

INQUIRY INTO PROVISIONS OF THE VOLUNTARY ASSISTED DYING BILL 2021

Organisation: Christians Supporting Choice for Voluntary Assisted Dying
Date Received: 3 November 2021

Submission to NSW Legislative Council VAD Inquiry

On behalf of the Group, **Christians Supporting Choice for Voluntary Assisted Dying**.

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Dated 1.11.2021

This submission assesses current practice in palliative care and end of life and gives argument in favour of an additional law in New South Wales to give the legal CHOICE of voluntary assisted dying for the terminally ill with intolerable suffering.

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Our Belief: *"We 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."*

"Euthanasia is not a choice between life and death, but a choice between different ways of dying". Jacques Pohier, a former Catholic Dominican Priest.

"After studying the changes in social values, medicine and the law, and in light of our comprehensive review of the issues and the arguments raised by hundreds of witnesses and thousands of comments, we have come to the conclusion that an additional option is needed in the continuum of end-of-life care: euthanasia, in the form of medical aid in dying. "

Quote from the Quebec National Assembly all-party select committee Report, 2012.

This led to the passing of the Quebec "Act respecting end-of life care" Bill 52, by 94 votes to 22 on June 5, 2014, with a standing ovation from the MPs present.

The Supreme Court of Canada, February 2015, in a unanimous decision by 9 judges stated "The prohibition on physician-assisted dying infringes the right to life, liberty and security of the person in a manner that is not in accordance with the principles of fundamental justice," and gave the Canadian Parliament 12 months to introduce legislation to comply with the Supreme Court guidelines. **NSW residents deserve the same fundamental justice!**

Summary of the case to legalise voluntary assisted dying

- **Even optimal palliative care cannot relieve all suffering** – five to ten percent of the terminally ill express a rational, genuine desire for an assisted death, to quote Dr Roger Hunt, Senior Palliative Care Specialist, South Australia. (Ref 1a)
- **The excuse of ‘sufficient safeguards are not possible’ is not supported by facts and data from Oregon State (1997), and the other US states with legal voluntary assisted dying, and now also data from Canada and Victoria.**
- **The Advance Care Directive, incorporating the option of legal voluntary assisted dying, would provide an ultimate protection against possible abuse.**
- **Voluntary euthanasia laws are working responsibly without a ‘slippery slope’ to abuse in Oregon State, and the other countries and states with legal assisted dying.**
- **The current law prohibiting voluntary assisted dying/voluntary euthanasia is not working** – there is no monitoring over the use of “the double effect”, and the extension of this, terminal sedation. The fact that palliative sedation (terminal sedation), when a slow death is inevitable, is accepted as part of palliative care, makes opposition to assisted dying illogical.
- **The current law is driving desperate people to desperate self deliverance.**
The fact that a person may legally end their own life, but for any other person to assist under any circumstances is a crime, is illogical.
- **Palliative care is not threatened by voluntary euthanasia legislation** - in practice palliative care services improve when assisted dying is also available.
- **Many who request and are accepted for an assisted death actually live longer and have a better end quality-of-life than those who do not request assistance.** It provides peace of mind. In Oregon a third do not actually go on to use their fatal medication.
- **The Victorian Inquiry into End of Life Choices** recommended the legalisation of Voluntary Assisted Dying and the Ministerial Panel gave the means to implement it, resulting in their Voluntary Assisted Dying Bill being passed in November 2017.
- **Quebec, Canada, passed assisted dying legislation in June 2014.** The vote was 94 to 22, with all party support and a standing ovation from the MPs. This followed a Government Report in favour after a two year Inquiry. **New Zealand recently ratified their VAD law.**
- **The Supreme Court of Canada, February 2015, in a unanimous decision by 9 judges stated** "The prohibition on physician-assisted dying infringes the right to life, liberty and security of the person in a manner that is not in accordance with the principles of fundamental justice," and the **Canadian Parliament has since passed their Medical Assistance in Dying Bill C-14 with the support and input of the Canadian Medical Association.**
- **70 - 85% of Australians including a high majority of Christians want and are entitled to the option of an assisted death if terminally ill.** – It is a basic human right.
Five states in Australia have now passed legislation and it is inhumane and undemocratic to deny this choice to the residents of New South Wales
- **The small minority of conservative Christians** who oppose assisted dying, for whatever reason, are entitled to endure whatever suffering comes their way, but must never impose these views on others.
- **VAD is supported by two former AMA Presidents, Prof, Brian Owler and Dr Kerry Phelps.** The RACGP (Royal Australia College of General Practitioners), with much larger membership than the AMA, welcomed the Victorian Assisted Dying Act..

SOME DEFINITIONS as used in this document

Voluntary Assisted Dying, (VAD), is the term used when the patient takes or administers to themselves the fatal dose of a medication prescribed after their rational and continued request. It can also be referred to as Medical Assistance in Dying (MAID)

Administration can also be by a medical practitioner, when permitted by law in regulated conditions, at that patient's request, for what he or she sees as being in his or her best interests.

Self administration does constitute an important safeguard. However administration by a doctor, as mainly used in Canada, is safer, with fewer complications, has no bitter taste, and is much quicker.

The ideal compromise is that the doctor sets up an IV line that the patient activates either by turning a tap, or even activates the IV flow by eye movement, when they decide to proceed. As used by Dr Erika Preisig, Life Circle, Switzerland since 2012.

Terminal Sedation, in palliative care. The treating doctor decides the only means of relieving uncontrollable suffering is to put the patient into a coma until they die. (See also page 10)

Terminal illness, in relation to a patient, means an illness which will, in reasonable medical judgment, result in the death of the patient within 12 months.

Incurable/hopeless illness, means an illness for which there is no cure, the prognosis is death, but the time frame for the progression of adverse symptoms and that death is not predictable.

Advance Care Directive, a document containing your personal values and preferences, to be used as a guide to your future health care in the event that you become unable to speak for yourself. Usually used in conjunction with eg an **Enduring Guardian**, to act on your behalf.

In the context we are seeking to legalise choice, it is the right of an individual to choose a painfree, peaceful and dignified death, when the individual has no prospect of quality of a life with either dignity or purpose ahead of them. It applies either in a **terminal illness** eg the latter stages of cancer, particularly in the approx 5% of cases where palliative care is not effective, or an **incurable illness with suffering that cannot be controlled to the satisfaction of the patient**.

Examples include Motor Neurone Disease, where the patient's only prognosis is slow, lingering death, usually due to choking as muscles lose their capacity to enable the person to breathe. While the action of voluntary assisted dying would still result in grief for the bereaved, this grief is greatly relieved by the knowledge that the person they loved dearly did not have to suffer unnecessarily.

Currently an option used where there is no VAD law for a person with a terminal or incurable illness who decides they have reached the stage of having no future except "life" as a vegetable, or endless pain, is suicide. In that case not only do they have the terminal illness, but they are forced to die by themselves in a totally unloved environment, by drinking weed killer, driving a car into a tree, shooting oneself, etc. Having the legal option of assisted dying enables an individual with the same terminal illness to die peacefully surrounded by love and compassion.

Voluntary Assisted Dying is NOT suicide. It is a rational choice between two ways of dying.

Assisting in a suicide would still remain illegal. Canada has been very careful to differentiate with their law.

Suicide is the deliberate and conscious attempt to kill oneself, most commonly a result of relationship difficulties and/or mental illness (not necessarily depression - it may be bi-polar disorder, schizophrenia etc) and/or substance abuse. There are other explanations given by persons attempting suicide, including a desire for relief from extreme pain, and anniversaries of past losses. Suicide may either be completed or attempted. The action would normally cause extreme anguish and grief to the bereaved family and friends.

With appropriate intervention it is possible that a completed suicide can be prevented and the person go on to live a happy and purposeful life.

A change in the laws of New South Wales is needed to allow citizens to include the additional option of choosing a voluntary assisted death as part of informed decisions regarding their own end of life.

- General Background - Christian support for assisted dying

The usual Newspoll question on voluntary euthanasia is, “If a hopelessly ill patient, experiencing unrelievable suffering, with absolutely no chance of recovering, asks for a lethal dose, should a doctor be allowed to give a lethal dose or not?”

In 1962 47% said “yes” to a similar question and the percentage has steadily increased since then. **This clearly indicates a major shift in public opinion over the 60 years.**

In four polls through the 1990s the positive response was 76 to 78%.

In 2002 a Morgan poll showed national support at 73%. **The responses among religious groups in South Australia were: Anglican 81%, Methodist 87%, Presbyterian 66%, Catholic 69%, Uniting Church 74%, Lutheran 74%, and Baptist 68%.**

In 2007 the same question was asked in a Newspoll survey, with 80% of Australians saying “yes”. Of respondents who stated they had a religious affiliation 74% answered “yes”. (Ref 1)

In 2012, Newspoll found an overwhelming majority said yes (82.5%), a very small minority (12.7%) said no, with 3.8% don’t know and 1.0% refused. Nearly nine out of ten Australian Anglicans, more than three out of four Catholics, and nearly all Australian atheists advocate assisted dying law reform. **That is, the proportion of Anglicans in support is higher than among the general population!** Religious hierarchy who comprise an organised opposition to law reform do not represent the views of the majority of their flocks. (Ref 2)

In the UK -

Most religious people ignore their leaders and support a relaxation of the law

An absolute majority of religious adherents – i.e. those who identify with a religious tradition – support assisted suicide: 64% of religious people support a change in the law on euthanasia, 21% think the law should be kept as it is, 14% don’t know (sums to 99 due to rounding).

Anglicans are in favour of change by a margin of 57% (total in favour 72%) - which is greater even than the general population at 54% (total in favour 70%). Only those who say they have “no religion” show greater support – by a huge margin of 72% (total in favour 81%). (Ref 3)

Although not widely known, there has been support for assisted dying/voluntary euthanasia from Christian theologians since at least the 1930s.

The Right Rev. Dr W. Inge, former Dean of St Paul’s Cathedral, London, when founding the British Voluntary Euthanasia Legalisation Society in 1935, said, “It is not contrary to Christian principles.”

Among the founders of the American Euthanasia Society, in 1945, were prominent Christians such as the New York divines Henry Sloan Coffin, the President of Union Seminary, and Harry Emerson Fosdick, the minister of Baptist Riverside Church.

Rev. Trevor Bensch, a co-founder of Christians Supporting Choice for VE, former hospital chaplain and Minister of North Adelaide Baptist Church, South Australia, said: *“My call for legal Voluntary Euthanasia is compassionate and thoroughly consistent with the teachings of Jesus.”*

Ref 1 <http://www.dwdnsw.org.au/index.php/article/publicopinion#sthash.QwRILQvI.dpuf>

Ref 2 YourLastRight.com: Australian public desire for legal assisted dying — 2012 research Ref 3

http://www.religionandsociety.org.uk/events/programme_events/show/press_release_westminster_faith_debate_6_should_we_legislate_to_permit_assisted_dying

Highly respected Catholic theologian, Prof. Hans Kung, states: *"As a Christian and a theologian I am convinced that the all-merciful God, who has given men and women freedom and responsibility for their lives, has also left to dying people the responsibility for making a conscientious decision about the manner and time of their deaths. This is a responsibility which neither the state or the church, neither a theologian or a doctor, can take away"* (Ref 4)

More recently, Lord Carey former Archbishop of Canterbury and head of the world wide Anglican church, speaking in support of the Falconer Assisted Dying Bill before the House of Lords, UK, said: it would not be *"anti-Christian"* to ensure that terminally ill patients avoid "unbearable" pain, and *"One of the key themes of the gospels is love for our fellow human beings ... Today we face a terrible paradox. In strictly observing accepted teaching about the sanctity of life, the church could actually be sanctioning anguish and pain – the very opposite of the Christian message."* (Ref 5)

Former Archbishop Desmond Tutu, one of the most revered religious leaders, also speaking in support of the Falconer Bill says: *"I have been fortunate to spend my life working for dignity for the living. Now I wish to apply my mind to the issue of dignity for the dying. I revere the sanctity of life - but not at any cost."* (Ref 6)

Please view the Archbishop Tutu video as part of evidence to this Inquiry. (Ref 6a)



Canon Rosie Harper, vicar of Great Missenden and chaplain to the Bishop of Buckingham in UK, said she supports Lord Falconer's Assisted Dying Bill which received its second reading in the House of Lords on July 18, 2014.

Canon Harper was one of three faith leaders backing the Bill during a debate on the issue hosted by Interfaith Leaders for Dignity in Dying in Westminster, London, July 17, 2014.

She described the assisted death of her uncle with Dignitas in Switzerland. "My uncle had a beautiful death, with his family around him - good music, good wine, and a pain-free end. The days that would have followed as he struggled through the end stage of a brain tumour would have been terrible. He had no choice about dying. He did have choice about the manner of his death. That's all this bill is offering."

...."Nor do I believe that holding on to life at all costs is the uncontested goal of humanity. The crucifixion itself demonstrates that there are higher goals than the preservation of one's life. John 15.3: There is no greater love than to lay down one's life for one's friends."

She argued that a God who offered "freedom of will" would not insist on "extreme suffering" at the end of life when there was a different, better way. Addressing the arguments against, she continued: "First there is the contention that pain can always be controlled. We know that simply is not the case. Anyway - in what way is there value in a person being technically still alive if they are sedated to the point of oblivion?"

Secondly, what this bill proposes is infinitely more honourable than what routinely happens now when a dying person is gradually and cruelly starved to death." (Ref 7)

There is a significant indication of support for Physician -Assisted Death from the Society for Humanistic Judaism. (For full details see Ref 8)

Ref 4 Book "A Dignified Death", Hans Kung.

Ref 5 <http://www.theguardian.com/society/2014/jul/12/archbishop-canterbury-carey-support-assisted-dying-proposal>

Ref 6 <http://www.bbc.com/news/uk-28282323>

Ref 6a View Archbishop Tutu video here> <http://christiansforve.org.au/archbishop-desmond-tutu-gives-his-blessing-to-the-voluntary-assisted-dying-campaign-in-australia/#more-371>

Ref 7 See Canon Harper's compassionate interview (approx 5 min) Youtube here <http://www.christiantoday.com/article/senior.cofe.priest.why.i.am.pro.assisted.dying/38052.htm>

Ref 8 <http://www.shj.org/physician-assisted-death/>

The scaremongering and general lack of factual supporting data by religious opposition

An analysis of Parliamentary debate on assisted dying reveals opposing MPs who are known to have a religious background, rarely acknowledge their religion has influenced this opposition.

The trend for religious opposition is to use the alleged 'slippery slope' and the alleged coercion of the elderly and vulnerable, rather than the 'sanctity of life' and the 'Thou shalt not Kill' arguments in previous years. This is presumably because the 'Thou shalt not Kill', which should be translated as 'Thou shalt not murder', (that is kill with malice), is easily rebutted by citing the numerous examples of Biblical killing apparently approved or authorised by God . (Eg the story of Noah, genocide of the Midianites in Num. 31.7-9 & 17-18, etc)

Prof. Hans Kung commenting on the Evangelium Vitae on abortion and euthanasia by Pope Paul II, states: "The remarkable thing is the same Pope, who still allows the imposition of the death penalty for 'cases of absolute necessity, when it would not be possible to otherwise defend society' thinks that in questions of help in dying he must advance a thoroughly rigorous view with reference to the sanctity of life (which now once again is made absolute)" Kung also questions how Pope Paul II would allow the "passive help" of turning off a ventilator, but not the increasing of a dose of medication with fatal consequences, pointing out the distinction is theoretically contradictory – can any action be passive?

NSW MLC Dr JOHN KAYE said during debate on Rights of the Terminally Ill Bill: 2013

"Some objections are emerging from a purely dogmatic narrow interpretation of the right to life. Many of those arguments have relied on misleading and downright mendacious tactics and none more so than Cardinal George Pell in his letter of 8 May on behalf of the Catholic bishops of New South Wales.. The letter contains four substantial lies. It is a deliberate attempt by the cardinal to mislead the people of New South Wales and, in particular, to mislead his flock. Cardinal Pell states:

Despite talk of "dignified death", dignity is not served by telling the old and dying, through our laws, that they would be better off dead and we would be better off if they were dead. It is simply a lie to say that this bill tells anyone they would be better off dead," said Kaye. (Ref 9)

Cardinal Pell's letter failed to mention that a voluntary request from the terminally ill person was required, used emotive language such as killing and incorrectly stated that overseas experience shows that others will be involuntarily euthanased once a country goes down the euthanasia path.

The Anglican Synod of Sydney in 2010 expressed opposition to voluntary euthanasia along predictable lines. They stated palliative care is sufficient, except for a tiny minority. (but have no empathy for that minority) They alleged legislation will lead to patient mistrust, creeping expansion, reduced funding for PC and that most supporters for euthanasia are young and healthy, none of which is supported by data from overseas

The Synod failed to note the legislation they were referring to was only for the terminally ill. (Ref 10)

During debate on the Tasmanian Giddings/McKim Assisted Dying Bill 2013 (Ref 11) Ms Jacquie Petrusma MP made a number of questionable statements. For example, note the way this sentence is worded. *The Oregon 2013 report indicates that being a 'burden on family, friends and care givers' is the major reason for requesting assisted suicide for 38.6 per cent of those who had died versus 23.5 per cent for 'inadequate pain control or concern about it.'* This is misleading, as she does NOT quote anywhere the actual 3 major end-of-life concerns: loss of autonomy (93.0%), decreasing ability to participate in activities that made life enjoyable (88.7%), and loss of dignity (73.2%) (Year 16 Oregon Report) Ms Petrusma did not acknowledge she is a conservative Christian.

Ref 9 NSW Hansard, Legislative Council, 22 May 2013

Ref 10 <http://www.sds.asn.au/assets/Documents/synod/Synod2010/bp5.191010.pdf>

Ref 11

TASMANIA Hansard Voluntary Assisted Dying Bill 2013 (No. 61) 16 October 2013 Second Reading
<http://www.parliament.tas.gov.au>

- A more reliable statement on the true value of Assisted Dying Choice in Oregon

Ann Jackson is a co-investigator of published studies about the experiences of Oregon's hospice workers with medical aid-in-dying and has participated in numerous state, national, and federal task forces to improve the quality of care at the end of life. She works for people and organizations regardless of their positions on medical aid in dying.

"I served as chief executive officer and chief spokesperson of the Oregon Hospice Association, a member of the National Hospice and Palliative Care Organization, between 1988 and 2008, before and after the implementation of the Oregon medical aid-in-dying law."

"I voted against the 1994 Oregon Death with Dignity Act referendum and voted for the unsuccessful 1997 referendum to repeal it because I believed the law was unnecessary if terminally ill Oregonians had access to high-quality hospice and palliative care. But I too came to realize that it was arrogant of me to believe that hospice and palliative care professionals could meet all the needs of the dying. The truth is fears raised by opponents of the Oregon Death with Dignity Act turned out to be 100 percent unfounded." (Ref 12)

The need to get the numbers of persons using Voluntary Assisted Dying in perspective.

Opponents frequently raise the increasing numbers of person exercising their choice with VAD, for example in Oregon. The facts are: In 1998, the first year of operation in Oregon, 9994 people per 10,000 deaths did not use assisted dying. In the 2020 year, 9934 people per 10,000 deaths did not use the assisted dying option. In addition, the opposition choose to overlook more people are dying peacefully rather than being forced to die in extremis against their own deeply-held wishes. (Ref 13)

- Reputable polling in support vs the manipulation of on-line polling

The importance of reputable scientific Polling was outlined in Point 2, however it appears on-line polls have been manipulated by those opposing.

For example, I have no reason to doubt the authenticity of this email from the HOPE no euthanasia group. Wed, Nov 24, 2010 Subject: Vote tonight on euthanasia

Dear Friends, Thank you so much to everyone who took the time to get involved in the two online polls yesterday – both won hands down! When I first sent out the message about the advertiser [the Adelaide Advertiser newspaper] poll the NO vote was at an abysmal 16%. Just a moment ago the No vote was at nearly 74%. Alex Schadenberg from Canada thanks you all for your support with his poll and, likewise, we need to thank our Canadian friends for their votes.

This really proves the power of networking. I encourage you all to ask all your friends to register on the HOPE website so we can keep building the opposition and the network. This is so important for the long haul. (Ref 14)

Another example of poll rigging –

The BMJ invited its readers to respond to the editorial by voting for or against neutrality. Astonishingly, over 80 per cent of those who voted were against neutrality – the opposite of what had been found in the scientific poll. This surprising result prompted an analysis. In a two-day period, there were many anomalies, the most striking being one individual, apparently located in Iceland, who voted against neutrality 168 times. One could not have clearer evidence of how the debate against assisted dying is being hijacked. This is a rerun of what happened in 2006 when Lord Joffe's Bill for legalising assisted dying was being debated in the House of Lords.

Ref 12 <http://vtdigger.org/2016/09/26...>

Ref 13 <https://www.oregon.gov/oha/ph/providerpartnerresources/evaluationresearch/deathwithdignityact/pages/ar-index.aspx>

Ref 14 Email on file

The Euthanasia Prevention Coalition – an international body based in Canada – flooded two polls of British public opinion, one run by Bath University and one by the Evening Standard, with “No” votes from Canada and USA. (Ref 15)

- The reality when good palliative care is not effective in relieving suffering

Pain and existential suffering

Physical pain should not be the ultimate criteria for a rational request for an assisted death.

Perhaps more important is the suffering endured when the body becomes “unbound”.

“ ‘unbounded’ includes symptoms such as incontinence of urine and faeces, uncontrolled vomiting (including blood and faecal material), fungating tumors, gross oedema causing the skin to burst, rupturing tumors”, states Julia Lawton. (Ref 16)

“If I was dying with pain, delirium and vomiting faecal material, for example due to an inoperable blocked bowel, I would prefer the legal choice of a death within minutes, thanks.” Ian Wood.

There is increasing evidence that, for many terminally ill patients, having their request approved for an assisted death is of immense psychological and palliative value to them. Dr Erika Preisig, of LifeCircle, an assisted dying organisation in Switzerland, says, *“Again and again it (my experience) shows that members find new energies to go on living when they know they have the green light for an assisted voluntary death.”* It provides peace of mind, and in many cases they live longer than a person who does not request assistance! (Ref 17)

Dr Rodney Syme, Victorian Doctor, states: *For over 25 years I have been counselling people about their end of life concerns. Those conversations are prolonged and open ended. At all times, I endeavour to help people to go as far with their lives as possible. From that experience I have learnt one invaluable lesson – my first self-evident truth – **that giving people control over the end of their lives is one of the most valuable palliative tools we have at our disposal.*** (Ref 18)

The Truly Vulnerable Those opposing assisted dying often allege concerns about ‘vulnerable’ groups, the elderly and those with disabilities. Yet they do not talk about another major group others consider truly vulnerable. Those who are actually suffering with a terminal or incurable illness, who are vulnerable to futile treatments being needlessly inflicted on them by doctors who refuse to face the FACT that the patient is going to die and in many cases the side effects of this futile treatment are worse than the illness itself.

“Up to 70% of people now die in acute hospitals, surrounded by well meaning strangers, inflicting all that medicine has to offer; often resulting in a painful, distressing and degrading end to their life.” and “Clinicians themselves are often complicit in refusing to face the inevitability of dying and death.”, states Dr Ken Hillman, Professor of intensive care at the University of NSW in Sydney. (Ref 19)

Dr Charlie Corke, Palliative Care, Geelong Hospital, VIC has stated, *“He “inflicts” treatments he would not want done on himself.”*

He had a problem stopping doctors inflicting treatment on his dying father. The doctors were acting against the wishes of the father and Dr Corke.

He states that the greatest act of LOVE is permission to “let go”. (Ref 20)

Ref 15 <http://rationalist.org.uk/articles/2848/the-case-for-assisted-dying>

Ref 16 *The Dying Process. Patient's experiences of Palliative Care*, Julia Lawton Page 127

Ref 17 <http://www.lifecircle.ch/>

Ref 18 Dr Rodney Syme <http://www.dwdv.org.au/documents/item/56>

Ref 19 Ken Hillman, Dr Ken Hillman is a professor of intensive care at the University of NSW in Sydney, Book, “Vital Signs” 2009.

Ref 20 Book Saving Life ...or prolonging death, Dr Charlie Corke

Flora Lormier was pleading for help to die. Her plea went unanswered.



Flora Lormier, suffered from multiple sclerosis since she was 20 but her condition worsened over the past two years. She begged her family to help her die (left, taken by her daughter Tracey Taylor in her final days, and pictured right at a family wedding when she was younger. The photos are even more graphic on the ShoutforFlora Facebook page.

Ms Taylor, from Glenrothes, Scotland, says: *'Mum was just left to suffer – it was torture, absolute torture. We were all around her when she passed but it wasn't peaceful.*

'These pictures are what people need to see – this is why we are fighting for the right to die. There wasn't a thing we could do to help free her from her pain. We had morphine and sleeping pills and she begged us to help her end it, but we couldn't.

'She was like a prisoner of war who had been in a concentration camp. 'So why is it OK for a human to suffer? The Government need to see why people want the choice to decide when to die.' (Ref 21)

- Data from Palliative Care itself clearly demonstrates that a significant number of dying patients do not obtain adequate relief from their suffering.

Phase type	Symptom distress	0 (Absent)	1-3 (Mild)	4-7 (Moderate)	8-10 (Severe)
Terminal	Difficulty sleeping	93.2	3.8	2.4	0.6
	Appetite problems	92.6	3.6	2.4	1.3
	Nausea	94.3	3.2	1.9	0.6
	Bowel problems	88.8	6.3	3.8	1.1
	Breathing problems	72.6	12.8	10.4	4.2
	Fatigue	79.2	7.5	8.8	4.6
	Pain	59.8	24.2	13.4	2.6

National Report on Patient Outcomes in Palliative Care in Australia, July - December 2016. (R 22)

NOTE 4.2% of patients in the terminal phase report severe distress from breathlessness, 2.6% severe distress from pain

Ref 21 <https://www.facebook.com/shoutforflora/>

Ref 22 <http://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow231313.pdf>

Please be aware that some patients still with inadequate relief may be terminally sedated, and therefore unable to report anything. The incidence of terminal sedation in Australia is not recorded, and that is surprising for something as important as this.. One study in a specialist PC facility reported 43 % receiving continuous deep sedation until death. (Ref 22a)

The tragic death of Clive Deverall is one of thousands of examples why more is needed than Palliative Care. Clive suffered for 20 years from a rare blood cancer. **A former CEO of WA Cancer Council, and President of Palliative Care WA, he knew the limitations of palliative care.** He rationally decided his best option to avoid futile suffering was to take his own life while his wife was out walking their dog.

Mr Deverall told the ABC in an interview that palliative care was not the answer for between 4 and 8 per cent of patients.

"Certainly I still embrace what palliative care stands for, but even with their clinical guidelines, they avoid the elephant in the room which is the very end stage patients where symptoms cannot be controlled," Mr Deverall said.

"Patients in that distressed state, those patients should be offered voluntary euthanasia."

"The take home message is that we have a cruel law at the moment that is prejudicial to the interests and wishes of patients, that needs to be changed." "The lack of compassionate law in this state will force some people into taking their own lives in a fairly brutal way." (Ref 23)

- Terminal sedation – slow euthanasia?

All members of my group would agree that the terminally ill need to be treated with compassion and care, supported by family, friends and the community, and treated as precious members of the human family.

We also believe that palliative care provides an essential service for the dying. However we know that the facts show even the best PC does not provide 'remedial solutions' to 2 to 5% of those dying. Symptoms such as uncontrollable vomiting of blood and faecal material due to an inoperable blocked bowel, is an example where pain relief is not effective.

The last resort in palliative care, when all else fails, is to put the person into a **medically induced coma, known as terminal sedation**, where they gradually starve or dehydrate to death, a circumstance that family and the nursing and medical staff can find extremely distressing to watch.

Terminal sedation is accepted by the medical profession and the Catholic Church as an appropriate and religiously ethical last resort, as the stated intention is 'to relieve suffering'. No reporting is involved, and the patient need not even be asked.

Yet if the dying patient requested, "Rather than starve me to death in a coma, with the trauma of having my family watch this slow death, please give me the next few days medication in a single dose", this would be illegal. **That dying patient should be able to say: You have set up an IV line, now please attach a bag of pentobarb solution, and allow me to active the flow so that I can die in minutes.**

As Christians we ask why it is morally acceptable that the slow death procedure should be legal but not the other alternative?

To quote Dr Rodney Syme AM: *It (terminal sedation) remains the 'Achilles heel' of palliative care because it is used in exactly those circumstances where other doctors might provide assisted dying if they were asked. And this very process is only associated with patient consent in up to 50% of deaths, with no opportunity to say goodbye.*

Ref 22a <https://www.sciencedirect.com/science/article/pii/S0885392408001395>

Ref 23 <http://www.abc.net.au/news/2017-03-22/cancer-pioneer-clive-deveralls-death-spotlight-on-euthanasia/8376890>

Dr Syme continued. *Far from acknowledging terminal sedation, palliative care has been assiduously arguing, that neither it nor morphine alone, if used in a proper palliative way, ever hastens death. **Terminal sedation is justified for the treatment of 'refractory' or 'intractable' symptoms, as determined by the clinician, not the patient.** Maltoni and colleagues stated that **"Despite the huge progress made in palliative medicine in terms of symptom control, many are intractable symptoms, either because the treatment is ineffective or because the treatment itself is intolerable"**.* (Ref 24)

I have quoted in more depth on pages 13 to 14 of this submission the conclusions of the Quebec Parliamentary Inquiry but the following point is particularly relevant here: *"Regarding the issues surrounding end-of-life practices, there seems to be a very fine line between continuous palliative sedation, refusal or cessation of treatment, and medical aid in dying. In all three cases, the end result is death,"*

"A review of the literature has found great variability in the prevalence of palliative sedation, ranging from 2% to 52% among terminally ill patients. The study conducted by Ventafridda et al found that more than 50% of cancer patients dying at home die with physical suffering that is only controllable by means of sedation. Between 10% and 50% of patients in programs devoted to palliative care still report significant pain 1 week prior to death. The most common symptoms experienced by these patients were dyspnea (uncomfortable shortness of breath), pain, delirium, and vomiting. Most symptoms are reported to be physical in nature. In a retrospective analysis by Kohara et al, 54% of patients were found to have more than one uncontrollable symptom."

(Ref 25)

The current law on assisted suicide is irrational

Dr Rodney Syme, a Victorian doctor, recently awarded an AM, has publicly admitted supplying fatal medication to Steve Guest and later to Ray Godbold, both with terminal cancer. Strictly speaking this is against the law, but it seems the Prosecutor did not charge Dr Syme with any offence and rationally most Australians would agree that Dr Syme is acting with due care in the best interests of the dying patient and is not committing any offence.

It therefore seems completely logical to CHANGE the law. Every state or territory can still maintain that assisting a suicide is, in general, against the law, but provide the legal exception for medical assistance, subject to adherence to a list of proscribed criteria. We note the action of Dr Syme in supplying fatal medication to Steve Guest was supported in an unpublished letter to an editor signed by 98 other doctors. (Ref 26)

- Alzheimer's – a difficult situation and the need for compassionate choice.

Alzheimer's would be without doubt the illness most feared by the members of Christians Supporting Choice for VAD! We ask if this could be considered in reviews of legislation.

We note that Belgian legislation does permit a person with Alzheimer's to use an assisted death, during the window between a confirmed diagnosis and the lack of ability to make a rational conscious request.

The assisted death of Hugo Claus, an Belgian author who had Alzheimer's, as described by his wife, Veela Claus-de Wit, in the Terry Pratchett documentary, "Choosing to Die" 2011.

"After we had shared champagne and he had a cigarette, he said I think I want to lie down. I lie down next to him and I hold him and I sing a song to him and he started singing with me – he died singing. It was so intense and warm – how can people be against it?"

I could do without the cigarette, but would love to die singing! (Ian Wood personal comment)

Ref 24 <http://www.dwdv.org.au/documents/item/56>

Ref 25 http://www.medscape.com/viewarticle/550666_2

Ref 26 <http://www.rationalist.com.au/dr-rodney-syme-champion-of-human-rights/>

Ref 27 <https://vimeo.com/229120539>

Compare this death of Hugo Claus, with the more typical situation described below.

A visit to any high dependency nursing home in Australia will show patients suffering from dementia, Alzheimer's, severe Parkinson's disease, massive strokes and other demeaning and crippling conditions.

Bedridden, needing to be fed and changed like babies, incontinent lying in napkins soiled with urine and faeces despite the best efforts of dedicated nursing staff, unaware of their surroundings and close relatives unrecognised, would they want this if they could choose?

In lucid moments rather do they plead " God take me, please let me die " (Ref 27a)

The submission by Mr Kevin Rickson to the WA EOLC Inquiry provides a comprehensive assessment relating to ACDs and dementia and I recommend to the NSW Inquiry they take this submission dated 26 Sept 2017 into account with their deliberations. The onset of dementia does not negate a valid Will and the same should apply to a valid ACD.

- Chantal Sebire and a reason why the author of this submission personally supports choice in assisted dying for the terminally or hopelessly ill.....



Chantal Sebire



Chantal before her illness

Ms Sebire told AFP that she suffered from a very rare disease called esthesioneuroblastoma, which attacks the nasal cavity. It had left her blind and had robbed her of almost all other senses, leaving her in terrible pain.

"In 2000, I lost my sense of smell and taste, and then the tumour evolved and ate into my jaws, before attacking the eye socket. I lost my sight in October last year," she said. The disease caused "atrocious bouts of pain that can last up to four hours at a time".

Pleading to be allowed to die serenely, the mother of three said that only 200 cases of the disease had been reported globally in the last 20 years. (Ref 28)

This article was a deciding factor in Christians Supporting Choice for VAD co-founder, Ian Wood's decision to take a public stand on DWD in 2009.

Mr Wood says, "Had Chantal lived at that time in Switzerland, Netherlands, Belgium, Luxembourg or Oregon, and some other states of USA, or in Canada she would not have had to suffer and asks why so different in France. Even Spain now has a VAD law.

If Chantal lived in Victoria after mid 2019, and now WA, she could obtain assistance. In TAS, SA and QLD, the law is now passed, but in NSW she would still have to die slowly with unbearable suffering. This is why NSW needs a law to give humane choice!

Ref 27a Letter on file from a doctor

Ref 28 <http://www.news.com.au/story/0,23599,23283804-2,00.html>

- The conclusions of the Quebec Parliamentary Inquiry 2012

These conclusions for Quebec citizens are equally valid for all Australians.

Some conclusions (quotes) from the Quebec National Assembly all-party select committee that held hearings and deliberated for two years. (178 page Report) 2012)

After studying the changes in social values, medicine and the law, and in light of our comprehensive review of the issues and the arguments raised by hundreds of witnesses and thousands of comments, we have come to the conclusion that an additional option is needed in the continuum of end-of-life care: euthanasia, in the form of medical aid in dying.

Furthermore, we find that a growing number of physicians believe it is their responsibility to comply with a request for help to die. For them, when the end of life becomes intolerable, medicine must intervene out of compassion, in a spirit of human solidarity and respect for the patient's freedom of choice.

Many believe that if medicine can act when a person is born, it should also do its part to help with death when justified by the circumstances. A large majority of physicians seems to share this opinion, as evidenced by the results of member polls conducted by the Fédération des médecins omnipraticiens du Québec (FMOQ) and the Fédération des médecins spécialistes du Québec (FMSQ) towards the end of 2009. According to the FMOQ⁴² poll, 75% of physicians would like to see "new regulatory and legislative guidelines allowing recourse to euthanasia", while the FMSQ⁴³ poll concluded that 75% of physicians are in favour of "legalizing euthanasia within a clearly defined legislative framework".

We are therefore seeing a change in the mentality of the medical profession in Québec. The Collège des médecins itself has suggested that euthanasia could today be viewed as consistent with the spirit of the Code of Ethics of Physicians and constitute, under exceptional circumstances, the final step in the appropriate end-of-life continuum of care.

Some suffering cannot be effectively relieved, and individuals who want to put an end to what they consider senseless, intolerable suffering face a roadblock that goes against Québec society's values of compassion and solidarity.

Medical aid in dying would therefore become an option for this small number of patients in exceptional situations, provided the act is strictly controlled and limited, and the patient himself makes a free and informed request to this effect.

The medical aid in dying option takes into account the issues raised by the experts and witnesses at the general consultation as well as by the thousands of citizens who participated in the online consultation. It provides a solution to the issues of suffering and compassion in many end of life situations. It also addresses the fear of abuse. Finally, it meets a need that was stated with emotion and maturity, and is a safe course of action, provided the necessary precautions are diligently taken.

Despite its undeniable importance, palliative care is not always the right answer for all end of life persons, particularly those with uncontrollable pain.

The medical aid in dying option would thus offer an alternative to this small number of people. It would not be in keeping with our social values to refuse such assistance just because palliative care is not uniformly accessible across the province.

Based on the experiences abroad, we are convinced that medical aid in dying would in no way compromise the future development of palliative care.

Regarding the issues surrounding end-of-life practices, there seems to be a very fine line between continuous palliative sedation, refusal or cessation of treatment, and medical aid in dying. In all three cases, the end result is death,

*In this regard, despite the reticence of an age-old medical culture committed to maintaining life at all costs, the **medical aid in dying option should, like continuous palliative sedation and refusal or cessation of treatment, be one of the choices available at the end of life.***

Medical aid in dying does not endanger the common good; rather, it forms an integral part of it by offering one more option for those nearing the end of their lives, without posing a threat to society's most vulnerable members.

The Report comment on the 'euthanased without consent' in Belgium.

It is false to say that many patients are euthanized without their consent. These patients receive continuous palliative sedation when they are unable to express consent, when they are dying, and when the doctor and family believe that it is the best way to ease their suffering. (Ref 29)

The Supreme Court of Canada, February 2015, in a unanimous decision by 9 judges has stated "The prohibition on physician-assisted dying infringes the right to life, liberty and security of the person in a manner that is not in accordance with the principles of fundamental justice," and the **Canadian Parliament has since passed their Medical Assistance in Dying Bill C-14 with the support and input of the Canadian Medical Association.**

The conclusions of the **Australia 21 Report** *The Right to choose an assisted death: Time for legislation?* clearly demonstrates the need for legislative change from the Australian viewpoint. (Ref 30)

Quotes from the Victorian Inquiry into End of Life Choices Report and the recommendation for voluntary assisted dying. Prepared by Ian Wood, 19.5.2017

RECOMMENDATION 49:

That the Victorian Government introduce a legal framework providing for assisted dying, by enacting legislation based on the assisted dying framework outlined in this Report in Annex 1, Assisted Dying Framework Summary.

- **Laws regarding providing assistance to die are inconsistent.** On one hand, doctors, on a patient's request, can withdraw life sustaining treatment with death the certain outcome, while they can also deliver lethal doses of morphine and other drugs, as long as the intent is to relieve pain. On the other hand, a loving husband who assists his frail, suffering and near death wife to die could be guilty of murder, while **a person near death and in unacceptable pain, cannot receive help to end their own suffering.**

- With a lack of end of life choices, many older members of the community are taking their own lives, often in horrific circumstances.

- **We found no evidence of** institutional corrosion or **the often cited 'slippery slope'**. Indeed, the regulatory framework has been unchanged in Oregon, the Netherlands and Switzerland for many years.

- **The evidence is conclusive that assisted dying can be provided in a way that guards against abuse** and protects the vulnerable in our community in a way that unlawful and unregulated assisted dying does not.

- Like in other jurisdictions, the Committee anticipates that while **a comparatively small number of Victorians will die using the assisted dying framework** (approximately 0.4 per cent of all deaths in Oregon and Switzerland), **many others will take comfort from its existence, knowing that another option exists.**

Government support and funding of palliative care has not declined when assisted dying frameworks have been introduced.

Ref 29 http://www.dyingwithdignity.ca/database/files/library/Quebec_death_with_dignity_report.pdf

Ref 30 http://gallery.mailchimp.com/d2331cf87fedd353f6dada8de/files/A21_The_Right_to_Choose.pdf

The effect of the end of life legal framework on the lives of Victorians and on the practice of medicine and the law signifies that it does not reflect our contemporary society's values.

The objective of the recommendations in the Report are to not only enable patients' end of life wishes to be respected, but also to protect patients, particularly vulnerable people, from abuse and coercion.

- The recommendations also aim to increase transparency around end of life medical practice and to improve clarity on end of life law so that health practitioners can be confident knowing where the boundaries of legal medical practice lie.

The Committee is of the view that **the existing end of life legal framework needs reform.**

- The Committee heard from health practitioners that not all pain can be alleviated. **Palliative care cannot always be the solution to managing pain and suffering at the end of life.**

The findings here are equally applicable to every Australian State and Territory.

Please view the complete End of Life Choices Report (Ref 31)

- Victorian Ministerial Advisory Panel on VAD Final Report.

The credentials and backgrounds of the Panel members were impressive. They included Prof. Brian Owler, a past President of the AMA, Emeritus Prof. Ian Maddocks AM (the 'father' of Palliative care), Dr Roger Hunt, South Australian Palliative Care Specialist, Prof. Margaret O'Connor, health ethics and palliative care, Julian Gardner AM, lawyer, disabilities advocate, Mary Draper, health issues, and Tricia Malowney OAM, disabilities advocate. The Report contained a thorough and very comprehensive analysis of the voluntary assisted dying issue. Appendix 3 - Safeguards and jurisdictional comparison - is comprehensive

- Victoria passed their Voluntary Assisted Dying Bill

After a protracted debate in both houses of the Victorian Parliament, the Voluntary Assisted Dying Bill 2017 was passed finally on 29.11.2017, with some amendments to the original Bill. This provided both an incentive and a rationale for other states and to enact their legislation to give this additional choice in dying.

OUR RECOMMENDATION: That the NSW Standing Committee on Law and Justice recommend to the NSW Parliament that the Voluntary Assisted Dying Bill 2021, as introduced by Alex Greenwich MP, with 27 co-sponsors, be adopted and passed without amendment.

OUR RECOMMENDATION:

- Following the confirmed diagnosis of a terminal or incurable illness, the doctor must be able to initiate discussion on VAD as part of a full discussion on all treatment options available.
- The patient, and the degree of suffering being experienced by that patient approaching death should be a main criteria for access to assistance.
- Period for reflection between requests should be minimal, as this also prolongs the suffering. If the patient could request VAD in an ACD this would indicate 'reflection'.
- There are reported cases where a patient has refused adequate pain relief during 'reflection' as they are fearful loss of mental faculties could mean they are unable to indicate their final assent required immediately before taking the fatal medication.

Ref 31 https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/EOL_Report/LSIC_58-05_Text_WEB.pdf

Ref 32 <https://www2.health.vic.gov.au/about/health-strategies/voluntary-assisted-dying-bill>

- Conclusion in support of Voluntary Assisted Dying choice

The Northern Territory Rights of the Terminally Ill Bill was passed in 1996 then overturned by the Howard Federal Government. Since that time conclusive evidence from a number of jurisdictions has demonstrated having the legal choice of an assisted death can and does operate successfully.

My group, Christians Supporting Choice for Voluntary Assisted Dying, believe that, as a demonstration of love and compassion, those with a terminal or hopeless illness should have the option to choose a pain-free, peaceful and dignified death with legal voluntary euthanasia or assisted dying.

This New South Wales Inquiry presents a wonderful opportunity to endorse compassionate CHOICE in dying for the terminally and hopelessly ill, in legislation with rigorous safeguards, to residents of New South Wales.

Please consider the facts and ignore the scaremongering.

I would welcome an invitation to appear before the Inquiry.

Ian Wood

National Coordinator, Co-founder and Spokesperson

Christians Supporting Choice for Voluntary Assisted Dying

Website: www.christiansforvad.org.au

Please note that our group has been known since inception in 2009 as *Christians Supporting Choice for Voluntary Euthanasia*, and in 2019 we modified our name to reflect current terminology, including that used in the Victorian legislation.

I have made submissions on behalf of Christians Supporting Choice for Voluntary Assisted Dying to -

- Queensland Inquiry that included assisted dying choice in 2019
- ACT End of Life Choices Inquiry 2018
- Western Australia Inquiry into end of life choices in September and October 2017
- New South Wales Draft Bill in June 2017
- Victorian Inquiry into end of life choices in June 2015 and January 2016
- All South Australian MPs in 2016
- Federal Senate Medical Services (DWD) Bill 2014 in August 2014
- Tasmanian discussion paper in 2013
- Submission to The Federal Rights of the Terminally Ill (Euthanasia Laws Repeal) Bill 2008 in 2010
- Tasmanian Parliament in 2009

I appeared at, and addressed, the Victorian Inquiry into end of life choices on 15.10.2015 on behalf of our Group and spoke by video link to the Western Australia Parliament Inquiry and addressed by video link a group of MPs in the Tasmania Parliament last year.

I also make this Submission personally in memory of -

- Auntie Dorothy Williams, who died a horrendous death from bladder cancer. Many years later I still vividly recall the stench as her body rotted from the inside while she lay in her hospital room.

- Murray White, who was 'best man' at my wedding, who had a terrible prolonged dying from Parkinson's and Lewy body dementia, spending much of his last weeks strapped in a 'Princess Chair' to the distress of his loving wife, who is a strong Christian supporter of VAD.

- Cousin Glenda, who fought the ravages of cancer for many years, and whose final days were anything but peaceful.

- Darcy White, whose last days were agonising as he slowly died from anal cancer.

- Sister-in-law Joyce, who died in February 2017 aged 78. Approximately six months from diagnosis to death as ovarian cancer spread throughout her bones and liver. Joyce said goodbye to her family on a Sunday then lingered on in a semi coma for 3 more days.

The option to choose an assisted death could have spared her the suffering of these last days, and greatly diminished the grieving of her husband and family.

Significantly, before transfer from a major South Australian hospital to a PC unit, Joyce suffered severe break-through pain on at least one occasion. A visitor and Joyce were pleading with nursing staff for more pain relief only to be told it was too soon since the last dose, and the nurse would have to try to phone her doctor first! How inhumane!!

During the process of preparing this submission, I referred frequently to the book "*A Good Death - An argument for voluntary euthanasia*" by Dr Rodney Syme.

Dr Rodney Syme, who spent decades lobbying for voluntary assisted dying, in June 2019 was made a Member of the Order of Australia (AM) for "significant service to social welfare initiatives, and to law reform." Sadly, he has died in October 2021.

I also purchased and read another excellent book by Canadian author and journalist Sandra Martin, with a very similar title "***A Good Death - Making the most of our Final Choices***". Sandra's book gives fascinating background information on how, for example, the Quebec Bill actually came to be and was passed, and hitherto unknown (to me) background on the Canadian Supreme Court decision I have quoted in this submission.

May I respectfully suggest that the Inquiry Committee purchase and read both these books as part of the evidence needed to be fully informed on this issue. Please note that the paperback and e-book editions of the Sandra Martin book have an important additional chapter written after the introduction of the Canadian law.

Another useful reference book is - "*Is there a Christian case for Assisted Dying?*" Yes! By Prof. Paul Badham.

Why a Voluntary Assisted Dying law is needed.....

It is all about choice! A compassionate choice that must be permitted by law for the people of New South Wales.

Practical examples of why a VAD law is needed in every state. RIP Keith Died October 26 2013, aged 85 years

I'm writing to state my case for the legislation of choice for an assisted death. On Friday 1 November 2013 I buried my husband of 61 years. Early this year he was diagnosed with aggressive Lymphoma which was strangling his Intestine. Sounds horrendous, doesn't it?

His final 3 days were spent in hospital and on the 3rd night he lapsed into semiconsciousness. He had been having litres of fluid drained from his abdomen at intervals during the treatment process and in the early hours of the 4th day fluid in large quantities continued to rise into his throat as he was gurgling and drowning while he struggled dreadfully to get a breath. All the while he kept raising his hand to his head imploring someone to help him. This inhumane action continued without ceasing for 7 hours!! **How I wished we lived in a compassionate, loving society that approved an injection that would save him from this hideous state.**

A Nurse entered the room towards the end, saying, "I have been crying reading his Advanced Health Directive where he wrote that it was his wish to have some kind person euthanise him." This document had been signed by him, a Doctor and a Justice of the Peace some years ago but of course that wish is entirely overlooked by Australian Law at the present time. It was just his wish – as it was mine. Towards the end, one and a half litres of blood soaked fluid gushed out of his mouth before he took his final breath. **Those hours will haunt me forever.** Why should anyone die that horribly?

When it's your own family having to endure this cruel, inhumanity and it's you sitting beside the bed waiting and wishing someone had bitten the bullet for change on this grievous, outmoded law of ours, you feel and know the need of the urgency for change. **As a practising Christian couple we viewed the present law as ungodly.** We are God's hands and feet, he has no other, and **while we do nothing this horrendous practice will continue.** Please, please be strong enough to give the Ending Life with Dignity (No2) Bill 2013 the thumbs up. The majority of Australians would be enormously relieved. South Australia would be applauded.

Sincerely, Joan Smith QLD A Christians supporting Choice for VAD member.

Note by Ian Wood.

Joan prepared this plea in early 2014 to go the South Australian politicians, and has since endorsed it to go to all MPs throughout Australia.

It is included in the book *The Damage Done*, published by Go Gentle Australia and Andrew Denton. This book, with its 70 stories of futile suffering, is essential reading for every MP when considering the evidence in support of assisted dying choice.

Joan, a committed Christian, pleads that our politicians support Voluntary Assisted Dying choice.

A doctor explains her personal motivation, and her case for an assisted dying law:

Dr Ann McPherson, founder of Healthcare Professionals for Assisted Dying. (Ref 33)

'Faced with a painful death, I wanted to take control of my final hours,' said Dr Ann McPherson

At a cancer check-up in early June 2009, I got the news I most dreaded. The tumour doctors had discovered in my pancreas three years earlier, and from which I'd been free for two wonderful years, had returned and spread to my lung.

'We can't say for sure how long you will live, but you know as well as I do the prospects of living for more than a few months are not great,' my oncologist - a friend as well as a colleague - told me.

I was dumbstruck, unable to think beyond the horror of sharing the news with my family. Telling Klim, my medical scientist husband, was the easy part. 'Bad news,' I told him, catching him on his mobile. 'The scan results have shown that it's come back.'

I didn't need to say anything else. We knew the statistics: only three per cent of people with pancreatic cancer are alive five years after the initial diagnosis.

Speaking of the option for assisted dying: It seemed - and still does seem - unjust that such a choice is not available to the **70 to 80 per cent of the public** who say in surveys that they **want such a choice**.

Even more unfair is that assisted dying is forbidden largely because those making the legal and political decisions tend to have a vested interest professionally against assisted dying or have particular religious views.

I felt incensed that the British Medical Association, which claims to represent doctors, opposes physician-assisted suicide without having canvassed its members.

When I went public with my bad news in the British Medical Journal, **the response to my article was wonderful, with hundreds of doctors emailing me to support the stand I'd taken on assisted dying.**

But there was also hostility from palliative care specialists who felt a campaign for assisted death was an accusation that their branch of medicine has failed.

Such a view is absurd to me, as a grateful recipient of palliative care. I'd be in considerable pain if my GP didn't prescribe the morphine I take almost every day. Far from being opposed to palliative care, I see assisted dying as one part of this important speciality.

Unfortunately Ann could not receive that assisted death she craved. Her daughter Tess described Ann's last weeks in The BMJ June 2012, as follows. Ref 34

Ref 33 <http://www.hpad.org.uk/>

Ref 34 Cite this as: BMJ 2012; 344, e4007 "

"For at least three years, mum's life with cancer was worth living. She put up with many "new normals" as she called them, such as taking regular morphine to control pain, having an afternoon nap, smelling at times toxic; having a chest drain, which she drained daily herself; and eating only baby food.

The cancer had spread to around the gastric outlet so that she could no longer eat anything solid and even fluids were difficult. Her chest drain had started to leak and was pouring out fluid that drenched her dressings. She had lost so much weight. She was getting pressure sores. She had had enough.....

The weeks before she died were terrible.By now she had two morphine drips, one in each wasted leg, which needed re-siting often. Her drain site poured fluid; her bed clothes were drenched...There was no dignity.

There was no mum, just a wounded animal who needed drips changed.

...She could not receive the drugs that would relax her tiny gasping frame. She was literally wasting away. ...It is an honour to care for someone you love, but it no longer felt honourable to try to care for someone who wanted to be dead.

On the final day the doctor was getting the syringe drivers ready when something changed in my mum's breathing....**As she died her body seemed furious with its final fight, gasping to the end. With a desperate haunting shudder from mum I found myself sitting in pools of expelled fluid.**

That was not what she wanted. Mum had seen this happen before and wanted it avoided for future patients and their families.

It is simple: the law needs to change to allow terminally ill but mentally competent people the right to a more dignified death than my mum was allowed."



Dr Ann McPherson.

Photo Andrew Crowley

Dr Ann McPherson, who died on May 28, 2011 aged 65, was a general practitioner who campaigned for a change in the law to allow terminally ill patients to be helped to die if that was their wish.

Yes, contrary to the 'official line' of the BMA and the AMA, many doctors ask MPs to legislate for Voluntary Assisted Dying.

In Australia this doctor group asks that MPs legislate for Voluntary Assisted Dying choice....

drs4assisteddyingchoice.org

Respecting rational patient end-of-life choices

Prior to my preparing this submission, I was sent the tragic story of **Genevieve McCool**, a Canadian who died just prior to the Canada legislation. I have read many stories of horrendous end of life suffering, but this must rank among the most horrific!

Refer to C4VAD website news: <https://christiansforvad.org.au/genevieve-mccool-a-story-of-horrendous-futile-end-of-life-suffering-inflicted-by-doctors-and-a-catholic-hospital-canada/#more-529>

Theresa McCool, Ontario, Canada, has given permission to circulate this story (abridged)

My Mom was Genevieve. She was diagnosed with basal cell carcinoma in her shoulder. In May 2015 She became very ill with a blood infection that went throughout her body and she was put on an aggressive treatment of antibiotics for seven weeks. She hadn't wanted to go to hospital when she became sick and I had insisted that she must go. I now wish I had not have taken her. She would have died a much more peaceful death than she did.

She was told at the hospital (a Catholic Hospital) that there was no guarantee that she would survive the treatment and life expectancy was given as anywhere between 6 hours, 6 days, 6 weeks, 6 months or 6 years.

She ended up surviving 15 weeks and 6 days (103 days) and I will never know how she managed to last that long with all that she had to endure.

Whilst she was in hospital she had many doctors who saw her, who were trying to decide how they could "cure" her – their words, not mine. She was in a Catholic hospital at this time.

During the many tests she was to go through, they also discovered an aggressive cancerous tumour in her back that was growing rapidly.

Medical Assistance In Dying, (MAID) in my country Canada, was not in place at that time – in 2015. Even had it been legalised, because her death, according to the doctors in the catholic hospital, was deemed to be "not foreseeable", and they believed the tumour could be removed, she would not have met the criteria.

The doctors in the Catholic hospital decided they wanted to give Mom aggressive chemotherapy and radiation treatment. They wanted to operate and remove her right shoulder and arm. This would have meant she would lose half of her torso and her arm. They were also planning to cut the skin off her buttocks to perform a skin graft where her missing shoulder and arm would have been – and with no guarantees that she would actually survive the surgery and treatments.

Mom said she had wanted to be euthanised but the doctors at St. Joseph's hospital had obviously refused her request. She wanted to be with her family who live in Toronto, St. Joseph's Hospital had refused to transfer her to Toronto. I was told, "Only God can take her".

It was arranged for Mom to be transferred to a 3rd hospital, St. Michael's in Toronto, and that is where she died 5 days later.



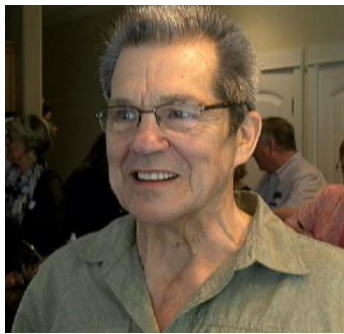
I spent 103 days in hospitals watching my Mom suffer, as she begged to be euthanised. Do you know how that feels? It was very hard to have to watch her be in pain.

Her last words were "Pain – Pain" and again she was refused pain medication because she had reached the "legal dosage" that the doctor could give.

When she took her last breath, her eyes bugged out and she cried out in pain. Her back ripped open to her spine, from the cancerous mass in her back. This is the image that never leaves my mind.

Instead of dying peacefully in her sleep, free from pain, she died in agony. Mom was seventy-eight – she had hoped Assisted Dying would become legal. She died waiting for it.

The compassionate alternative to those tragic deaths with futile suffering as described on the previous pages.



We have **Ed Ness**, pictured here shortly before he died from terminal lung cancer. Ed said goodbye to his closest friends and family .

A reporter for ChekNews, Canada, continues the story

Then at 1:45 p.m., Ed took a seat in his recliner. The shades were pulled down, candles were lit and soft music is playing. He reads his last Epitaph to everyone and the doctor arrives at 2 p.m. Ed still sips at a glass of wine, a picture of his wedding day 35 years ago sits on the table beside him. Ed shares a final tender moment with his wife Gloria saying goodbye and I love you.

Dr. Daws asks if he is ready, he says yes and the procedure begins. He is given medication that will make him fall asleep and his last words to everyone are, “this is perfect”.

He passed away peacefully within a few minutes.



Please compare the emotional tranquility of Ed, to the distress experienced by Chantal, Keith, Flora, Ann and Genevieve on the previous pages.

Why the difference? Ed Ness lived in Canada and in Canada every terminally ill adult has this choice if they wish, and if they meet the other strict criteria to have access.

We note that the legislation that Canada has to allow this choice is endorsed by the Canadian Medical Association. Indeed, the CMA has awarded an Alberta doctor their most prestigious award for “Medical Ethics”, for his role in developing a “framework for medically assisted dying.”

Ed Ness typifies an example of compassionate choice.

Fact: “Peaceful, perfect, beautiful.” These are the words most used to describe a Voluntary Assisted Death that a terminally ill person has chosen to access in Victoria.

Fact: The second person to utilize her choice to access VAD in WA was indigenous community leader Mary-Ellen Passmore, with Motor Neurone Disease. MND is an incurable illness that progresses until the sufferer can no longer walk, talk, swallow or breathe. **In public statements just before her death, Mary-Ellen said how she was at ‘peace’, she was grateful to the WA Parliament for allowing her to choose the time and the manner of her dying - a quick, peaceful, beautiful death rather than slow death by choking or suffocation!**

Fact: The dying of Ms Passmore was not lonely or depressed but instead it was reported as; **“surrounded by her children, partner, sister and hospital staff who sang Hallelujah to her during her final moments.”**

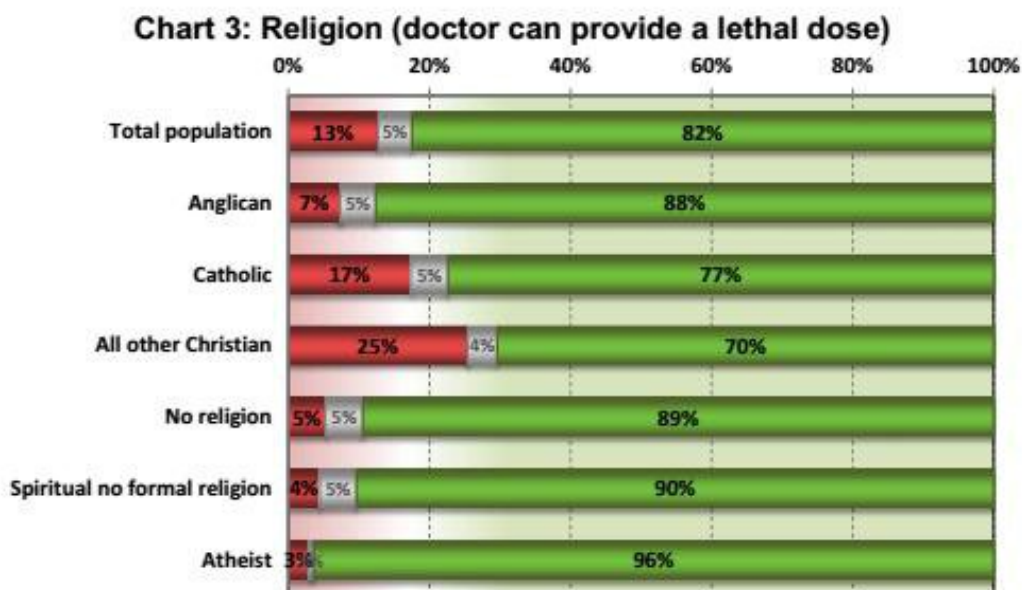
As Christians we fully support palliative care but sometimes PC is not enough, and an extra choice is needed.

Additional data on Christian support for voluntary assisted dying

In 2012, Newspoll found an overwhelming majority said yes (82.5%), a very small minority (12.7%) said no, with 3.8% don't know and 1.0% refused. Nearly nine out of ten Australian Anglicans, more than three out of four Catholics, and nearly all Australian atheists advocate assisted dying law reform. That is, the proportion of Anglicans in support is higher than among the general population! Religious hierarchy who comprise an organised opposition to law reform do not represent the views of the majority of their flocks. (Ref 36)

Results by religion

Chart 3 shows the breakdown of support amongst major religious and non-religious groups.



A sermon in support of Voluntary Assisted Dying was given recently by Rev Craig Kilgour of New Zealand. **This sermon is significant as Rev Kilgour's nephew had an assisted death in Canada.** (Ref 37)

The final paragraphs from this sermon sum up the compassionate Christian approach to assisted dying choice.

***“Let me finish this with what my family members said and repeated often using these words about my nephew’s death: It was compassionate, it was humane, it was right and good. And the family are very proud and humbled with the courage he showed in his battle with cancer. And to me no one has the right to be critical and judgemental of the choice he made.*”**

So for me and my family this is not a philosophical debate, it is not a theological debate, it is not a theoretical debate, it is a reality and it was right and my nephew was fortunate he lived in Canada.”

Please compare this with an inhumane comment made by a Christian candidate in the 2017 WA Election.

“I once had an uncle who rebelled against the Lord all his life. On his death bed he refused to acknowledge his sin and his Savior. God gave him time to repent but he refused. If he had been administered an assisted death the time he had to repent would have been so much shorter.”

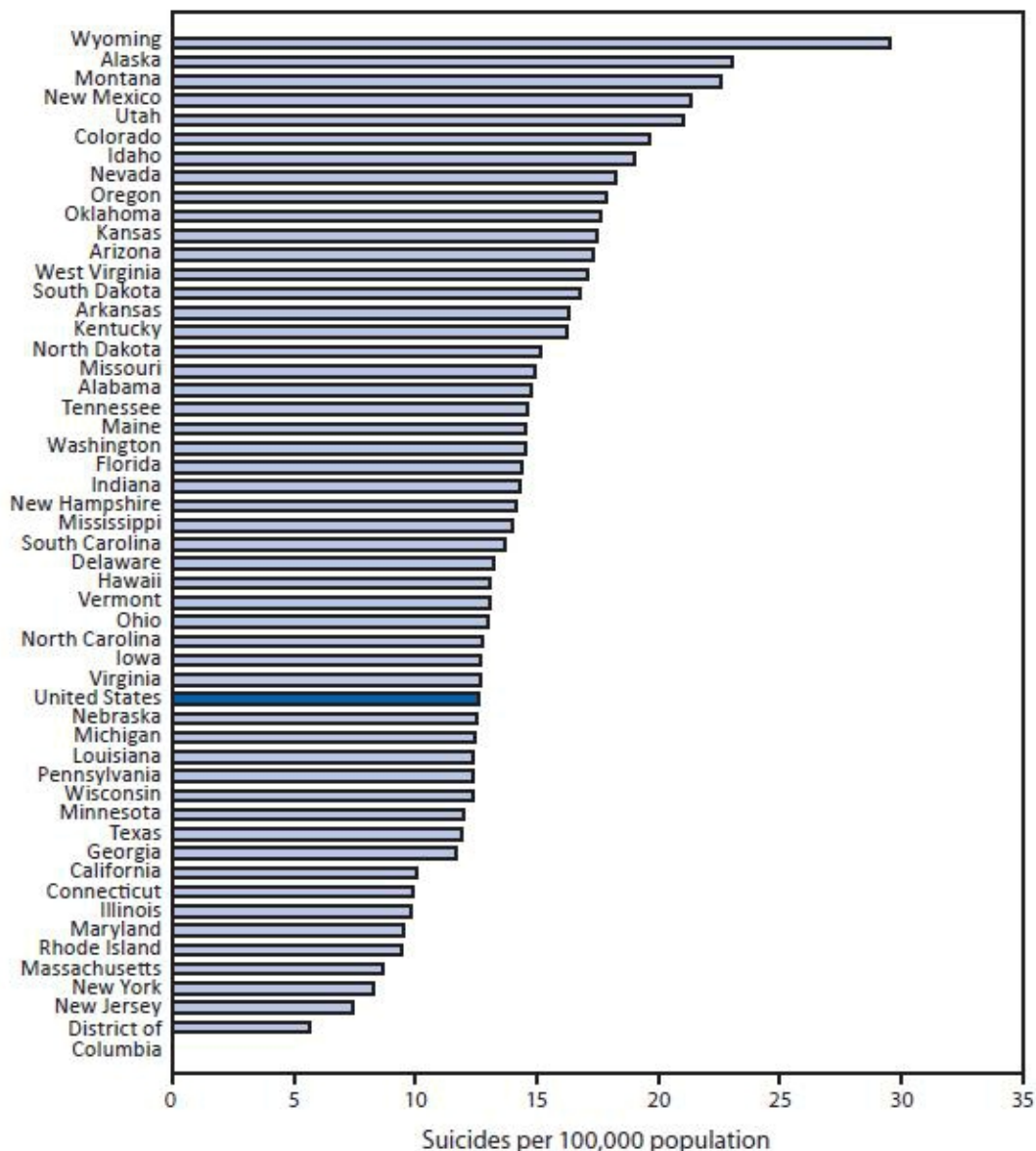
Ref 36 http://www.yourlastright.com/sites/default/files/YLR_Public_Opinion_On_Assisted_Dying_2012_Whitepaper.pdf

Ref 37 <https://christiansforve.org.au/rev-craig-kilmour-new-zealand-sermon-my-nephew-had-an-assisted-death-in-canada-it-was-compassionate-it-was-humane-it-was-right-and-good/#more-498>

An important note.

Many submissions to the WA Inquiry on End of Life Choices opposing VAD quoted an article in the Southern Medical Journal. This article states that the rate of suicide in Oregon is higher than the USA average, and attempts to correlate this to the fact that Oregon has VAD. What the article, or the opponents of VAD cannot explain is that Wyoming and Alaska and some other states have far higher suicide rates than Oregon, but they do not have VAD. Please refer to table below.

This Southern Medical Journal article is also comprehensively rebutted by Neil Francis of “DyingForChoice. Mr Francis calls on the authors of the article, Jones and Paton to withdraw their claim. (Ref 38)



Ref 38 <http://www.dyingforchoice.com/blogs/new-report-slams-unscientific-jones-paton-study>

Ref 39 Suicide rates in USA:

https://www.google.com/imgres?imgurl=https://www.cdc.gov/mmwr/preview/mmwrhtml/figures/m6345qsf.gif&imgrefurl=https://www.cdc.gov/mmwr/preview/mmwrhtml/mm6345a10.htm&h=620&w=560&tbnid=VsowoHgbXIVBJM:&tbnh=160&tbnw=144&usg=__xEkDYFkzzItMLOj4-9PKLTR1m4Y%3D&vet=10ahUKEwia9vX5oOXXAhWDGZQKH6PCk0Q9QEIKzAA..i&docid=-58ZEXa6PoarsM&client=firefox-b&sa=X&ved=0ahUKEwia9vX5oOXXAhWDGZQKH6PCk0Q9QEIKzAA

ADDENDUM - a request for an assisted death is generally a rational choice.

The following article is quite recent and relevant to the voluntary assisted dying debate. I submit that the entire article should form part of the INQUIRY evidence.

Pathologizing Suffering and the Pursuit of a Peaceful Death

BEN A. RICH (Professor and Chair, Bioethics University of California–Davis School of Medicine Sacramento, California)

Abstract: The specialty of psychiatry has a long-standing, virtually monolithic view that a desire to die, even a desire for a hastened death among the terminally ill, is a manifestation of mental illness. Recently, psychiatry has made significant inroads into hospice and palliative care, and in doing so brings with it the conviction that dying patients who seek to end their suffering by asserting control over the time and manner of their inevitable death should be provided with psychotherapeutic measures rather than having their expressed wishes respected as though their desire for an earlier death were the rational choice of someone with decisional capacity. This article reviews and critiques this approach from the perspective of **recent clinical data indicating that patients who secure and utilize a lethal prescription are generally exercising an autonomous choice unencumbered by clinical depression or other forms of incapacitating mental illness.** (My emphasis)

Conclusion of this article

In reviewing the ground that we have covered, some perspective is important. If the experience with the ODWDA teaches us anything, it is that a very small subset of terminally ill patients seek a lethal prescription, and an even smaller group actually utilize that option. Consequently, the impact of permitting this option has not had a profound impact on how people confront terminal illness or how most patients are cared for by physicians. Like abortion, legalizing lethal prescriptions for the terminally ill has generated a level and intensity of bioethical controversy that is markedly disproportionate to the number of persons actually impacted by it. Nevertheless, confronting these issues compels us to elucidate the core values in medicine and the limits, if any, on the well-recognized duty to relieve suffering.

The increasing involvement of psychiatry in palliative care has, up to this point, been a mixed blessing, for reasons I have sought to illuminate. To the extent that suffering associated with terminal illness is viewed as something that the patient must work through with a therapist, it is removed from the domain of natural human experience. By the same token, to the extent that we think of suffering as an often inescapable dimension of life's final chapter, physicians are absolved of their professional responsibility to alleviate it. Either way, the suffering patient is caught in the middle. **One could understandably conclude that those who seek to expand the range of options for addressing terminal suffering, up to and including legalization of lethal prescriptions and recognition of a professional obligation to offer sedation to unconsciousness as a legitimate palliative option, are (properly in my view) focused on the plight of the patient, whereas those who would pathologize suffering and strictly curtail the patient's ability to determine that she has had enough of suffering and wishes to pursue a peaceful death are obsessively and inappropriately focused on the plight of the physician.** (My emphasis)

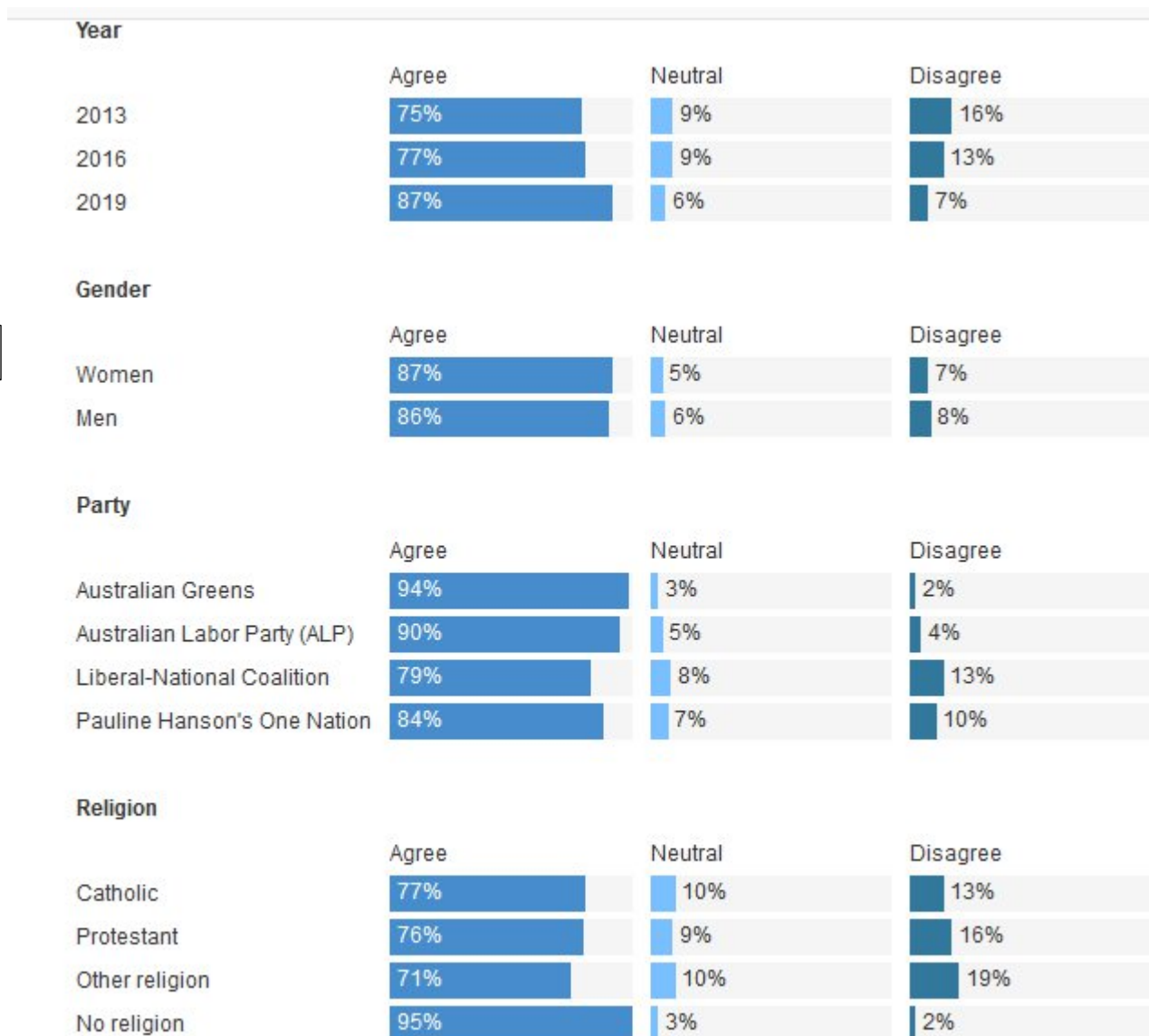
Ref: Cambridge Quarterly of Healthcare Ethics (2014), Page 1 of 14.

© Cambridge University Press 2014.

doi:10.1017/S0963180114000085

Strong support for voluntary assisted dying for the terminally ill across gender, party and religious lines. Vote Compass 2019.

Proportion of Vote Compass responses to the statement: "Terminally ill patients should be able to end their own lives with medical assistance."



Based on 450,479 respondents to Vote Compass between April 10 and May 5, 2019

The following submission was made initially to the ACT Inquiry into End of Life Choices. However it is equally applicable, perhaps more so, to this NSW Inquiry, and it is therefore included here as a Supplementary Submission, with permission.

Supplementary second submission by Tim Edwards and Ian Wood, to be read and considered in conjunction with the main submission on behalf of the group Christians Supporting Choice for Voluntary Euthanasia by Ian Wood. Dated 10.1.2018

To the ACT Inquiry into End of Life Choices

My name is Tim Edwards and I have mesothelioma. I have been through the four different chemotherapies – none of which have impeded the cancer since diagnosis in January 2017. In October 2017 I was advised that my illness is terminal in the short term.

Further treatment is futile. I have an estimated 3 months to live as the cancer takes over my entire chest.

I have accepted this as a fact, but I can speak from extensive research that the end stages of this disease can be horrific. Basically we are dealing with unimpeded growth of the cancer in my lungs to the extent that it takes over the other vital organs in my chest.

I have two treatment options. I can reduce the increasing pain using high strength pain relief (opioids) to the extent that pain is not the major problem. But with the reduction in pain I loose control of all other functions and become a frail, drug addled, bed-ridden burden on my family and myself. The pain becomes my failure and is heavily transferred to my loved ones. They do not need to suffer in this way and nor do I.

Or I can accept the pain by reducing the use of pain relief and loose control of my life in all regards. I would have to rely on others to decide how to manage the end of my life whether it is starvation or dehydration or judicious use of pain relief administered by others. But do not misunderstand, in the final stages they will control my death, no one else.

I have worked hard and long to serve the national interest in better environmental outcomes. I have been handed a reduction in my life by about 20 years through no fault of my own. I do not deserve to be forced to suffer the last three months of my life, nor does my family. I am not choosing suicide. I am choosing to make the last weeks of my life consistent with a life well lived under my direction and with the full understanding and support of my family.

Essentially I know that being able to rationally make a choice to access a medically assisted death would provide great comfort to me. I have a loving wife and family who understand and support my decision.

I was greatly disappointed when the NSW Parliament upper house defeated the NSW Voluntary Euthanasia Bill by one vote. The passing of this Bill would have meant much to me, even though it would not have been in time for me to make use of the legislation.

I have visited my local NSW MP, Jai Rowell, together with Ian Wood, since the defeat of this Bill, to explain my position and why I desire this compassionate end of life choice.

I am encouraged by the fact that Victoria, at almost the same time, did manage to pass their Voluntary Assisted Dying Bill. This does show that at least one Australian Parliament is capable of sifting out the facts and ignoring the scaremongering!

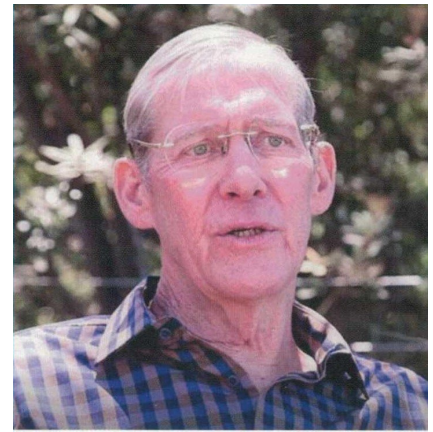
I have read the submission prepared by Ian Wood and endorse the content. I urge this ACT Inquiry to especially read the case studies in that submission. Please approach these cases with true empathy, and also place yourself, at least hypothetically, in my shoes as I am facing a similar real life and death situation. I do not have a choice between one or the other, but wish for a choice between two ways of dying from the same terminal illness.

I sincerely ask the ACT Inquiry into End of Life Choices to reach a conclusion that has the option for people in my situation to request and be granted Voluntary Assisted Dying.

Tim Edwards
Bowral 2576

POST SCRIPT by Ian Wood

Bowral resident, Tim Edwards, died on 16 February 2018 from his mesothelioma. Tim had been a passionate advocate for assisted dying. He endured many rounds of chemo, but as his cancer spread around his heart and lungs he was in a great deal of pain, could barely eat or drink, nor breathe without oxygen. His loving family say he suffered terribly in his last days, despite palliative care, leaving them devastated and angry. His disease was terminal - an assisted dying law would have given Tim the compassionate choice to be in control - to die well at a time of his choosing, rather prolong the agony of his slow death.



Tim Edwards: "Surely I have the right to make my end as good as it can be?"
- 21 January, 2018

Also very relevant as evidence to this NSW Legislative Council Inquiry is the following letter that I, Ian Wood wrote to our then MP for Wollondilly, Jai Rowell, responding to questions Mr Rowell raised during the meeting with Tim and myself.

Dear Jai (and Tracey too)

Thank you for listening to Tim Edwards, outlining why, given his terminal illness of mesothelioma, and the prognosis, he very rationally would like the legal option of an assisted death that he could use at a time of his choosing.

It seemed there are essentially two areas of concern to you that need to be addressed before you can bring yourself to support this issue. Note that by 'support' I mean that you agree to empower a person such as Tim with access to the required prescription - not that you support to a degree that you would want it for yourself. A person such as Tim is entitled to your empathy - not just your sympathy.

One area is the variety of opinions you say that have been expressed to you from your Electorate. I did forget to point out that the on-line poll conducted by local papers showed overwhelming support for VAD. The last time I checked on 24.10.17, the vote was 356 in favour of VAD and only 32 votes against (92% yes vote!) I also note that it can be relatively easy for a church whose doctrine opposes choice, to persuade members to say "Jai please do not support."

I did attend three forums organised by MPs to explain the legislation. Those opposing VAD had every opportunity to be present and voice their objection - yet there was an overwhelming majority of support and endorsement for VAD indicated at every meeting. Yes, there were some questions of concern raised, but these were answered to the satisfaction of the questioner. So to sum up this aspect, a variety of opinions is not a valid reason for denying Tim his choice. People who are against it simply do not ask for the prescription.

I do also point out that in Oregon, USA, for example, with VAD for over 20 years now, there are many people saying that they did oppose initially for various reasons, but their fears have been proved groundless and they now support.

The other area you both expressed concern about was elder abuse, and the extrapolation of this to Voluntary Assisted Dying Choice.

To my thinking there are three types of abuse to consider here (I will ignore here the abuse perpetrated by pedophile priests on young children often leading to the suicide of the innocent victim - ironically by the same churches who oppose VAD choice for others!)

There is the abuse that you are very aware of - especially financial, but also intimidation, physical or psychological abuse etc. I read in The Senior there is to be yet another conference of experts discussing this next February in Sydney.

There is what we currently believe is acceptable in our nursing homes. Where a well meaning family or government official decides that a person can no longer look after themselves at home, so for their 'safety' transfers them to an institutionalised setting. This can involve giving up every freedom. Formerly they could eat when they were hungry- now they are often force fed. They could go to the toilet when they felt the urge - now they may have to wait in their own excrement for staff to change their nappy. They could walk outside if they wished - now they are kept behind a coded door in case they wander. I have attached two docs setting out what many would call abuse here in more detail.

Finally there is the abuse of what the Canadian Supreme court declared is the basic human right of individual to self determination - the denial of our right to have this choice in how we may die.. We make decisions throughout our lives that affect our health, our lives and our well-being. Yet when it comes to our dying for some reason our MPs in Australia, with the exception now of Victoria, have assumed they have the right and the power to control and restrict the way a person may choose to die, together with our palliative care folk.

Your concern is that unscrupulous family may coerce a person into requesting an assisted death. As I pointed out, the family first must somehow coerce the person into having a terminal illness with suffering the patient finds intolerable, and wait until they have less than a predicted 6 months to live. Forcing someone to become terminally ill is difficult!! You then assume that this family would risk public exposure by getting the person to make 3 separate applications to two different doctors, one being a specialist in the relevant terminal illness, and witnessed by independent witnesses, when the family are not present to exert any pressure. These doctors have to certify that the patient has decision making capacity. This unscrupulous family then have to wait while the doctor applies for a Permit to Prescribe. This application is assessed by the Secretary (Department Head of Health and Human Services) to ensure all boxes are ticked and all information is supplied. There are 137 pages of rules and regulations in the Victorian Act! Once the Doctor has the Permit he writes the prescription. The pharmacist must hand the medication over to the patient with appropriate labelling and giving appropriate warnings, and send copy of the Rx to the Review Board. All procedures are under the watch of this Review Board. Every step involves the risk the family would get caught out. The family risk 5 years imprisonment if caught. For the complete Act-
[http://www.legislation.vic.gov.au/Domino/Web_Notes/LDMS/PubStatbook.nsf/f932b66241ecf1b7ca256e92000e23be/B320E209775D253CCA2581ED00114C60/\\$FILE/17-061aa%20authorised.pdf](http://www.legislation.vic.gov.au/Domino/Web_Notes/LDMS/PubStatbook.nsf/f932b66241ecf1b7ca256e92000e23be/B320E209775D253CCA2581ED00114C60/$FILE/17-061aa%20authorised.pdf)

An unscrupulous family would be far more likely to just have the person placed in a nursing home, at no risk to themselves, and once the person is incarcerated, they access the finances, sell the possessions and home etc, rather than attempt to go through this highly regulated.VAD procedure.

The lack of an Assisted Dying law means that the elderly are subject to other scams. Eg Bill Alcock, a 92yo War veteran emails me with: *Hi Ian, There is just no way I will be confined in a nursing home indefinitely suffering from dementia, Alzheimer's, incontinence or the like - to give me peace of mind I have been trying to get some Nembutal, from china but have been scammed out of \$3,000. - What is you opinion of the nitrogen tank, it appears to me to be a reliable alternative? Kind regards Bill.*

One of the reasons why some palliative care doctors oppose VAD is that at present in the worst case scenario of suffering they can use terminal sedation. Place the patient in a coma until they die slowly from dehydration or starvation. This procedure is unregulated, the doctor simply makes a decision, and they would like to keep it this way. Yet putting the person quickly into a coma then having them die within minutes is against the law. This is both irrational and inhumane.

I urge you to please study the comments included in my Presentation Folder given to you quoting from numerous studies that continually determine that concerns of elder abuse and coercion, as related to VAD, while an understandable question to raise, are not borne out by any of the evidence available.

Jai. It is my hope that you will consider this whole issue further in the near future, You did offer to meet again with Tim. This would have to be as soon as possible, given that the progression of mesothelioma is very unpredictable. I have a video here of Trish Doyle, the MP for Blue Mountains, publicly stating to her local resident Anne Gabrielides, who is dying from MND, that she would support VAD when a Bill was debated in the NSW Lower House.

<https://www.facebook.com/trishdoylebluemtns/videos/1558043694258077/> It would be a fitting tribute to Tim for you to make a similar commitment.

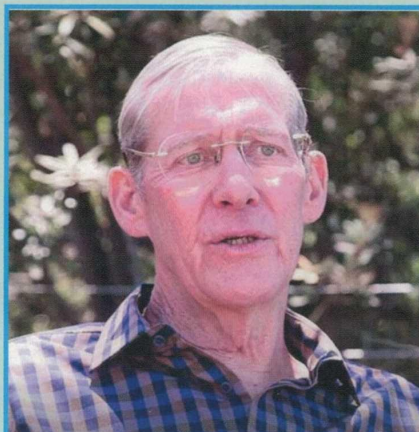
Dying from a terminal illness - a family perspective

by Jessica Edwards

Tim Edwards, or 'Big Man' as I called him, was my father and a daily reminder of the person I am and the person I should strive to be. Many people who met Tim briefly thought him to be a cynic. In truth he was an idealist. After many years as an accomplished professional, Tim spent the last decade of his life working tirelessly at educating people on climate change and chipping away at the political framework that has for years prevented the adoption and implementation of an effective climate change policy in Australia and globally.

Tim was a passionate but likeable man - though spending time with him often felt like getting caught in the intellectual equivalent of a spin cycle. He was a great Dad and mentor to all four of his children (myself, Matt, Andy and Chris) and along with his 'partner in crime', my mother Jan, led a life to be admired.

Tim Edwards passed away on 16 February 2018, after fighting mesothelioma to the bitter end for the better part of two years. He acquired 'meso' (as he called it) from being exposed to asbestos during a summer job when he was 18. Almost five decades later the disease had taken over his body and he could not breathe. I watched him take his last peaceful breath at home with his family and ever faithful dogs.



Tim Edwards: "Surely I have the right to make my end as good as it can be?"
- 21 January, 2018

Throughout his disease Tim suffered from depression, extreme breathlessness and a never-ending list of painful symptoms from the disease and from multiple rounds of chemotherapy. In the final months Tim was in a great deal of pain, could barely eat or drink and could not breathe or function without the oxygen machine. His heart and lungs were surrounded by cancer. He had multiple pulmonary embolisms and a plethora of secondary medical issues.

Tim approached death as he approached everything in life, practically and with extreme clarity of mind. He was an outspoken advocate for assisted dying and believed strongly in having the right to choose when and how he ended his life. The passions of Tim's life were his family, his dogs, the outdoors and changing the world for the better. His disease progressed to a level that these passions were taken away from him. It was at this point that Tim should have been entitled to call it quits.

His disease was terminal. He had only two choices remaining to him – dying well or dying horribly.

In the end, Tim's position on assisted dying worked strongly against him, with his palliative care doctors and nurses, in my view, undertreating him and one of them repetitively lecturing a grieving family about the illegality of assisted dying (even the day before he passed away). In the final days of his life, we took turns sitting with him and watching him sleep. At one point he woke up, looked at me and asked "when are they going to let me go". All I could do was look at him in tears and say "I don't know – this is not the way it should be".

When Tim passed away the first feeling I had was not sadness, but immense relief. Relief that his suffering was over. Relief that he would no longer be poked and prodded by the palliative care staff. Relief from a feeling that we had somehow failed him by letting him suffer the way he did in his final days.

I believe that if Tim had been given the opportunity to choose his time and his way, those final days would have been drastically different. My hope for the future is that for all those families who face a similar fate, the NSW Government gives them the opportunity to do it with dignity and with the least amount of pain and suffering possible.

Dying with Dignity NSW is an advocacy organisation pursuing a change in the law that will enhance choice at the end of life. We seek legislation that enables competent adults, experiencing unrelievable suffering from a terminal or incurable illness, to receive medical assistance to end their life peacefully, at a time of their choosing.

JOIN US NOW.

website www.dwdnsw.org.au

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