LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON VOLUNTARY ASSISTED DYING BILL
Ms Suzanne Orr MLA (Chair), Ms Leanne Castley (Deputy Chair),
Mr Andrew Braddock MLA, Mr Ed Cocks MLA, Dr Marisa Paterson MLA

Submission Cover Sheet

Inquiry into the Voluntary Assisted Dying Bill 2023

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SUBMISSION BY

THE CLEM JONES GROUP

TO THE ACT PARLIAMENT'S
SELECT COMMITTE ON THE

VOLUNTARY ASSISTED DYING BILL 2023

7 DECEMBER 2023

Ms Suzanne Orr MLA
Member for Yerrabi
Chair
Select Committee on the *Voluntary Assisted Dying Bill 2023*
ACT Parliament

C/- LACommitteeVAD@parliament.act.gov.au

VOLUNTARY ASSISTED DYING BILL 2023

Dear Ms Orr,

On behalf of the Clem Jones group I wish to lodge this submission to your Committee's inquiry into the *Voluntary Assisted Dying Bill 2023.*

It is very pleasing to be able to do so given that the ACT's rights to make its own determination on voluntary assisted dying (VAD) laws was denied it for so long by draconian federal legislation.

Following the scrapping of those federal laws late last year I hope that ACT residents will soon enjoy the ability to choose to seek access to VAD if they wish at the end of life.

We should all remember that the very term voluntary assisted dying makes it clear that any VAD law simply gives choice to individuals.

It offers those experiencing intolerable suffering another option through a legal, regulated scheme with legislated criteria and accompanying protections and safeguards.

As with any VAD scheme, voluntary assisted dying if enacted in the ACT will not cause a single extra death. But it will prevent a lot of unnecessary suffering for many people.

I wish you and your Committee members well in your deliberations.

I consent to having this submission published. Please contact me if your require further information.

Yours sincerely

David Muir
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BACKGROUND:

The Clem Jones Group has been working in recent years with a wide range of groups and individuals in all states and territories to promote voluntary assisted dying law (VAD) reform across Australia.

The desirability of enacting VAD laws across Australia was one of the express wishes made by former Brisbane Lord Mayor, the late Dr Clem Jones AO, in his will.

Dr Clem Jones AO

Throughout his life — in business, politics, and in retirement — Clem Jones played many active roles in numerous community and philanthropic causes, contributing his energy, ideas, and financial support to a variety of causes.

Those who knew him testify to the fact that Clem wanted a fairer society, with all individuals being offered the same opportunities and meaningful choices.

It was that philosophy and his personal experiences watching friends and loved ones die that made Clem resolve to support voluntary assisted dying laws across Australia.

In his will Clem stated:

> *"Having witnessed and experienced the trauma of death, I have become appalled that human beings can impose on their loved ones days, months and years of terrible pain and misery by preserving their life causing them not only to suffer that pain but to suffer too, the mental anguish that comes with it.*
>
> *"If we have a definition of living of any sort, it cannot include the existence of people simply artificially kept alive against their will and in circumstances that can only be described as totally inhuman or barbaric.*
>
> *"I do not of course criticise the splendid endeavours that the medical fraternity make to preserve the quality of human life but when that quality falls to a level where life is one of pain and suffering or where one's mind can no longer function, those self-same medical practitioners should have the right and the responsibility of releasing persons from that torture, misery, and indignity."*

In line with his wishes we have supported legislative reform efforts in state jurisdictions since Clem's death in December 2007. It is pleasing to note that all states now have passed their own VAD laws.

We also advocated for the scrapping of federal laws passed in 1997 that overturned the Northern Territory's *Rights of the Terminally Ill Act 1995* and which until themselves being overturned in late 2022 had prevented the Northern Territory and the Australian Capital Territory from drafting their own VAD laws.

We are currently now making separate submissions as part of the consultation processes established by the NT and ACT governments on their respective proposed laws.

SUMMARY OF SUBMISSIONS:

- We note and support the fact that the Bill aims to strengthen the rights of ACT residents to make a free and informed choice to seek access to voluntary assisted dying and that any VAD scheme operating in the ACT will not cause a single extra death but will relive a lot of personal suffering.

- We support the objects of the Act as outlined in Clause 6 of the Bill which taken together show that the proposed ACT VAD law provides a compassionate yet strictly regulated response as an additional end-of-life option for individuals experiencing intolerable suffering at the end of life.

- We support the principles proclaimed in the Bill and note that the Bill's drafting process has had the benefit of considering previous experiences with VAD laws in Australia and overseas.

- We support the clear statement within the Bill that VAD is not suicide.

- We urge the removal of Clause 11 (4) (c) – "the individual is in the last stages of their life" – as a determinant of an "advanced" terminal or neurological condition when assessing an individual's eligibility to access VAD.

- We believe existing Clause 11 (4) (a) and 11 (4) (b) are adequate determinants of an advanced condition that will inevitably cause an individual's death.

- We recommend that the unrelievable suffering experienced by a person — either a terminally ill individual or one with a neurodegenerative condition — as determined by that person should be the overriding clinical criterion on which the timing of access to voluntary assisted dying should be based.

- We support the proposed overall process for delivering VAD outlined in the Bill which broadly reflects the systems now operating in all states.

- We support the involvement of nurse practitioners in the proposed VAD process outlined in the Bill.

- We support the proposed processes governing the supply, handling, and disposal of VAD substances which we consider will provide a secure VAD system while avoiding overly onerous conditions imposed in some state laws.

- We support the conscientious object provisions contained in the applicable to those holding such objections to being involved in the VAD process on religious or other grounds.

- We recommend that in the interest of patients receiving timely information about VAD that the definition of "working day" be adjusted to cater for circumstances where it applies to relevant decision made by an individual specified in the Bill who may take such a decision immediately prior to commencing recreational or some other form of leave of absence.

- We support and commend the inclusion in the Bill of provisions aimed at accommodating the position of individuals seeking to access VAD and facility operators holding conscientious objections to it and recognise the need for other jurisdictions currently without such provisions to amend their VAD Acts accordingly.

- We suggest that Clause 100 (2) of the Bill be amended to remove the discretion it currently offers facility operators to decide that it is not reasonably practicable to provide access to an individual involved in a patient's VAD process.

SUMMARY OF SUBMISSIONS (continued):

- We further suggest that Clause 100 (2) and any other similar provisions be redrafted to reflect the approach taken in Queensland's VAD Act to the roles and responsibilities of facility operators in the granting of access by individual involved in the VAD process.

- We support the establishment of the Voluntary Assisted Dying Oversight Board as outlined in the Bill, but in the interest of retaining corporate knowledge and experience which can help deliver an optimum VAD scheme, we recommend an amendment to provide for the reappointment of board members for more than one three-year term.

- We support provisions protecting those involved in delivering VAD from liability.

- We submit that such provisions are relatively straightforward and should be followed in principle by the federal government as a matter of urgency as a means to resolve concerns about the conflict that arises between parts of the *Commonwealth Criminal Code Act 1995* and VAD laws when telehealth technology is used in the VAD process.

- We commend the approach taken in the Bill to the relevant parts of the law covering the initiation of conversations about VAD and we believe the approach embodied in Clause 152 will benefit those seeking to use the law at the end of life.

- We recommend that that Clause 159 of the Bill "Review of Act" be amended to provide for reviews of any ACT VAD Act and the operation of the territory's VAD scheme every three years instead of the current proposal requiring reviews at intervals of five years.

- We submit that reviews every three years instead of every five years would optimise opportunities where they arise for the timely harmonisation of VAD laws across Australian jurisdictions.

- We recommend that in addition to "the operation and effectiveness of the Act", ongoing periodic reviews of any ACT VAD Act should also consider eligibility criteria of any the VAD scheme.

- We urge the Committee in its report to advocate for a meaningful public awareness and education program about voluntary assisted dying in the lead-up to and following the start of any VAD scheme in the ACT.

- We recommend that the Committee through its report on the VAD Bill highlights the need for adequate remuneration for medical practitioners involved in the VAD process, either through changes to the Medicare Benefits Schedule by the Federal Government or through direct support by the ACT Government.

- We urge the Committee through its report to highlight the need to resolve the issue of practitioner remuneration which in turn can help alleviate financial challenges faced by VAD patients in cases where their practitioner's unfunded costs are passed directly on to them.

- We recommend that the Committee urgently seek clarification from the Albanese Government about the status of its plans to amend the *Commonwealth Criminal Code Act 1995* in light of its possible impact on VAD telehealth services and urges the federal government to take steps as soon as possible to ensure no conflict exists between the federal law and existing state or future territory VAD laws.

- We urge all ACT MPs to support this Bill on behalf of all of all current and future ACT residents who may seek to use it.

THE ACT'S *VOLUNTARY ASSISTED DYING BILL 2023*:

In our submission we do not address every clause of the Bill but confine our comments to elements for which we wish to register support or to make suggestions for change.

OVERVIEW – HUMAN RIGHTS:

We note that the minister responsible for the Bill is the ACT's Minister for Human Rights. While that fact will likely have no tangible effect on the contents of the government Bill, it underlines the fact that voluntary assisted dying can be seen as a human rights issue as well as a health issue.

We also acknowledge in the Bill's explanatory notes the proposed VAD Act's material compatibility with human rights as set out in the Human Rights Act 2004 (ACT).

Those who seek access to VAD are already dying and are simply exercising their right to make their own decision to die on their terms and to free themselves from intolerable suffering.

The rights of those who hold personal objections to VAD are respected in this Bill and in existing state laws, most obviously by the fact that those who oppose VAD are also free to make a personal choice not to seek access to the VAD system. But neither side should be able to foist their views on the other.

We believe the single most important fact to bear in mind in any discussion of voluntary assisted dying is that a VAD scheme operating in the ACT will not cause a single extra death. But it will relieve or avoid a lot of suffering.

- **We note and support the fact that the Bill aims to strengthen the rights of ACT residents to make a free and informed choice to seek access to voluntary assisted dying and that any VAD scheme operating in the ACT will not cause a single extra death but will relive a lot of personal suffering.**

OBJECTS, PRINCIPLES AND IMPORTANT CONCEPTS:

Objects of the Act:

Clause 6 in Part 2 of the Bill outlining the objects of the proposed VAD Act help reinforce some of the key elements of any legislated voluntary assisted dying scheme.

It reflects the fact that VAD laws do not offer the unquestioned availability of voluntary assisted dying.

But they do enable an individual to make their own informed choice, free from coercion, to seek access to a VAD scheme and then be assessed against legislated eligibility criteria.

They further ensure that the VAD process is compassionate but also contains protections for those involved in the process as well as for those who exercise their rights not to be involved after expressing a conscientious objection.

The ACT Bill, like VAD laws elsewhere in Australia, also establishes strict delivery and monitoring procedures, an expert oversight body, and penalties for breaches.

In total the objects outlined in the Bill prove that VAD is a proper and workable response to the needs of those individuals who are already dying from a terminal condition or neurological condition and wish to relieve their intolerable suffering.

- **We support the objects of the Act as outlined in Clause 6 of the Bill which taken together show that the proposed ACT VAD law provides a compassionate yet strictly regulated response as an additional end-of-life option for individuals experiencing intolerable suffering at the end of life.**

Principles of the Act:

The seven principles governing the operation of an ACT VAD Act outlined in Clause 7 of the Bill are in line with the principles outlined in state VAD laws.

Drafters of the ACT Bill have had the advantage of drawing on those same state laws developed and passed over several years since the successful passage in 2017 of Victoria's *Voluntary Assisted Dying Bill*.

It also has the benefit of drawing on the experiences with VAD laws overseas, while being a Bill framed within an Australian context.

However, while overwhelmingly in agreement with the Bill's contents this submission also touches upon issues within the Bill which we believe should be addressed.

- **We support the principles proclaimed in the Bill and note that the Bill's drafting process has had the benefit of considering previous experiences with VAD laws in Australia and overseas.**

VAD not suicide:

The tactics employed by VAD opponents include their repeated and misleading efforts to conflate voluntary assisted dying with suicide. But VAD and suicide are not the same.

Tragically, most people would know or know of individuals who have taken their own lives. Suicide usually involves an irrational action by someone who can otherwise have their life ahead of them but who tragically decides to cut it short.

VAD on the other hand involves a decision by a rational person whose life is ending soon through a terminal illness or neurological disorder and who wants to control the time and manner of their death and to avoid pointless suffering.

Former Victorian premier and former Beyond Blue chair, Jeff Kennett, has made a clear distinction between suicide and VAD.

"This issue [VAD] is totally different from the issue of suicide within our community," Mr Kennett has stated.

Tasmanian state MP Jenifer Houston put it simply in her contribution to debate on the state's VAD law, passed in March 2021.

The MP for Bass told the Tasmanian Parliament in December 2020: "I find it disturbing that VAD has been likened to suicide. Suicide is a choice between life and death, whereas VAD is a choice between two deaths – a prolonged, agonising death, or a dignified death."

In 2017 the American Association of Suicidology issued a statement clearly distinguishing suicide from VAD, or physician aid in dying as it is often known in the USA.

Its lengthy statement said in summary: "Suicide is not the same as physician aid in dying." It also said: Unlike most cases of suicide, the person who has requested and receives aid in dying does not typically die alone and in despair, but, most frequently, where they wish, at home, with the comfort of his or her family."

The difference between VAD and genuine cases of suicide may be better understood by considering a ruling made by New York City's Chief Medical Examiner, Charles Hirsch, who investigated the deaths of people who jumped from the Twin Towers in New York at the time of the September 11 terror attacks in 2001.

He found that those people realised they had no escape and that they faced an imminent death. They were confronted by a terrible choice between a slow, agonising death by fire or a quick death by jumping, many people chose to jump.

He found that this was a rational choice by those who fell from the towers as a way to avoid needless suffering. In his findings, Hirsch refused to classify the deaths of those who jumped as suicides.

Clause 8 of the Bill under review reflects provisions in most state VAD laws by declaring that voluntary assisted dying is not to be equated to suicide.

This is essential to the operation of any ACT VAD scheme, to rebut false statements to the contrary by VAD opponents, and to protect the rights of all choosing to be involved in the VAD process and contractual rights including insurance.

It is also relevant to the application of the Commonwealth Criminal Code and carriage services under the *Telecommunications Act 1997* in order to avoid any criminal sanction under those laws. *(See "OTHER ISSUES – telehealth" at the end of this submission)*

- **We support the clear statement within the Bill that VAD is not suicide.**

Eligibility requirements:

We note that the eligibility requirements in the Bill for anyone seeking access to VAD reflect in many ways criteria in state laws including the requirement for a patients to be an adult (an individual who is at least 18 years old as defined in the ACT *Legislation Act 2001*), have decision-making capacity, are acting voluntarily and without coercion, and meet specific residency requirements.

However, we do recognise that the Bill improves upon those existing state laws by not imposing an estimated time frame for a patient's expected death.

State VAD laws generally have eligibility criteria covering incurable conditions that are advanced, progressive, will cause death, and which cause intolerable suffering to the patient.

States then impose a time frame for a patient's life expectancy – six months in the case of terminal conditions, or 12 months for a patient with a neurodegenerative condition. In Queensland's VAD law a 12-month period applies to both.

By not imposing such a time frame the ACT Bill recognises the fact that medical practitioners themselves acknowledge that it is difficult to set with precision any time periods covering the rate of deterioration in the condition of a person suffering a terminal illness or progressive illness that will ultimately lead to their death. It is not uncommon for some terminally ill patients to live far longer than an initial prognosis and doctors rightly caution against accepting such time frames as being absolute.

The latest annual report (July 2022 to June 2023) by Victoria's Voluntary Assisted Dying Review Board itself states: "It is recognised that prognostication is not an exact science."

We consider arbitrary time frames in any voluntary assisted dying law represent an unfair impost on medical practitioners as well as being a potential barrier to those seeking access to VAD.

There will always be those who are caught by arbitrary time frames and who may end up suffering more if they deteriorate to a state in which they cannot proactively seek access to VAD.

While we welcome and support the lack of such a time frame in the Bill, we must express concern at the inclusion at Clause 11 (4) (c) of the wording "the individual is in the last stages of their life" as part of the definition of "advanced" applied in Clause 11 (1) (b): *"they have been diagnosed with a condition that, either on its own or in combination with 1 or more other diagnosed conditions, is advanced, progressive and expected to cause death (the relevant conditions)"*

We believe this requirement – "the individual is in the last stages of their life" – could be used to negate the advantage achieved by not having a specified time to death, including the advantage of not relying on acknowledged potentially erroneous subjective assessments.

We fear its inclusion may result in otherwise eligible patients having access to VAD withheld for "failing" to provide evidence of the advanced nature of their terminal or neurodegenerative condition.

We see no reason to include that criterion and submit that the inevitability of death is already proven if an applicant for VAD satisfies the preceding two criteria in Clause 11 (4), namely:

- Clause 11 (4) (a): the individual's functioning and quality of life have declined, and
- Clause 11 (4) (b): any treatments that are available and acceptable to the individual lose any beneficial impact.

We believe the overriding clinical criterion on which the timing of access to voluntary assisted dying should be based is the unrelievable suffering by a person — either terminally ill or suffering a neurodegenerative condition — as determined by that person and we therefore seek the removal of Clause 11 (4) (c).

- **We urge the removal of Clause 11 (4) (c) – "the individual is in the last stages of their life" – as a determinant of an "advanced" terminal or neurological condition when assessing an individual's eligibility to access VAD.**

- **We believe existing Clause 11 (4) (a) and 11 (4) (b) are adequate determinants of an advanced condition that will inevitably cause an individual's death.**

- **We recommend that the unrelievable suffering experienced by a person — either a terminally ill individual or one with a neurodegenerative condition — as determined by that person should be the overriding clinical criterion on which the timing of access to voluntary assisted dying should be based.**

ASSESSMENT PROCESS / ACCESSING VAD / VAD SUBSTANCES:

We note that the Bill mirrors state laws by including at Part 3 and Part 4 request, assessment, and administration of VAD processes involving three separate requests for VAD by an eligible patient including conditions for making, recording, and reporting such requests , accompanying assessments, as well as the involvement of coordinating, consulting, and administering practitioners, and eligible witnesses.

We also note that in the case of any individual accessing VAD Clause 92(3) provides nurse practitioners may perform the duties of either coordinating practitioner or consulting practitioner – but not both – and administering practitioner.

This should have a positive impact on the proposed VAD system, especially in terms of the pool of available and qualified health professionals able to assist patients.

Part 5 of the Bill outlines processes for the supply and secure handling, storage, and disposal of a VAD substance which provide for a workable but safe VAD system while avoiding conditions imposed in some state laws we believe are overly-onerous.

- **We support the proposed overall process for delivering VAD outlined in the Bill which broadly reflects the systems now operating in all states.**

- **We support the involvement of nurse practitioners in the proposed VAD process outlined in the Bill.**

- **We support the proposed processes governing the supply, handling, and disposal of VAD substances which we consider will provide a secure VAD system while avoiding overly onerous conditions imposed in some state laws.**

CONSCIENTIOUS OBJECTIONS:

Provisions in Part 6 the Bill providing for health practitioners or health service providers with conscientious objections to VAD to not be involved in the process reflect the approach taken in state VAD laws.

- **We support the conscientious object provisions contained in the applicable to those holding such objections to being involved in the VAD process on religious or other grounds.**

Those with conscientious objections are entitled not to undertake certain actions if approached by a patient seeking access to VAD, including the provision of information about the VAD process.

In such instances the Bill requires health practitioners or health service providers holding such objections to ensure that a patient is made aware of an approved care navigator service to obtain the information or advice they seek.

It specifies that such contact information is to be provided in writing "within two working days" after the day the health practitioner or health service provider declares their refusal to be involved in the VAD process.

The "two working days" deadline is used in several parts of the Bill. Current definitions in the Bill say that a "working day" for an individual "means a day when the person is working".

We believe that in the interests of a patient receiving information about VAD as soon as possible after requesting it, the definition of "working day" should be adjusted to cover the possibility of an individual with conscientious objections taking recreation or other leave which could mean that the period covered by two working days is interrupted by another possibly longer period.

Our suggestion would be to specify a period expressed in hours or to cite a time frame of a specific number of hours as well as the expression "two working days" and qualify it by adding "whichever is sooner". However, we will leave our suggestion for the Committee to consider.

- **We recommend that in the interest of patients receiving timely information about VAD that the definition of "working day" be adjusted to cater for circumstances where it applies to relevant decision made by an individual specified in the Bill who may take such a decision immediately prior to commencing recreational or some other form of leave of absence.**

OBLIGATIONS OF FACILITY OPERATORS:

Part 7 of the Bill, according to its explanatory notes, seeks "to strike a balance between the rights of the individual seeking access to VAD and the interests of facility operators, particularly those that operate a facility in accordance with an ethos or faith that opposes VAD".

In this aspect the Bill reflects Queensland's *Voluntary Assisted Dying Act 2021* and associated subordinate legislation which also address these type of issues by placing obligations on facilities not offering VAD (eg: certain faith-based entities) to ensure eligible patients are still able to access VAD without compromising the conscientious objections of the facility or its staff.

The Queensland Act also requires certain steps to be taken to inform would-be VAD applicants of its non-availability.

We commend and support the inclusion in the ACT VAD Bill of these type of provisions.

Problems that arise without such provisions can be illustrated by the latest annual report by WA's Voluntary Assisted Dying Board.

In it the board noted concerns that had been raised with the Board during the year under review "from patients, their families, participating practitioners and statewide service providers, regarding barriers to access to voluntary assisted dying for patients residing in health service facilities, such as private hospitals, including those providing public health services as contracted health entities".

The WA board said: "The [WA VAD] Act does not currently contain provisions to support access to voluntary assisted dying for patients who are permanent or non-permanent residents of health service facilities.

The Act does not require health service facilities to publicly disclose when they do not provide access to voluntary assisted dying.

To ensure the principles of the Act are upheld, specific provisions should be included in the Act to ensure health service facilities, including those with an institutional objection, do not impede access to voluntary assisted dying."

WA's Voluntary Assisted Dying Board recommended the state's VAD Act be amended to include:

- protections for access to voluntary assisted dying for patients and residents of health service facilities, and
- the requirement for public information to be available on whether a health service facility provides access to voluntary assisted dying.

The inclusion of provisions in the ACT Bill covering the obligations of facility operators should avoid such problems now evident in WA.

- **We support and commend the inclusion in the Bill of provisions aimed at accommodating the position of individuals seeking to access VAD and facility operators holding conscientious objections to it and recognise the need for other jurisdictions currently without such provisions to amend their VAD Acts accordingly.**

While supporting the provisions covering facility operators in general we wish to make suggestion for change to a specific provision, namely Clause 100 (2):

> *Unless the facility operator decides that it is not reasonably practicable to do so, the operator must, with the consent of the individual, allow a relevant person to have reasonable access to the individual at the facility.*

The "relevant person" refers to an individual such as a patient's doctor.

It is not our preferred position to have a facility operator deciding if access to such an individual "is not reasonably practicable".

A preferred approach would be similar to that in the Queensland VAD Act at "Division 2: Participation by entities" which requires reasonable access to such individuals and does not enable the facility operator to exercise discretion to decide that it is not reasonably practicable to allow access.

- **We suggest that Clause 100 (2) of the Bill be amended to remove the discretion it currently offers facility operators to decide that it is not reasonably practicable to provide access to an individual involved in a patient's VAD process.**
- **We further suggest that Clause 100 (2) and any other similar provisions be redrafted to reflect the approach taken in Queensland's VAD Act to the roles and responsibilities of facility operators in the granting of access by individual involved in the VAD process.**

VAD OVERSIGHT BOARD:

We support the creation of the Voluntary Assisted Dying Oversight Board, a body similar to boards established in legislation by all states.

We also support the proposed size of the board – minimum four and maximum seven members – as well as the eligibility criteria applicable to those serving on it.

However, we question those parts of the Bill which state that the broad members, chair, and deputy chair must be appointed "for not longer than three years".

The Bill, as far as we can determine, does not provide for a board member's reappointment suggesting that the composition of the VAD Oversight Board will change every three years.

If our interpretation is correct, we do not view this as desirable as it means a loss of corporate knowledge and experience in a relatively short space of time.

We believe oversight of any VAD scheme requires board members who not only bring their own professional and personal knowledge and skills, but can also apply the knowledge and skills they acquire as board members.

The reappointment of members and retention of their experience and skills could assist in delivering the optimum VAD scheme for ACT residents.

We believe this goal could be achieved by an amendment making explicit that board members may be reappointed at the end of their three-year terms.

This arrangement still allows the board to be "refreshed" with new members, but avoids a situation where all members are new and inexperienced as board members every three years.

- **We support the establishment of the Voluntary Assisted Dying Oversight Board as outlined in the Bill, but in the interest of retaining corporate knowledge and experience which can help deliver an optimum VAD scheme, we recommend an amendment to provide for the reappointment of board members for more than one three-year term.**

PROTECTION FROM LIABILITY:

Part 9 of the Bill outlines protections offered to those involved in the VAD system who might otherwise face being charged with various offences in relation to the loss of an individual's life in other circumstances.

These provisions reflect those included in state VAD laws.

Interestingly, these provisions of the Bill illustrate how relatively simple it would be for the federal government to draft amendments to the previously mentioned *Commonwealth Criminal Code Act 1995* in relation to put beyond doubt that the use of a carriage service when telehealth facilities are employed in discussing or assessing VAD applications does not conflict with the Code's provisions relating to incitement of suicide. *(See "OTHER ISSUES – telehealth" at the end of this submission)*

- **We support provisions protecting those involved in delivering VAD from liability.**
- **We submit that such provisions are relatively straightforward and should be followed in principle by the federal government as a matter of urgency as a means to resolve concerns about the conflict that arises between parts of the *Commonwealth Criminal Code Act 1995* and VAD laws when telehealth technology is used in the VAD process.**

MISCELLANEOUS:

Initiating conversations about VAD

We are pleased that the ACT VAD Bill at Clause 152 embodies a sensible approach to the issue of health professionals initiating conversations about voluntary assisted dying with patients.

Some state VAD laws, notably Victoria's, have taken an overly restrictive approach to this issue which we believe has the potential to deny patients sufficient knowledge of all of their end-of-life options.

On this issue the ACT Bill represents an evolution of VAD law-making which we believe will be beneficial to those seeking to use it.

- **We commend the approach taken in the Bill to the relevant parts of the law covering the initiation of conversations about VAD and we believe the approach embodied in Clause 152 will benefit those seeking to use the law at the end of life.**

Review of the Act:

Clause 159 of the Bill provides for ongoing review of an ACT VAD Act. It requires a review of "the operation and effectiveness" of the Act as soon as practicable:

- three years after it commences, and
- every five years after the first review.

We support the provision for future reviews but consider a five-year period between reviews following an initial review to be too long.

All state VAD laws require an initial review of their schemes:

- Victoria – in the fifth year of operation (underway)
- WA – after two years of operation (underway)
- Tasmania – after three years of law's passage (from March 2024)
- NSW – after two years of operation (November 2025)
- Queensland – after three years of operation (January 2026)
- SA – after the fourth but before the fifth year from start of operation (January 2027).

But not all state VAD laws require ongoing reviews following their initial review:

- Victoria – no further reviews specified
- WA – no more than five years after initial review
- Tasmania – every five years after initial review
- NSW – at intervals of no more than five years
- Queensland – no further reviews specified
- SA – no further reviews specified.

We believe all VAD laws should be reviewed at least every three years to enable them to more readily incorporate beneficial ideas from other jurisdictions, accommodate advances in medical science and treatments that may affect decisions by individuals considering seeking access to VAD, or to address in a timely manner potential problems that may arise within the operation of their schemes.

Such three-year reviews would also optimise opportunities where they arise for the harmonisation of VAD laws across Australian jurisdictions.

- **We recommend that that Clause 159 of the Bill "Review of Act" be amended to provide for reviews of any ACT VAD Act and the operation of the territory's VAD scheme every three years instead of the current proposal requiring reviews at intervals of five years.**

- **We submit that reviews every three years instead of every five years would optimise opportunities where they arise for the timely harmonisation of VAD laws across Australian jurisdictions.**

Clause 159 of the Bill also outlines the matters that are required to be considered in the initial review after the Act has been operating for three years. They include:

- residency requirements,
- access to VAD by mature minors
- possible access to VAD through advanced care planning.

We recognise the logic in deferring possible inclusion in the current Bill of the issues encompassed by the three subjects. But we also believe that by listing only those criteria, the initial review may be too restricted.

An ongoing subject of discussion in relation to all VAD schemes is the issue of if and how any schemes could or should deal with applicants with a form of dementia.

This issue may be covered under the third element mandated for review after three years – VAD through advanced care planning – but at the time of the foreshadow review there may be arguments made that end up excluding it from consideration by more closely defining what subject matter is covered by the third dot point above.

Because of community expectations surrounding the operation of VAD scheme and their application to those with dementia, we consider the wording of Clause 159 in relation to future reviews should be broadened.

We do not believe there is a workable solution to the questions surrounding VAD and dementia at present and in this submission we are not advocating for its inclusion as a condition to be encompassed by a VAD scheme. However, we recognise the depth of community concern about it as evident at public hearings held into VAD Bills by all states and in submissions received by them

We therefore suggest that the wording of Section 159 in relation to the subject matter to be considered in the initial three-year review should be broadened and also made applicable to any following future reviews.

We direct the Committee to Section 154 of the Queensland *Voluntary Assisted Dying Act 2021* which mandates a review of the Act three years after it starts operation and which declares that such a review "must include a review of the [Queensland VAD scheme's] eligibility criteria". This wording, in our opinion, provides suitable scope to enable future reviews to consider matters of public concern such as patients with dementia and not be limited to the three elements currently listed as topics for review.

- **We recommend that in addition to "the operation and effectiveness of the Act", ongoing periodic reviews of any ACT VAD Act should also consider eligibility criteria of any the VAD scheme.**

OTHER ISSUES:

While not directly connected to the contents of the VAD Bill, we wish to make some comments and submissions on matters that have arisen in other jurisdictions since the passage and their VAD laws and the start of their VAD schemes.

Public awareness and education:

Delegates to the initial Voluntary Assisted Dying National Conference organised by VAD advocacy group Go Gentle in Sydney in September 2023, were told of the need for a greater effort in the area of public awareness and education on voluntary assisted dying.

Professor Lindy Willmott – a world expert on VAD laws based at QUT Brisbane and a member of Queensland's VAD Review Board – identified some barriers to accessing VAD including:

- lack of public awareness
- some people not knowing VAD was an option
- eligibility criteria
- people not knowing how to connect to the VAD system, and
- not knowing how to talk to their doctor/s about VAD.

Conference delegates confirmed her concerns, saying some state laws – especially Victoria's with its so-called "gag clause" prohibiting health professionals initiating conversations with patients about VAD – were unhelpful when it came to raising awareness.

We present these remarks in the hope that the Committee's report will advocate for a meaningful public awareness and education program about voluntary assisted dying in the lead-up to and following the start of any VAD scheme in the ACT.

- **We urge the Committee in its report to advocate for a meaningful public awareness and education program about voluntary assisted dying in the lead-up to and following the start of any VAD scheme in the ACT.**

Practitioner remuneration:

Again, although not an issue directly related to the contents of the Bill, we wish to mention an issue that has become a matter for discussion in some state VAD schemes – practitioner remuneration.

In a number of states there have been concerns raised about the need to better remunerate medical professionals for the time and effort they invest in the VAD process for their patients. Inadequate remuneration can adversely impact the availability of practitioners willing to be involved in the VAD process.

In its latest annual report WA's Voluntary Assisted Dying Board said it was concerned that there was no secure funding for practitioners' services.

> *Practitioners deserve to be adequately remunerated for the extensive time they spend assessing and supporting patients through the voluntary assisted dying process and for the mandatory administrative and reporting activities involved. To date most participating practitioners have absorbed the costs of providing these services where Medicare Benefit Schedule item numbers available to remunerate practitioners are insufficient to reasonably account for the time and effort involved. In 2022–23, the Board has become increasingly aware of voluntary assisted dying being provided as a private fee for service model. Practitioner remuneration and ongoing support for voluntary assisted dying within the WA Health system should be addressed as a matter of priority.*

Similarly, the latest annual report by Victoria's Voluntary Assisted Dying Review Board states:

> *Medical practitioners have expressed that the clinical time required to complete a voluntary assisted dying assessment process is not adequately compensated through the existing Medicare Benefits Schedule remuneration items. Some practitioners choose to apply private fees to complete these assessments. Conversely, some applicants have indicated that the financial burden associated with the process has impeded access or put pressure on finances for those supporting them through the process.*

The WA and Victorian boards as well as Queensland's Voluntary Assisted Dying Review Board in its latest annual report all suggested that the Medicare Benefit Schedule should be reviewed to include appropriate item numbers to ensure remuneration is sufficient to reflect the work undertaken by practitioners.

However, in its 2022-23 annual report the South Australian VAD Review Board alludes to the possibility of state funding support.

It says although medical practitioners involved in VAD understand their role in supporting people through their end-of-life choice, and strive to be as flexible and available as possible for their patients, they can incur significant time and travel.

"Participating medical practitioners in the primary care sector have expressed concerns about the limitations of seeking remuneration under the Medicare Benefits Schedule as there are currently no Medicare rebates specifically related to voluntary assisted dying," the SA board said.

"To further support practitioners, SA Health can provide funding to facilitate regional access for patients through travel and time reimbursement for practitioners where no suitable mechanism exists, for example when a practitioner travels to a rural community to see a patient for a first assessment.

"SA Health will continue to advocate with the Federal Government for remuneration for voluntary assisted dying to promote the sustainable provision of voluntary assisted dying in Australia and will consider a local remuneration framework for medical practitioners in the next year."

We raise the remuneration issue in the hope that Committee members, through their recommendations, may cause the issue to be raised with the Federal Government or recommend that the ACT itself explores the approach being considered in South Australia and provides direct remuneration support to practitioners.

Unless this issue is addressed it may have negative impacts on patients using the VAD system, especially if practitioners seek to pass on costs to patients.

- **We recommend that the Committee through its report on the VAD Bill highlights the need for adequate remuneration for medical practitioners involved in the VAD process, either through changes to the Medicare Benefits Schedule by the Federal Government or through direct support by the ACT Government.**

- **We urge the Committee through its report to highlight the need to resolve the issue of practitioner remuneration which in turn can help alleviate financial challenges faced by VAD patients in cases where their practitioner's unfunded costs are passed directly on to them.**

Telehealth:

As mentioned above the Bill contains the express provision that VAD is not suicide.

But we note that there are ongoing concerns about a potential conflict with provisions of the *Commonwealth Criminal Code Act 1995* in relation to use of a carriage service when telehealth facilities are employed in discussing or assessing VAD applications.

All states have expressed concerns about the challenges to their VAD schemes potentially posed by parts of the federal law whose original aim was to outlaw the use of carriage services to facilitate suicides, eg: through online bullying.

There have been longstanding fears that the use of telehealth in parts of the VAD process, especially in relation to patients in remotes areas, may be deemed illegal under the federal law.

Although small in its size compared to the states and the Northern Territory, it is possible to image that the ACT could contain people seeking access to VAD whose circumstances place them remote from the wider community and therefore in need of telehealth connections in the VAD process.

While most state VAD laws clearly state that the procedure is not suicide, there persist calls for amendments to the federal law to put the matter beyond doubt.

In discussions we have held with the Albanese Government it has previously indicated a willingness to amend the *Commonwealth Criminal Code Act* to ensure there is no conflict with state VAD laws.

At the time of writing this submission no such action has yet occurred despite representations from state governments and the outcome of a test case launched by a Victorian doctor in the Federal Court. In addition, two crossbench federal MPs are supporting a private member's bill to clarify the position of VAD scheme and give certainty to those using them.

- **We recommend that the Committee urgently seek clarification from the Albanese Government about the status of its plans to amend the *Commonwealth Criminal Code Act 1995* in light of its possible impact on VAD telehealth services and urges the federal government to take steps as soon as possible to ensure no conflict exists between the federal law and existing state or future territory VAD laws.**

CONCLUSION:

The Clem Jones Group congratulates the Australian Capital Territory Government for its initiative in drafting and introducing to the ACT Legislative Assembly the *Voluntary Assisted Dying Bill 2023.*

Although proposed by the government, the Bill's fate will be in the hands of all members of the ACT Parliament.

As seen in other jurisdictions, VAD laws have received bipartisan support because the majority of MPs, regardless of party affiliation or their personal views on VAD, have believed that decisions on voluntary assisted dying should be left to those who may seek to use it.

Evidence from Australia and elsewhere shows many people approved to access a VAD scheme end up not using it, but its mere availability as an end-of-life option provides comfort to them.

Bearing in mind the suggested amendments we have put forward, the Bill – like VAD laws in Australian states – aims to provide a workable, secure regime with suitable protections and oversight that should be supported by ACT MPs.

As we have mentioned previously, a VAD scheme will not cause a single extra death, but will alleviate or eliminate a lot of suffering.

We believe the arguments for backing the aims of the Bill are overwhelming.

We believe that ACT MPs will acknowledge that fact if in the forthcoming debate on this Bill they assess it as parliamentarians representing people and not as partisan politicians.

- **We urge all ACT MPs to support this Bill on behalf of all of all current and future ACT residents who may seek to use it.**