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A submission by

THE CLEM JONES GROUP

to the

HEALTH AND ENVIRONMENT COMMITTEE OF THE PARLIAMENT OF QUEENSLAND

VOLUNTARY ASSISTED DYING BILL 2021

Wednesday 30 June 2021

The Clem Jones Group is part of the

MY LIFE MY CHOICE

coalition supporting voluntary assisted dying
law reform in Queensland and in other
Australian states and territories.

Wednesday 30 June 2021

Mr Aaron Harper MP
Chair
Health and Environment Committee
Member for Thuringowa
Parliament House
Brisbane Qld 4000

Dear Mr Harper

I am pleased to provide this submission to the Committee to assist in its examination of the *Voluntary Assisted Dying Bill 2021.*

This submission urges the Committee to recommend to the Queensland Parliament the *Voluntary Assisted Dying Bill 2021* in full, as it stands, and without amendment.

Our reasons are detailed in this submission which addresses key parts of the legislation as drafted by the independent Queensland Law Reform Commission.

The Bill as drafted delivers equity of access for those seeking VAD and necessary safeguards while providing for conscientious objections, and aligning with human rights principles.

We urge the Committee to recognise that voluntary assisted dying laws give terminally ill people or those with a neurodegenerative condition more options about how they end their lives and can help ensure their lives come to a close in a way and at a time they choose and without unnecessary suffering.

All such laws should focus on the needs and wishes of the dying individual – to give them control over how and when their life is drawn to a close.

The Bill as it stands does so.

It is important to remember that no VAD law gives automatic access to voluntary assisted dying. But they do allow competent individuals to seek access according to set criteria and subject to legislated protections and safeguards. VAD laws elsewhere also recognise that applicants approved to access VAD may ultimately decide not to use it.

The Bill as it stands meets these important requirements.

Like all other voluntary assisted dying laws, the Bill under examination will not result in a single extra death.

It will, however, result in a lot less suffering.

David Muir
Chair
The Clem Jones Trust
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BACKGROUND:

The Clem Jones Group has been working in recent years to promote voluntary assisted dying law (VAD) reform in Queensland under the My Life My Choice banner with numerous individuals and groups including:

- Dying With Dignity Queensland,
- Doctors for Assisted Dying Choice, and
- Everald Compton's Christians for Voluntary Assisted Dying Queensland.

Support for enacting VAD laws across Australia was one of the express directions made by former Brisbane Lord Mayor, the late Clem Jones, in his will.

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 several Australian jurisdictions since Clem's death in December 2007.

They have included a previously unsuccessful effort in South Australia where a VAD Bill failed on the casting vote of the Speaker in 2016. An SA VAD law has since been passed this year.

We also supported efforts in states where VAD laws have now been passed – Victoria, Western Australia, and Tasmania.

We continue to advocate for the scrapping of federal laws that overturned the Northern Territory's *Rights of the Terminally Ill Act 1995* and which prevent the NT and the Australian Capital territory from drafting their own VAD laws. We note strong and growing bipartisan support for removing the federal law.

VOLUNTARY ASSISTED DYING BILL 2021

INTRODUCTION:

The Clem Jones Group supports the *Voluntary Assisted Dying Bill 2021* as drafted by the Queensland Law Reform Commission.

We ask that the Health and Environment Committee recommend the Bill to the 57th Queensland Parliament in its current form, without amendment.

We acknowledge that the QLRC's stated approach in drafting the Bill was based on the following principles:

- the importance of upholding and respecting human rights and the dignity and autonomy of individuals;
- the need for safeguards to protect individuals who might be vulnerable to coercion or exploitation;
- recognising that health practitioners are subject to a comprehensive legal, regulatory and ethical framework;
- recognising, and not detracting from, the importance of high quality and accessible palliative care at the end of life;
- respecting the diversity of individuals' and health practitioners' views, values and beliefs, and avoiding value judgments about others' lives and choices;
- the need for the legislation to be clear and no more complex than it needs to be to achieve its purposes;
- the desirability of achieving reasonable consistency with the legislation in other Australian jurisdictions; and
- the need for the legislation to be well adapted to Queensland's geographic, cultural and health care environment.

We submit that the Bill meets these principles and draws upon and improves VAD laws passed elsewhere in Australia and in jurisdictions overseas.

The Bill under examination is the unique work of the QLRC but we note that the Commission's own extensive research and drafting work was informed in part by the model Bill for voluntary assisted dying drafted by Brisbane-based end-of-life law experts Professor Ben White and Professor Lindy Willmott which the Health Committee of the 56th Queensland Parliament recommended as "the basis for a legislative scheme for voluntary assisted dying".

We also note that VAD law pioneer, the former Chief Minister of the Northern Territory, Marshall Perron, gave evidence to the Health Committee Inquiry that he believed the White Willmott model Bill to be the best such law he had ever seen. It is notable that the QLRC's work has improved on that model Bill.

> **SUBMISSION 1: We submit that the Health and Environment Committee should recommend the *Voluntary Assisted Dying Bill 2021* to the 57th Queensland Parliament in its current form, without amendment.**

HUMAN RIGHTS:

In addition to the principles mentioned above to which the QLRC adhered in its drafting of the Bill, the Bill itself contains a distinct set of principles at Clause 5 which underpin the legislation's approach to voluntary assisted dying, namely:

> ***Principles of voluntary assisted dying***
>
> *The principles that underpin this Act are—*
> a. *human life is of fundamental importance; and*
> b. *every person has inherent dignity and should be treated equally and with compassion and respect; and*
> c. *a person's autonomy, including autonomy in relation to end of life choices, should be respected; and*

d. *every person approaching the end of life should be provided with high quality care and treatment, including palliative care, to minimise the person's suffering and maximise the person's quality of life; and*
e. *access to voluntary assisted dying and other end of life choices should be available regardless of where a person lives in Queensland; and*
f. *a person should be supported in making informed decisions about end of life choices; and*
g. *a person who is vulnerable should be protected from coercion and exploitation; and*
h. *a person's freedom of thought, conscience, religion and belief and enjoyment of their culture should be respected.*

The principles used to draft the Bill and the principles included in and underpinning the Bill show that human rights principles of sanctity of life, respect for human dignity, respect for individual autonomy, protection of the vulnerable and respect for different views on the sanctity of life are embraced by the Bill.

We accept the Statement of Compatibility under the *Human Rights Act 2019* and agree that the right to life is "not a duty to live" and how a person chooses to pass the closing moments of life is "part of the act of living".

> **SUBMISSION 2: We believe the Bill should be supported as it acknowledges and embraces relevant principles applicable to a terminally ill person's human rights.**

SAFEGUARDS:

We believe the Bill contains sufficient safeguards to address any concerns about the potential for the exploitation or coercion of patients.

Clause 7 of the Bill adopts the approach taken in Western Australia's *Voluntary Assisted Dying Act 2019* in relation to the raising of the issue of VAD by a health care worker.

Health care workers are not to initiate discussion about VAD except if at the same time they also inform a patient about treatment options and likely outcomes and palliative care and treatment options and likely outcomes of care and treatment.

We believe this strikes a correct and workable balance for optimal medical care and the right to information by a patient, allowing them to make informed choices.

Further safeguards are provided in Part 2 of the Bill (Clauses 9 to 13) – *Requirements for access to voluntary assisted dying* – which outlines, among other provisions, when a person may seek access to VAD, eligibility requirements, and provisions to determine decision-making capacity.

The eligibility criteria alone provide safeguards in prerequisites of having a terminal illness that is advanced and progressive, with death to occur within 12 months and the illness causing intolerable suffering, together with the age requirement of adulthood and decision-making capacity.

Clause 13 dealing with issues of mental illness and disability provides further safeguards by making it clear that those criteria alone are not sufficient to seek access to VAD.

It is disturbing that opponents of VAD, when peddling the comprehensively discredited "slippery slope" argument, often cite people with a mental illness or disability as potential unwilling "victims" of voluntary assisted dying.

We note that this provision in the Bill reflects laws elsewhere which also work on the basis that a decision cannot be made to reject an application by a competent and otherwise eligible person seeking access to voluntary assisted dying purely on the basis of their disability.

Safeguards have also been written into the Bill in Part 3 – *Requesting access to voluntary assisted dying and assessment of eligibility.*

A person seeking access to VAD is required to pass through a multi-stage request and assessment process with three separate requests dealing with voluntariness and lack of coercion, with at least two medical practitioners and independent witnesses.

Other safeguards include oversight by the Voluntary Assisted Dying Review Board (Part 8), availability of review of certain decisions by QCAT (Part 7), and ineligibility of involvement of people who might be beneficiaries of a person's death under the law (Clauses 21, 32, 38, 82, 83, 157).

We draw the Committee's attention to the experience in Victoria where its *VAD Act* has been operating for two years and where evidence shows that safeguards in the Bill before us, which draws on the Victorian laws and others, do work.

Betty King is a former Supreme Court judge who chairs Victoria's VAD Review Board which examines every single VAD case since the law took effect in June 2019.

She told the ABC in April: *"I have not seen one example so far of anyone who has been pushed, coerced, or inveigled in any way into taking the assisted dying medication."*

The Review Board's latest report to December 2020 shows that there has not been a single example in 224 cases in the first 18 months of the scheme alone.

US advocacy group Compassion and Choices has looked at data from American states with VAD laws – what they call "medical aid in dying".

It says: *"In more than 20 years of experience since the first law was enacted in Oregon, and an additional 40-plus years of combined evidence and cumulative data from the laws passed in other jurisdictions there is not a single substantiated case of abuse or coercion nor any civil or criminal charges filed related to the practice. Not one."*

We urge the Committee to reject arguments by VAD opponents claiming the Bill contains insufficient safeguards.

In reality the only safeguard opponents will support is to have no VAD laws, which is no safeguard at all when it comes to the current unregulated practice of terminal sedation.

> **SUBMISSION 3: We believe the Bill provides adequate safeguards against exploitation and coercion and that more or more onerous safeguards would erect barriers to access by terminally ill persons causing increased suffering.**

ELIGIBILITY:

As mentioned above we support the eligibility criteria in the VAD Bill.

We do wish to raise a specific eligibility provision, namely Clause 10 (ii) which states that a person can seek access to VAD if they have a condition expected to cause death within 12 months, along with other criteria.

In our submission to the QLRC we argued for the adoption of no timeframe as proposed in the White/Wilmott model Bill.

Eligibility criteria in Victoria's voluntary assisted dying legislation includes provisions that a person seeking access to voluntary assisted dying a person must be diagnosed with a disease, illness or medical condition "that is incurable, and is advanced, progressive and will cause death, and is expected to cause death within weeks or months, not exceeding six months", and is causing "suffering to the person that cannot be relieved in a manner that the person considers tolerable".

Another provision states that in the case of a person diagnosed with a neurodegenerative disease, illness, or condition, that person must be expected to die "within weeks or months, not exceeding 12 months".

In our submission to the QLRC we argued that the 6/12-month eligibility criteria could be viewed as being arbitrary and that some people may end up suffering more if they deteriorate to a state in which they cannot proactively seek access to VAD within a specified time frame.

However, we support the QLRC's approach as expressed in its VAD Bill and accompanying explanatory documents.

The QLRC has explained that the Victorian law in its original form contained a single time frame of 12 months as the anticipated period to death for people with a terminal illness or neurodegenerative condition. In the legislative process the period was reduced to a single period of six months then later amended again to the 6/12-month provision that stands in the Victorian *Voluntary Assisted Dying Act 2017*.

The QLRC has said: *"This amendment was made to address concerns that the six month timeframe was more suited to advanced cancers, and that a 12 month timeframe accounted for the different nature and clinical trajectories of neurodegenerative diseases."*

The WA law is consistent with Victoria's. In Tasmania the original Private Member's Bill contained no time frame but was amended to provide for the 6/12-month model.

As the QLRC has noted, the Tasmanian MP, Mike Gaffney MLC, who sponsored the Bill resisted the inclusion of a specific time frame, saying it ran the risk of prolonging a person's suffering and could mean them having "to wait until they have six months to go" before they could initiate the process for accessing VAD.

While we agree with Mr Gaffney, we believe the provision in the Bill that death should be expected within 12 months is a sensible one and in our view is preferable to the 6/12-month approach.

As the QLRC itself points out in its supporting documents, providing for a 12-month period "makes it clear that voluntary assisted dying is an option only for those who are at the end of life".

It also allows terminally ill people to begin the process of seeking access to VAD but that does not mean they would immediately secure access to a VAD substance and administer it.

As the QLRC states: "Experience shows they are likely to wait until they are closer to death."

> **SUBMISSION 4: We support the eligibility criteria in the VAD Bill and urge the Committee to resist efforts to impose time frames different to those currently in the VAD Bill for the reasons outlined by the QLRC.**

VAD IS NOT SUICIDE:

The statement at Clause 8 that VAD is not suicide is pivotal to the application for the scheme to protect the rights of all involved under the Act and all contractual rights including insurance.

The statement is similar to those expressed in VAD laws in Western Australia, Tasmania, and South Australia.

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 these laws.

The express provision that VAD is not suicide goes toward avoiding any conflict between state and federal laws where health practitioners may be using electronic means to deliver services under the VAD laws.

We note that concerns about a potential conflict in relation to use of a carriage service when telehealth facilities are employed in discussing or assessing VAD applications originated in Victoria which was not only the first state to pass a VAD law in recent years but which also did not contain an express provision stating that VAD is not suicide.

> **SUBMISSION 5: We believe the clear statement within the Bill that VAD is not suicide should alleviate concerns held by some medical professionals about the use of telehealth facilities in relation to VAD and furthermore we believe the provision at Clause 8 strengthens arguments that the Queensland Bill does not conflict with Commonwealth law.**

We support the inclusion at Clauses 8 and 81 of a provision stating that a person whose death is the result of them having accessed and used voluntary assisted dying in line with the proposed law, must have their cause of death recorded and registered (eg: on a cause of death certificate and death certificate) only as being their underlying terminal illness or neurodegenerative condition.

SUBMISSION 6: We support the requirement for a cause of death in VAD cases to be recorded as a person's underlying terminal illness or medical condition as this provision ensures the privacy of patients and their family while separate notification to the proposed Voluntary Assisted Dying Review Board ensures necessary statistical records are maintained.

VAD opponents continue to use emotive and misleading arguments linking VAD and suicide when the two are unrelated.

We believe VAD is not suicide. So too does Jeff Kennett, former chair of Beyond Blue who publicly made the distinction at the time Victoria was debating its laws since passed by its Parliament.

"This issue [VAD] is totally different from the issue of suicide within our community," Mr Kennett said in September 2016.

The US research and advocacy group, the American Association of Suicidology also refuted claims by VAD opponents in a 2017 statement.

Part of its lengthy statement on the issue said: *"In [VAD] the person with a terminal illness does not necessarily want to die; he or she typically wants desperately to live but cannot do so; the disease will take its course. Suicide, by contrast, even when marked by ambivalence, typically stems from seemingly unrelenting psychological pain and despair; the person cannot enjoy life or see that things may change in the future."*

A Tasmanian MP in the state's lower house, Jennifer Houston (Bass), put it clearly during debate on that sate's VAD Bill in December 2020 when she said: *"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 addition, we believe that suicide is a choice between life and death usually by a person in an irrational state of mind despite having reasons to live. Voluntary assisted dying is a choice made by a competent person whose life is already drawing to a close who simply wishes to avoid further suffering.

One effect of the Bill on genuine cases of suicide could be to reduce the number of self-inflicted deaths by people with a terminal condition who take steps themselves to end their lives in a bid to avoid future intolerable suffering.

These types of deaths have been identified by coroners or police at parliamentary inquiries in states which have considered or passed VAD laws.

Here in Queensland the previous Committee's inquiry was given data from the National Coronial Information System showing an average of seven such deaths a month in Queensland, often in lonely and isolated circumstances and by sometimes horrific means which have devastating impacts on family members as well as first responders such as police officers who attend the death scenes.

The mere existence of a VAD law being available could relieve anxiety by offering a legislated option if a person needs and wants it.

SUBMISSION 7: We urge the Committee to reject arguments likening VAD to suicide and to discourage the use of the term "suicide" by opponents of law reform because it is not only wrong and misleading but also disrespects those impacted by the tragedy of genuine cases of suicide.

CONSCIENTIOUS OBJECTION:

Similar to VAD laws elsewhere the Bill offers registered health practitioners the right of conscientious objection by refusing to provide information about VAD, participating in the request and assessment process, in administrative decisions, in prescribing supplying or administering a VAD substance, or to be present at time of administration of VAD substance.

But this right outlined in Clauses 84 and 85 is balanced with a requirement to inform a person that others can assist as well as providing information of those who can assist or details of the official assisted dying care navigator service.

This formulation represents the middle ground in balancing rights as it does not require a referral. We believe this is a fair and workable balance.

This fair balance is taken forward in Clause 90 to entities who are required not to hinder access to information about VAD and to allow access at the facility to a registered health practitioner or voluntary assisted dying navigator to provide information.

Important protections are provided in Clause 97 in regard to the administration of a VAD substance requiring entities to allow reasonable access for the coordinating practitioner in the case of permanent residents, for example in a nursing home. If the practitioner cannot attend then reasonable steps for a transfer must be taken.

If the person is not a permanent resident, reasonable steps must be taken for transfer. However, if such transfer, in the opinion of the deciding practitioner is likely to cause serious harm or adversely affect access to VAD, then that person must be treated as if they were a permanent resident.

It is important to recognise that in the case of a permanent resident, the entity in which they reside is their home. In Australia especially there is an expectation that “your home is your castle” with all the expectations of certain rights which that entails.

In summary, the rights of conscientious objection are extensive, however these rights cannot be a barrier to providing information that would enable access to VAD. It is important to note that this is a bare requirement that does not require a referral.

Once again we believe the right balance has been achieved in the interests of equity and access.

We note late amendments to the VAD Bill – a Private Member’s Bill – passed in June by the South Australian Parliament which aimed to put beyond doubt its provisions covering this issue in relation to occupants of retirement villages in SA.

Those amendments were moved by the state’s Health Minister Stephen Wade MLC who told the Legislative Council on 23 June: *“This amendment, consistent with the House [of Assembly] amendment No. 3, simply says that aged-care accommodation is a person's home and their home should be respected. They should be able to access medical services, if they wish to do so, in their home. I am just making the point that aged-care accommodation is not just Commonwealth residential aged-care facilities, it is also state-based retirement villages.*

“To be frank, I think it is significantly more their home than a residential aged-care facility. My understanding is that the average term of a resident at a residential aged-care facility is in the order of 18 months. So it is their home, it is their normal place of abode, but it may not be for an extended period, whereas at a retirement village, people can go into a retirement village and be a healthy, active resident for decades before they need any form of support.”

It is clear that the Minister’s amendment was designed to put beyond doubt an existing right expressed in the SA VAD Bill that entitled retirement village occupants to access VAD in their homes regardless of the stance taken on VAD by the village operator.

> **SUBMISSION 8: We support the provisions in the VAD Bill through which a terminally ill person’s access to VAD or a VAD-related process in their home should not be compromised in circumstances provided for in the Bill even if their home is provided by an institution holding a conscientious objection to VAD.**

PALLIATIVE CARE:

The VAD Bill at Clause 5 recognises that palliative care should be available to minimise suffering and maximise quality of life.

VAD can be complementary to palliative care and is not an “either/or” proposition. Palliative care will help most people, but not all. That is the imperative of VAD.

We want to see better resourcing and wider availability of palliative care, especially in regional Queensland, and note extra funds earmarked by the state government as a start.

Palliative care can help most, but not all, people. That is the evidence. That is the imperative of VAD.

This fact was put to the previous Committee's inquiry in evidence by several authorities.

We draw attention to evidence by Dr Edward Mantle, palliative care specialist with the Cairns and Hinterland Hospital and Health Service.

Dr Mantle said he was absolutely not a supporter of voluntary assisted dying, although he respected an individual's right to choose it if they wished.

But he also told the previous Committee's inquiry : *"I think it is disingenuous, and it is probably closer to a bald-faced lie, when palliative physicians say that they can relieve all suffering for all patients. It is simply not true."*

We believe this is a powerful statement by a VAD opponent who is a strong supporter of palliative care.

We believe it must also be recognised that palliative care is delivered by many general practitioners as well as medical specialists.

We believe that the State Government needs to address any inequality in access to palliative care in the regions of Queensland as well as metropolitan areas.

Hospices, in particular, are largely concentrated in South East Queensland and ought to be more available in regional Queensland.

> **SUBMISSION 9: We endorse the principle relating to palliative care underpinning the Bill and urge the Committee to recognise – as did the Health Committee of the 56th Parliament – that voluntary assisted dying and palliative care can co-exist and that VAD must be available for those for whom palliative care does not adequately address their end-of-life suffering.**

CONCLUSION:

In conclusion we wish to acknowledge the work of the Members who served on the Health Committee of the 56th Queensland Parliament for the work they did in conducting the end-of-life inquiry which resulted in a recommendation for voluntary assisted dying laws.

The continuing Members of that Committee, the Member for Thuringowa and the Member for Lytton, will know of the highly emotional evidence provided to their inquiry by so many Queenslanders at hearings they conducted across the state.

We take this opportunity to again thank all past and present MPs who served on that Committee, including those who did not end up supporting the recommendation for VAD laws. The opportunities they gave to so many to have their say on this sensitive issue were clearly much appreciated by those who told their individual and often heartbreaking stories.

We also wish to take this opportunity to thank and congratulate the Queensland Law Reform Commission, its chair Justice Peter Applegarth, its director David Groth and his staff for the work they undertook in drafting the VAD Bill after seeking the views of Queenslanders.

To the Members of the current Health and Environment Committee of the 57th Queensland Parliament, we thank you for the opportunity to make this submission.

We agree to its publication, and we again urge you to recommend the *Voluntary Assisted Dying Bill 2021* to the Queensland Parliament unamended.