person’s wishes about their affairs are able to be carried out via their wills and a memorandum of wishes, and the like
 - some monitoring and feedback from an individual may be required before their cognitive or general communication decline worsens (which might occur suddenly too). But if a person has taken responsibility to make their wishes known about VAD and the timing of their death in ways that satisfy authorities at the time (also they may have made their wishes on this known formally and regularly over many years too), then administration of a VAD substance should be provided to implement those wishes, just as action is taken when considering ACPs that state that certain drugs or other treatments are not to be administered if a person suffers certain conditions or illnesses and is unable to respond
 -

- recognition of wishes in ACPs is also a relevant gender issue for ACT VAD (**III D point 4 and IV D points 3-4** above refer, also Attachment A), and for all who have no wish to physically endure irreversible progression of a condition when their cognitive abilities are too poor to engage at all on any mind or body matter (**IV E point 6** above on the meaning of “*advanced*” also refers).
15. “*Compassionate grounds*” for VAD access exemptions (p. 28, last para) is fully supported
- some consequences including advice issues are discussed at **III B point 11** above
 - furthermore, an extension of a compassionate approach is encouraged in relation to the review and positive reform of eligibility requirements for ACT residents and relevant others.
16. “*Obligations on conscientious objectors*” (p. 29, point 1), should be monitored and analysed and reported on, plus a hotline line established to assist members of the public who encounter difficulties - these matters are discussed above at **III E point 4; III F points 5-6; and III G.**

Concluding remarks

This submission probably demonstrates, at least in some places, where members of the public can become confused or have poor understanding about this very important and major VAD initiative and service delivery commitment for the ACT.

I certainly accept that it is difficult to prepare supplementary documentation for the public in as much plain English as possible, with insights where possible, yet still retain the intent of a piece of legislation.

The public requires a good understanding of the final Act next year and support to interpret it accurately. This should include easily accessible information and useful points of contact for clarification etc, so that superficial, inadequate and misleading statements and other communications, eg via social media, are not prime sources of information for ACT residents and others.

Small group information sessions for those interested in these matters - for themselves or others they know are interested and may care for in various ways - should be considered as part of provision of a suite of easily accessible information sources well prior to the Act’s commencement in 2025.

Reaching out to interested individuals (and not just groups) at this time is important, given that this bill is a “*Significant Bill*” (ES, p. 1). Discussion of future consultations and communications is also at **IV D points 1 and 2** above.

I wish the ACT government and Assembly all the best for their efforts in ensuring that the intent and purpose of this bill has timely passage to enactment in 2024 and the resources to ensure implementation in early 2025.

Thank you

8 December 2023

(**Attachment A follows**)

Key background considerations and factors influencing this response

Contents

- I Government needs to trust individuals more
- II ACT demographics and their expectations

References to aspects of the VAD bill are included

I Government needs to trust individuals more and recognise that VAD needs to take account of a wide range of personal, health, wellbeing and quality of life factors

1. My experience is that:
 - those who put effort and thinking into their will, estate plan, Enduring Power of Attorney, memorandum of wishes, and an Advance Care Plan, have no wish to waste their savings on institutional care (including palliative care), and the pharmaceutical and medical sectors, in order to eke out an existence that has no hope of improving, let alone being reversed
 - those who do not mind using savings for these purposes – or are forced to do so - 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 (Federal inquiry into the *'Quality of care in residential aged care facilities in Australia'* refers)
 - many desire that, on their death, the remains of their hard-earned income are directed to the well-deserving philanthropic causes and national institutions: desirably individuals should be respected for wanting more than a pittance left for such causes especially when a sizeable proportion of any 'estate' has been nominated for this.
2. Government should not deny broader VAD access and options when increasing costs of health and aged care face all generations. Rising costs are a real concern and will not disappear. It is also unreasonable to expect governments to meet every cost, but governments should not expect, or assume, or force individuals to fund themselves into penury if they don't wish to.
3. Governments have made it clear that it is impossible and unrealistic to expect that they can guarantee financially that anyone can access all the

resources and support needed 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, as described in the media regularly for many years now. It is a world many do not wish to enter.

4. Since the Royal Commission on Aged Care, many Australians are waking up to the numerous and growing costs (financial and non-financial) and associated deficiencies in living a long, yet worsening life, even without a terminal illness.
5. Governments should therefore give people real choices and options 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.

II ACT demographics and their expectations

6. The ACT's demographics, its more highly educated and socially aware population and its willingness to give freedom of choice to others (the same sex marriage survey results refer), suggest that a more progressive and humane VAD set-up in the ACT would be acceptable for this specific jurisdiction to pursue
 - residents are quite aware of the personal, social, and economic impacts of ageing and chronic conditions on a large cohort of individuals and the tax-paying public and that those with specific terminal illnesses only make up a small minority of the population
 - the general response so far to the 2023 bill has been positive, at the community level it is seen as a source of hope and relief, but also a pathway that should be made more progressive, compassionate and humane.
7. Canberrans are also quite aware that governments expect individuals to take responsibility for most aspects of their lives for decades, and encouragement is given for this in various supportive and also 'stick and carrot' ways
 - being able to exercise end of life choices in a timely, compassionate and non-violent way at a time of their choosing is another responsibility and life-management matter which individuals should not be prevented from exercising by any government, territory or federal

- and particularly for women who have longer and more debilitating conditions and are more 'alive' to the realities and impacts of declining quality of life, eg total incontinence, cognitive and physical impairments, given their closer involvement in support and care for ageing family members, and their own personal longer years of living
8. It is not the business of any family, churches, religious or other non-government organisations and institutions to determine if, when, and how an individual exercises end of life choices
 - the current bill fortunately seeks to keep the role of 'church and state' a separate one and is commended for this ; yet efforts are needed to reduce other interferences in VAD for those who choose to pursue it.
 9. Individuals who make their views well known, eg in writing, in Advance Care Plans, etc and/or who may have expressed particular end-of-life views and wishes for decades, 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.
 - work on this in the final Act's first review should start well before 2028 (II in main submission refers).
 10. It should be recognised that many do not want to be forced to live a long life regardless of its quality and cost (to themselves and governments/ taxpayers)
 - the review should also address this.
 11. It should also 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), due to the costs, risks of abuse, and increasing inability of an individual to rectify deficiencies in these service provision arrangements and assessments
 - in addition, many 'baby boomers', especially in the ACT, 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 incur exorbitant costs.
 12. 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) and generally cope day-to-day 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.

13. It also needs to be recognised that a large proportion of the ACT population has no access to potentially better support and servicing under NDIS, because it is not available for those over 65. Meeting the costs of any existing or new major disability and early intervention needs is increasingly having to be borne by governments or - most likely - the individual. It is clear that Medicare is less and less able to provide adequate financial coverage. This, like the purchase of certain drugs, can be financially destructive not just of individuals but also of their family, if they have one with the means and interest to assist

- a person who increasingly loses independence and quality of life (mental, physical, social), and is recognised as being in such a situation, should be able to 'opt out' when they wish, and not endure and suffer a much worsening and irreversible existence.
- no one should be forced into full time residential care, including high care. That sector is also struggling and many who have had to engage with it for others consequently wish to avoid it, and all that it involves, for themselves
- the current strong community calls for an Ombudsman for ACT residential aged care facilities also indicates the endemic problems faced by those concerned about delivery and value for money in the aged-care sector here.

14. 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' yet onerous will increasingly have to spend large amounts of money on, eg:

- independent nursing
- advocacy for and monitoring and remediation of care provision
- 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
 - many have no wish to get embroiled in and controlled by the administrative burdens associated with the dot points above either.

15. The broader 'aged care support industry', involving 'outside helpers', costs money and also requires much monitoring and organisation, usually by additional 'others' – if they are available. 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, for services that often are barely adequate
- 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 'propped up' lives, especially when the main antidote to this is expenditure of large amounts of money for little real benefit or purpose. The great majority do not have this degree of funds 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.
16. If frail individuals, and those with one or more debilitating chronic conditions, for example, 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 potentially horrific experiences – and failures – especially for women, given they do not have the physical ability and access to means as men to bring about a quick and successful suicide
 - with a broader access to VAD they could access support and assistance to improve what they might have to experience to achieve death, and so cause less stress and trauma to themselves and others in the process.
17. Rejection of palliative care for those with terminal illness and/or chronic conditions should be recognised as a valid reason for accessing VAD or similar. I have friends who face years of extremely poor 'living' in an increasingly painful states of incapacity . Currently people are forced to do this, while enduring a horrible and still painful worsening and increasingly incapacitated state of 'living' – yet they are still to be denied VAD
18. The above comments are based on personal experience of being involved with friends and elderly relatives while they have died unwanted lingering deaths, both in and out of formal care arrangements and for conditions/situations that would seem not to make them eligible for VAD .

19. 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 the onset of disease, disability, or immobility, arising from long-term chronic conditions and other life-linked circumstances that currently would not seem to meet VAD eligibility.
20. I, and others, therefore wish to have access to the means to implement end of life choices safely and reliably , and having some assistance available (for a fee if required) in recognition of personal wishes, as this is a highly desirable and comforting thought, especially when you are in your later years
- I know many others in the ACT, especially women, who feel the same.
21. The VAD bill should go further to recognise and meet the needs of those who would identify in full or in part with the comments provided at 1-20 above, especially since none of the determining factors will magically disappear or change to substantially improve end of life experiences.

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