

'The right to die is as inviolable as the right to life'. Sir Mark Oliphant

The Joint Committee on End of Life Choices

The Joint Committee on End of Life Choices (EOLC) was appointed in the South Australian Parliament on 4th April 2019. The six committee members are Hon Kyam Maher (Chairperson), Opposition Leader in the Legislative Council and Shadow Attorney General; Hon Mark Parnell, MLC (Greens); Hon Dennis Hood, MLC (Liberal); David Basham (Liberal); Hon Tony Piccolo (ALP); and Steve Murray (Liberal). (Mr Murray has replaced Sam Duluk). The EOLC Committee is expected to complete a report in the next couple of months.

Depending on the committee recommendations, there are various choices, including:

- The Committee could recommend that the Government introduce a voluntary assisted dying (VAD) Bill, as in Victoria and WA.
- The Committee may have a split report and recommendations.
- The Government may take responsibility for introducing a VAD Bill.
- The Government could ignore the findings of the EOLC Committee.
- A Private Member may introduce a VAD Bill.

If the Government takes responsibility for a Bill, debate time will be allocated in the normal course of debate for government business.

If a VAD Bill is introduced by a Private Member, it will be subject to the limit on debate for Private Members' business in the House of Assembly. While there are 3.5 hours allocated each sitting week for Committees and Private Members' business, spread over Wednesday and Thursday, there is significant competition for use of this time. Thursdays are taken by Committees and debate over reports and the establishment of a Committee. The 2.5 hours on Wednesday is mostly used for Motions. These debates have no time limit and can go beyond an

hour. There are multiple Motions listed each sitting Wednesday until December 2020.

Any MP can introduce a Private Member's Bill and can speak for 15 minutes explaining the background and purpose of the Bill.

A VAD Bill will need to be debated and supported in both the House Of Assembly and Legislative Council. The Legislative Council allocates all of Wednesday to Private Members' business.

It is anticipated that a VAD Bill will be introduced into the current South Australian Parliament this year and that the debate could be expected in the second half of 2020.

A number of the submissions to the Committee can be accessed at <https://www.parliament.sa.gov.au/en/Committees/Committees-Detail>

Understanding parliamentary processes

Many of us have sat in Parliament House watching part, or all, of the debates on one or more of the many VAD Bills that have been presented, over the last two and a half decades, without fully understanding the process. The parliamentary website provides explanatory material to help better understand these details: <https://www.parliament.sa.gov.au/en/Legislation/Bills-and-Motions>

It states that when changes to the law are proposed, a process is followed as set down in the Standing Orders or 'house rules' of the two Houses of Parliament. Bills may be introduced in either the House of Assembly or the Legislative Council, but must be passed in each before becoming law. A Bill is initiated when a Member gives a Notice of Motion seeking leave (permission) to introduce the Bill, usually on the next sitting day.

After the First Reading the member introducing the

Bill will move that it be read a second time and gives a speech outlining the purpose of, and reasons for, the Bill. This is usually followed by an Explanation of Clauses which details the effect of each clause.

Ordinarily, once the Minister has moved the Second Reading, the debate is adjourned to a future date to allow members an opportunity to consider the Bill. However, the Second Reading of a Bill can occur immediately after the First Reading if the House agrees that the matters addressed in the Bill are urgent and need to be dealt with accordingly. This requires the suspension of the Standing Orders. During the Second Reading Debate, members from both sides of the House express their opinions on the principles of the Bill.

They consider it in the context of party policies, or in some cases their conscience, and formulate their approach accordingly. There are varying time limits for speeches imposed on Members. The Second Reading Debate may extend over several days or weeks or months if a Bill is complex or if many members wish to participate in the debate.

At the conclusion of the Second Reading speeches, there is a vote of members to see if there is sufficient support to go into 'the Committee Stage'. If the Bill does not get sufficient votes at the Second Reading, it fails and there is no further debate. A member may be prepared to support the Bill at the Second Reading, to allow further detailed discussion of each clause, but later vote against the Bill at the final 'Third Reading'.

The Committee Stage deals with Bills clause by clause, and members can propose amendments to the Bill. Each clause and each amendment moved is voted on individually. This is a less formal procedure and members may speak more than once in Committee. At the end of the Committee stage, the Chair reports to the Speaker, stating if the Bill has or has not been amended. Once the result of the Committee Stage has been reported to the House the Third Reading may take place immediately, or on another sitting day.

If the House agrees to the Third Reading, the Bill has passed all stages. It is then sent with a message to the other House for the process to be repeated there. If amendments to the Bill are proposed, it is returned to the originating House and the Council's amendments are considered in Committee. After it has completed its passage through both houses the Bill is presented to the Governor who gives formal assent.

SA Police speak out in support of VAD laws

Assistant Commissioner Scott Duval has stated that South Australia Police (SAPOL) has given support to VAD law reform under strict guidelines. The impetus for this support is the number of terminally ill people who suicide in SA. This supportive stance was tabled in a submission to SA Parliament's Joint Committee on *End of Life Choices*, stating that these deaths accounted for about 11 per cent of the 90 investigated suicides from January – June 2019.

SAPOL's view mirrors that of the head of the WA police union, George Tilbury, who backed legislative change when WA was debating its own VAD law reform. Mr Tilbury argued:

...there would be fewer horrific suicides and first responders would be spared having to see as many graphic scenes, most of which stay with them for ever... Attending suicides takes a toll on police officers and is often very traumatic.

References:

- Girolamo, R 'SAPOL supports euthanasia law reform under strict guidelines', The Advertiser Feb 20th 2020
- Caporn, D 'WA Police Union boss George Tilbury backs calls for euthanasia laws' The West Australian, 6th March 2018 <https://thewest.com.au/news/perth/wa-police-union-boss-george-tilbury-backs-calls-for-euthanasia-laws-ng-b88763359z>

Successful law reform in WA

Western Australia under the McGowan Labor Government became the second jurisdiction in Australia and the 19th globally to deliver the legal choice for VAD. (The Northern Territory introduced a law in 1995, but this was overturned by the Howard Government in 1996). The year-long WA *Inquiry into End of Life Choices* recommended the introduction of VAD, with the August 2018 report stating:

Unnecessary suffering at end of life, and broad community agreement regarding individual autonomy, form the basis for the Committee's recommendation that the Western Australian Government draft and introduce a Bill for Voluntary Assisted Dying.

The inquiry was followed by an Expert Panel to advise on the details of the legislation. The Panel included SA palliative care physician Dr Roger Hunt, who was also a member of the Victorian

SAVES APRIL 2020 PUBLIC Meeting

The SA Voluntary Euthanasia Society Inc. (SAVES) holds public meetings twice yearly at

The Box Factory 59 Regent St South, Adelaide

The next public meeting will be held on Sunday **April 19th 2020 at 2.15 pm**

Guest speaker will be **Dr Sandra (Sandy) Bradley** speaking on the topic:

Everything you wanted to know about SA Advance Care Directive Review but were afraid to ask

Tea and coffee and light refreshments will be available after the meeting.

Bring your friends; all are welcome.

Please make a diary note!

SAVES 2020 AGM will be held on November 15th 2020

Government's Expert Panel. The Voluntary Assisted Dying Bill was introduced in August 2019 and passed the House of Assembly on 10th December 2019. This followed agreement on the 55 amendments made in the Legislative Council. More than 180 hours were spent debating the legislation, mostly in the Upper House.

There will be an 18 month implementation phase before VAD becomes a legal option in WA, with an anticipated starting date of June 2021. The WA Bill is similar to the Victorian

VAD Act (2017), but with three significant differences:

- two doctors must independently verify the eligibility of the person, but there is no requirement for one doctor to be a specialist in the person's disease or illness (a requirement in the Victorian VAD Act);
- the person can choose practitioner-administration or self-administration, and the practitioner can be a doctor or a nurse practitioner (in Victoria doctor administration is only allowed if the person cannot self-administer);
- doctors and other healthcare workers are permitted to raise the option of VAD with their patients; something prohibited by the Victorian VAD Act.

Health Minister, Roger Cook, who was applauded by MPs for his management of the Bill, said it was a significant moment for the 'typically conservative' state. He held back tears as he welcomed the passage

of the legislation. This will allow adults with decision-making capacity and living with a disease likely to cause death within six months (or 12 months for neurodegenerative diseases) to end their lives with medication. Premier Mark McGowan said it was a historic and important day.

SAVES congratulates everyone involved in the passage of this important legislation.

References

- Government of WA Joint Select Committee on End of Life Choices: My Life My Choice Report August 2018
- Hondros, N 'History made as voluntary assisted dying becomes law in Western Australia', Western Australia Today, Dec 10th 2019
- SBS World News 10th December 2019 'Momentous': Tears and hugs as Western Australia legalises voluntary assisted dying
- Western Australia legalises voluntary assisted dying after 'momentous processes' The Guardian and AAP 11th December 2019
- Dying with Dignity Queensland website <https://dwdq.org.au/interstate-news/>

Queensland update

Queensland has completed its *Inquiry into Aged Care, End-of-Life and Palliative Care and Voluntary Assisted Dying*. Premier Palaszczuk is being urged to introduce a VAD Bill before this year's October election. Unfortunately the report from the inquiry has been delayed from November 2019 to 31st March 2020, and it is unlikely that VAD laws will

be debated in time. Following success in WA, well known campaigner Andrew Denton is now focussing his attention on Queensland; and long term advocate and cancer sufferer, Tanya Battel, has launched a Change.org petition begging Premier Palaszczuk to act quickly. Queensland Advocacy organisations including Dying With Dignity Queensland, Voluntary Assisted Life Ending (VALE Qld), ‘My Illness, Body My Choice’, Nurses Supporting VAD, Doctors for Assisted Dying Choice, and the Clem Jones Trust are all hoping that, once completed, the Parliamentary Inquiry will recommend adoption of VAD laws. David Muir, Chair of the Clem Jones Trust said: *The matter is especially urgent when you consider that each week in our state a terminally ill person is likely to take their own life in horrific and lonely circumstances because they see no other way to relieve their suffering.*

As was reported by Coroners in Victoria and Western Australia, information from the Queensland Coroner showed that there are approximately 84 self-inflicted deaths each year in Queensland by people with terminal or hopeless physical conditions. Andrew Denton and many other commentators are concerned that if the Queensland government changes hands at the next election there is little chance that an elected conservative government would introduce VAD legislation. He stated:

I encourage the Premier to look at the evidence and have the political will to act on it. Not one more Queenslanders will die as a result of voluntary assisted dying legislation but far fewer will suffer needlessly at the end of life. The lesson of the Andrews government of Victoria, where they ran strongly on this, is that they were rewarded by the electorate for taking the lead on VAD laws.

References:

- Tanya Battel’s ChangeOrg campaign: <https://www.change.org/p/queensland-premier-annastacia-palaszczuk-i-have-terminal-breast-cancer-and-i-need-voluntary-assisted-dying>

Please note SAVES new bank account details for membership renewals and donations which is also recorded in the membership form on page 11:

People’s Choice Credit Union

Acct number 102 500 039

BSB 805 050

SA Voluntary Euthanasia Society Inc

[laws-in-queensland-now-today-the-voluntary-assisted-dying-bill-in-wa-was-passed-queensland-should-be-next?recruiter=68758140](https://www.change.org/p/queensland-premier-annastacia-palaszczuk-i-have-terminal-breast-cancer-and-i-need-voluntary-assisted-dying)

- Dying with Dignity NSW Summer 2019 newsletter <https://dwdnsw.org.au/wp-content/uploads/2019/12/Dying-with-Dignity-NSW-Summer-2019-Newsletter.pdf>

Victorian VAD law review

The Victorian *Voluntary Assisted Dying Act* came into effect on 19th June 2019. A review of operations reports that 52 people availed themselves of the Act in its first six months. The review details activity between 19 June to 31 December 2019. During that time 136 people commenced the assessment process, 81 people were issued with permits, and 52 people died from taking prescribed medications. Nine of the 52 deaths were assisted by a doctor administering the medication, while the remaining 43 took the substance themselves. All cases examined by the Board complied with the law. More than 370 doctors have now either finished or are undertaking the four hours of training required to participate. Of these, a third are in rural Victoria.

Her Honour, Betty King, Chair of the Voluntary Assisted Dying Review Board and former Supreme Court justice, told reporters in Melbourne. ‘I have not seen – and I have been looking, believe me – I have seen no indication of any type of coercion’.

However, while this report is very positive and has described the legislation as ‘working well’, it does not provide any information about patients requesting access to VAD prior to the formal first assessment. Therefore there is no information about patients who may have wanted to access the law but were unable to, or the reason why. This may relate to being unable to find a willing and qualified doctor, or problems for patients in rural and regional Victoria having difficulties due to the Federal law which prevents doctors from discussing the issue with patients over the phone or online.

These matters are in addition to the ‘gag clause’ which is a feature of the Victorian legislation. This prohibits all health practitioners from initiating a discussion about VAD with their patients. The report also doesn’t explain how long it takes patients to progress from a first assessment through to the permit application stage, although the review board noted the process can take several weeks. There was also

no reporting of any demographic data to give more nuanced understanding. Such information is integral to determining whether or not the legislation is truly ‘working well’.

References:

- Voluntary Assisted Dying Review Board Report of Operations June-Dec 2019 https://www.bettersafecare.vic.gov.au/sites/default/files/2020-02/VADRB_Report%20of%20operations%202019-2020.pdf
- Minister for Health (Victoria) 19 Feb 2020 Terminally Ill Accessing Voluntary Assisted Dying: <https://www.premier.vic.gov.au/terminally-ill-accessing-voluntary-assisted-dying/>
- Hempton, C ‘Much is missing from Victoria’s report into its assisted dying scheme’ Australian Doctor 21 Feb 2020 <https://www.ausdoc.com.au/opinion/much-missing-victorias-report-its-assisted-dying-scheme>

The conscience vote in a representative democracy

As different states including SA continue to deal with the issue of VAD law reform it is timely to reflect upon the role of the conscience vote in a representative democracy, as this will underpin the parliamentary process here in SA. A conscience vote is generally allowed on so-called ‘moral’ issues such as abortion, VAD and stem cell research. It allows MPs to vote, or to refrain from voting, according to what seems personally right or wrong; regardless of party affiliation or policy.

Emerita Professor of Politics, Dr Carol Bacchi, explains that political parties have several reasons for allowing conscience votes; most commonly to accommodate a member’s own beliefs on issues which make it difficult for her or him to support party policy. Politically it can also embarrass or destabilise opponents when it is understood that certain members or groups hold very strong views on a particular issue.

A conscience vote is obviously not a measure of universal truth, since individual consciences can be diametrically opposed on moral issues. Dr Bacchi argues that it is, at the very least, debatable whether or not conscience votes produce democratic outcomes due to the role and nature of political representation. It is important to understand the difference between elected members ‘acting on behalf of’ and ‘standing in for’ their constituents.

The first model (‘acting on behalf of’) is one of a trustee who is authorised to use his or her own

judgement when acting on behalf of electors. In the second model the person is a delegate who is ‘standing in for’ and strictly accountable to those who elect him or her. Conscience voting is ambiguous. On the one hand, it is presumed that the MP will vote based on personal conscience (‘acting on behalf of’) but, on the other hand, there is the view that accompanying political debate will make the decision more representative (‘standing in for’). Dr Bacchi argues that conscience voting appears to favour the ‘trustee’ model; exemplified by the classical liberal view of Anglo-Irish statesman and philosopher Edmund Burke (1729-1797) who famously argued ‘Your representative owes you, not his [sic] industry only, but his judgment; and he betrays you, if he sacrifices it to your opinion’.

In 1997 SAVES issued a statement in protest of the widespread abuse of the conscience vote by parliamentarians charged with determining the future of the 1995 Northern Territory Rights of the Terminally Ill Act [available on SAVES’ website]. In this statement SAVES posed the question ‘Are MPs

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Bequests

Different wording is used for a bequest of a specific sum or the whole of an estate. The wording for a gift of a specific sum is: ‘I bequeath to the South Australian Voluntary Euthanasia Society Inc. the sum of \$.....’ If you wish to leave your entire estate to SAVES the wording would read: ‘I give and bequeath the whole of my real and personal estate to the South Australian Voluntary Euthanasia Society Inc’.

SAVES is staffed entirely by volunteers. Since its formation in 1983, SAVES has worked towards law reform that enables a compassionate and humane response to unbearable and hopeless suffering.

who exercise a conscience vote answerable only to themselves?’ Suppose that what they deem ‘wrong’ is deemed ‘right’ by a majority of the electorate. As elected representatives in a liberal democracy, do their consciences no longer have to respect the views - indeed, the consciences - of their constituents? After all, we know for example that the overwhelming majority of Australians support VAD law reform.

In its statement SAVES also argued that the government’s task of balancing potential social benefit against potential social harm requires an assessment of probabilities, not a judgement of ‘conscience’. The questions facing elected lawmakers are not, ‘Is the proposal repugnant to you?’ but, ‘What do the people want and will society benefit?’ SAVES also posed the question of whether it is ethical in a secular liberal democracy for an elected member to knowingly vote against the wishes of the electorate, merely on personal, or often religious grounds.

The dilemma has been resolved for some elected representatives by the fortunate discovery that they have an ‘informed conscience’. This is presumably a combination of moral and intellectual wisdom possessed by MPs but lacking in most voters. Such a view depicts a world where MPs have been elected for their superior judgement, by people with inferior opinions who are best served by their ‘betters’.

A view is also expressed that political office is a ‘trust from Providence’. This view was invoked by the Rev Fred Nile in 1994, when he stated in parliament that his hope was that, ‘under the guidance of Divine Providence our labours may be so directed as to advance the best interests of all sections of the community’. SAVES argues that invoking Divine Providence is an appalling denigration of the universal adult franchise. The democratic system is essentially secular. The notion that voters choose as their representatives people who are to be guided in what they do by what they think a deity requires of them, rather than by those who elected them, substitutes a version of theocracy for democracy.

While the exercise of a conscience vote may enable individual representatives to dissociate themselves from something with which they personally disagree, it is still necessary to reconcile this with a representative democracy. Those whose personal or religious conscience puts them at odds with their constituents should abstain from voting. To

do otherwise is knowingly to thwart the will of the electorate; 85 per cent of whom support VAD.

References:

- Bacchi, C; ‘The ethics of problem representation: widening the scope of ethical debate’, Policy and Society, 26:3 [https://www.tandfonline.com/doi/abs/10.1016/S1449-4035\(07\)70112-1](https://www.tandfonline.com/doi/abs/10.1016/S1449-4035(07)70112-1)
- SAVES Opinion (1997) The Conscience Vote in a Representative Democracy https://988c9073-ec7c-40b2-8b6c-41fea61805a8.filesusr.com/ugd/1062e1_8ee9e3bd5b9342bea28bdad11e0e47e6.pdf
- Nile, F Legislative Hansard 16th March 1994

Palliative Care Australia adopts a neutral position on VAD

On the 5th September 2019, Palliative Care Australia (PCA) formally changed its position on VAD from ‘opposed’ to ‘neutral’. After wide consultation and careful consideration the organisation determined that introducing VAD laws will not be detrimental to palliative care provision. It also acknowledged that the wide range of views within the palliative care profession did not support their previous position of opposition to VAD.

PCA Board Chair, Dr Jane Fischer, stated that the organisation updated its position statement on Palliative Care and Voluntary Assisted Dying for the first time since 2016. This was within the context of legislative changes in Victoria and the current parliamentary action in other states. Dr Fischer stated ‘A decision about whether or not to legalise voluntary assisted dying is one for parliaments. PCA neither advocates for, nor argues against, the legalisation of voluntary assisted dying.’

PCA has new Guiding Principles related to VAD including that ‘people living with a life-limiting illness are supported and respected whether or not they choose to explore or access voluntary assisted dying’, and that ‘people exploring voluntary assisted dying will not be abandoned.’ SAVES welcomes this revised Position Statement by PCA.

Healthcare Professionals for Assisted Dying Choice

Healthcare Professionals for Assisted Dying Choice (HPAD) is a recently convened national list of practising, retired and student healthcare

professionals. It includes doctors, nurses, psychologists and other allied health workers. These healthcare professionals support mentally competent adults having the right to choose an assisted death, subject to strict safeguards, if they are experiencing intolerable suffering from a terminal or incurable medical condition for which there is no realistic chance of a cure or relief.

VAD laws would allow such people the right to end their lives at the time and place of their choosing and in the presence of their loved ones. Guiding Principles are highlighted on the website which also provides wide-ranging information including a list of supporters, and a portal for like-minded health care professionals to join: http://www.hpadchoice.org.au/join_hpad. Please support this initiative by spreading the word!

HPAD website <http://www.hpadchoice.org.au/>

The need for open discussion on VAD

As noted above, unlike the situation in Victoria, the Western Australia law allows doctors and senior nurses to raise the issue of VAD with their patients. This allows people to make fully informed decisions on the type of care they would choose to receive. SAVES supports such open and honest communication and patient-centered approach.

Recent research published in the *British Medical Journal* has explored the potential implications that arise from prohibiting such open communication between doctors and patients, as well as on a doctor's ability to provide optimum end of life care in some circumstances.

While full details of the research cannot be reported here due to copyright, the authors noted that 'open and honest communication between doctor and patient represents good clinical practice and will lead to optimal care'. Providing such information 'also reflects professional, ethical and legal norms'. They concluded that prohibiting health professionals from initiating conversations about VAD 'may, in cases where patients seek information about all end of life options, lead to less optimal patient outcomes.'

Reference

Willmott, L; White, B; Ko, D; Downar, J; Deliens, L (2019) 'Restricting conversations about voluntary assisted dying:

implications for clinical practice, *British Medical Journal* <http://dx.doi.org/10.1136/bmjspcare-2019-001887>

Terminal illness and the 'six-month' rule

The 'sixth month' rule concerns legal precedence in the UK whereby classification of terminal illness is based on a patient's prognosis of having six or fewer months left to live. A palliative care physician and a retired health researcher have recently published an article in the *British Medical Journal* arguing that the 'six-month rule' is 'arbitrary, discriminatory, and difficult to implement'.

Other opposition is growing to such a definition, as reported in the All-Party Parliamentary Group for Terminal Illness. This described the definition as 'outdated, arbitrary and not based on clinical reality'. This group recommended that the definition of terminal illness be uncoupled from any timeframe because clinicians' predictions of life expectancy are frequently inaccurate.

The report's authors cited a systematic review identifying 42 papers, spanning almost 30 years of research, and data on over 12,000 prognostic estimates where accuracy varied from between 23% and 78%. They argue that the very people most likely to feel the need for assistance to die are those who face a longer period of suffering, and questioned why such discrimination should be tolerated.

As well as the arbitrary prognostic timeframe of having six months or less left to live, terminal illness is also defined by four basic characteristics. These are that there is no chance of recovery; a certain progression to death; a rapid progression to death; and a short timeframe to death.

SAVES has consistently argued for the criteria of hopeless rather than terminal illness as the basis

SAVES membership renewals are due in February each year

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Thank you!

for VAD law reform. Hopeless illness shares only one clear characteristic with terminal illness. This is that there is no chance of recovery. However, the associated severity of hopeless illness leads to intolerable and futile suffering which should not be condoned under a legislative framework.

References:

- Sleeman, K & Chalmers, I 'Assisted dying: restricting access to people with fewer than six months to live is discriminatory' BMJ Opinion 25/9/2019: <https://blogs.bmj.com/bmj/2019/09/25/katherine-sleeman-and-ian-chalmers-assisted-dying%E2%81%A0-restricting-access-to-people-with-fewer-than-six-months-to-live-is-discriminatory/>
- SAVES newsletter 25 "End of Life Choice: Hopeless Suffering and Terminal Illness" <https://988c9073-ec7c-40b2-8b6c-41fea61805a8.filesusr.com/ugd/1062e1fd4544a728c442a8b837f63954cb03a3.pdf>
- White, N; Reid, F; Harries, P; Stone, P 'A Systematic Review of Predictions of Survival in Palliative Care: How Accurate Are Clinicians and Who Are the Experts?' PLOS ONE Aug 25th 2016 <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0161407>

Oncologist's role in Victorian law

Oncologist Dr Cameron McLaren is one of the few specialist practitioners supporting people under the Victorian VAD Act. To date he has been involved in 37 cases, and has been with patients who have elected to end their lives on 13 occasions. He said:

The atmosphere has been very peaceful. It's been a real moment of closure for the families to say goodbye,... I'm still surprised by how I've never seen a person flinch about picking up or taking the drink. They are so committed to it.

Dr McLaren undertook the training to become a co-ordinating medical practitioner under the VAD scheme. In what he sees as a logical progression from his oncology practice, he stated.

I didn't want a patient to come to me for a cancer journey but then at the end I wasn't prepared to, or able to, take them all the way to the finish line.

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He notes that some conscientious objection facilities including religious hospitals won't accept a pharmacist's visit, but day leave can be organised for patients to receive the medication. However, due to the federal law prohibiting discussion between doctors and patients by telephone or online Dr McLaren argues that this leads to an inequitable situation; especially for people in the regions where there are not enough specialists to assist.

Reference

- Lunn, S, 'They never flinch' when they take the deadly dose, says death doctor' The Australian 21st February 2020

Vale Phillip Beddall

SAVES sadly advises members that well-known disability advocate Phillip Beddall died on 30th August 2019, aged 51 years. Phillip was the convenor of the VAD support group MY BODY MY Choice-VE (MBMC). This is forum for representing the interests of people with disabilities who wish to exercise choice in all aspects of their life, including choice at the end of life. It is consistent with the view that choice and control are fundamental human rights for everyone.

As convenor of MBMC, Phillip argued:
People with disabilities know how it feels to lose personal autonomy through their ongoing fight for self-determination, independent living and disability rights... People with disabilities, who have struggled to control their own lives and bodies, must be allowed to maintain control and autonomy throughout their life, especially at its end.

Members of SAVES executive attended Phillip's funeral where many people from the disability, welfare and housing sectors, and political representatives spoke about his lifelong advocacy and activism for improved services and access for people with disability. They highlighted that his was a 'life well lived'. They noted his 'wicked' sense of humour, and his quiet, patient and fierce leadership. Phillip also had a radio program on 5RPH in which his direct speaking style resulted in a range of commitments being made by Ministers and other leaders. He was also on many boards and committees fighting for the rights of people living with disabilities. Phillip attended SAVES' rallies on the steps of Parliament House, and met with MPs as part of his advocacy for VAD and VE law reform.

Vale Phillip – you will be sadly missed.

End of Life Choice



Limits to palliative care: the call for voluntary assisted dying

Palliative care is an important and widely respected support for people with active, progressive, advanced diseases, who have little or no prospect of cure, and are therefore expected to die. The primary aim is to optimise quality of life:

As acknowledged by Palliative Care Australia and the Australian Medical Association, even with the best palliative care, both dying and incurably ill people face a range of difficult to manage symptoms. For example:

- cancer affecting nerve-rich areas such as the abdomen, chest, spine, pelvis, or throat leads to pain and possible incontinence of urine and faeces. Cancer growth also obstructs swallowing and the intestine, leading to vomiting and ultimately starvation.
- paralysing diseases of nerves supplying the muscles of the chest and throat cause gasping or choking to death (such as with motor neurone disease).
- mesothelioma (associated with incurable asbestosis) produces severe chest pain with each breath, causing difficulty in breathing and feelings of suffocation.
- difficult to treat neuralgia causes experiences similar to electric shock, with stabbing, agonising and jolting pain.

The above examples are indicative but not exhaustive.

SAVES strongly supports palliative care, with the option for voluntary assisted dying when suffering becomes unmanageable and the person asks for release.

References: * Palliative Care Australia <https://palliativecare.org.au/what-is-palliative-care>

* SAVES submission to the Joint Committee on End of Life Choices [file:///C:/Users/anaf0002/AppData/Local/Downloads/95%20South%20Australian%20Volunteer%20Euthanasia%20Society%20\(1\).pdf](file:///C:/Users/anaf0002/AppData/Local/Downloads/95%20South%20Australian%20Volunteer%20Euthanasia%20Society%20(1).pdf)

* Palliative Care Australia Experience internationally of the legalisation of assisted dying on the palliative care sector FINAL REPORT 28 October 2018 https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/12/Experience-internationally-of-the-legalisation-of-assisted-dying-on-the-palliative-care-sector-APEX-FINAL.pdf

SAVES

South Australian Voluntary Euthanasia Society

saves.asn.au



*Compassion for suffering
The freedom to choose
Add your voice to the call*



SAVES was established in 1983 to campaign for legal, medically assisted voluntary euthanasia. The aim is to end suffering by providing choice in dying. SAVES works in the community and with Members of Parliament to achieve law reform.

SAVE-YA Syndicated Australian Voluntary Euthanasia Youth Advocates

Facebook: Support SAVE-YA Law Reform

A national youth lobby group which aims to provide a youth voice in support of legalising voluntary euthanasia in all States and Territories. Members between ages 18 and 35 are encouraged to join, make contact with their local MP and inform them of their support for voluntary euthanasia law reform.



Christians Supporting Choice For Voluntary Assisted Dying christiansforvad.org.au

We are Christians who believe that, as a demonstration of love and compassion, those with a terminal or hopeless illness should have the option of a pain-free, peaceful and dignified death with legal voluntary assisted dying / voluntary euthanasia. This is strongly supported by the majority of Australian Christians.



South Australian Nurses Supporting Choices in Dying

facebook: SA Nurses Supporting Choices in Dying

We are a group of passionate nurses who believe in our patient's right to choose the end of life care they wish. The group provides a forum for the nursing voice and perspective on legalising voluntary euthanasia and other patient choices in end of life care.



MY BODY MY Choice-VE

facebook.com/pages/MY-BODY-MY-Choice-VE

MBMC provides a voice for people with disability in the VE reform debate. MBMC represents the interests of people with disabilities who wish to exercise choice in all aspects of their life, including choice at the end of life, with the view that choice and control are a fundamental human right for everyone.

MBMC argues that people with disabilities know how it feels to lose personal autonomy through their ongoing fight for self-determination, independent living and disability rights.

MBMC believes that people with disabilities, who have struggled to control their own lives and bodies, must be allowed to maintain control and autonomy throughout their life, especially at its end.



Doctors for Assisted Dying Choice

drs4assisteddyingchoice.org



We are a national organisation of Australian medical practitioners, both current and retired, who are committed to having a legal choice of providing information and assistance to rational adults, who, for reasons of no realistic chance of cure or relief from intolerable symptoms, would like to gently end their lives.

Assistance may be by doctor provision of medication for the patient to consume, or by doctor-administration.

Respecting rational patient end-of-life choices

Lawyers for Death with Dignity

https://docs.wixstatic.com/ugd/1062e1_dd077d6dd79648cbaec58200361f054a.pdf

Lawyers for Death with Dignity acknowledges the need for people with profound suffering to have the legal choice for a medically assisted and dignified death.



The current law says suicide is not illegal, but assisting suicide is. People in a terminal state may have profound, unbearable suffering and be in the undignified position of being unable to end their life without assistance.

Advances in medicine have improved life expectancy, but South Australian law has not changed to reflect the often forgotten deterioration in quality of life that a longer life expectancy may bring.

Paramedics Supporting Choices in Dying

facebook: Paramedics Supporting Choices in Dying



Paramedics Supporting Choices in Dying is an advocacy group promoting the rights of people to make decisions regarding their end of life wishes.

To go without pain, without trauma, without breaking the law, without endangering others and without suffering. To go gently, peacefully and with dignity.

We support good palliative care, encourage the use of Advance Care Directives and advocate for law reform to legalise the choice for voluntary euthanasia and voluntary assisted dying.

SA Voluntary Euthanasia Society Inc. Membership Form

Print and post or join online at <https://www.saves.asn.au>

- New Membership Renewal

Surname, including Mr/Mrs/Ms etc

Given Name(s)

Address

Suburb/Town & Post Code

Telephone

Email address

Year of Birth (Optional)

Membership Payment:

Annual membership is due at the end of February. Payment for two or more years is welcome, and is calculated by multiples of the annual fee – please mark accordingly

- \$30.00 Single Membership (\$15.00 concession) -----
 \$40.00 Couple Membership (\$20.00 concession) -----
 \$350.00 Life Membership Single
 \$500.00 Life Membership Couple
 Additional Donation to support the work of SAVES-----
TOTAL -----

Payment Options:

Cheques and money orders made payable to SAVES and send with this form to:

- SAVES Membership Officer, PO Box 2151, Kent Town SA 5071**

Or pay by Electronic Funds Transfer:

- People's Choice Credit Union BSB 805 050 Acct number 102500039**
SA Voluntary Euthanasia Society

PLEASE LODGE THIS FORM, along with EFT payment advice either via email to info@saves.asn.au or via Australia Post

How did you hear about us? _____

Do you have an area of expertise that could be of help to SAVES? _____

Do you wish to receive the Bulletin by post or email?-----

SAVES' members support the society's primary objective which is a change in the law, so that in appropriate circumstances and with defined safeguards, death may be brought about as an option of last resort in medical practice. These circumstances include the free and informed request of the patient and the free exercise of professional medical judgement and conscience of the doctor. SAVES IS NOT ABLE TO HELP PEOPLE END THEIR LIVES.

SAVES' Primary Objective:

A change to the law in South Australia so that in appropriate circumstances, and with defined safeguards, death may be brought about as an option of last resort in medical practice. These circumstances include the free and informed request of the patient and the free exercise of professional medical judgment and conscience of the doctor.



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SAVES Bulletin is published three times a year by the SA Voluntary Euthanasia Society Inc. (SAVES). Letters, articles and other material for possible publication are welcome and should be sent to *SAVES Bulletin Editor, SAVES, PO Box 2151, Kent Town SA 5071.*

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Editor: Julia Anaf