Inquiry into End Of Life Choices

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES
(LEGISLATION AND REFERENCES)

July 2015
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VEP (NSW) Submission – Inquiry Into End Of Life Choices 2015
Summary

The Voluntary Euthanasia Party (VEP) was created in 2013 to try to provide the choice and dignity that current legislation is denying terminally and incurably ill Australians. Although our party hopes to provide a clear political outlet for the overwhelming public support for voluntary assisted dying, in order to send a strong message to the two major parties, we are more than happy to support any inquiries, or bills, initiated by other political parties, if it brings us closer to this much needed law reform.

The NSW branch of the Voluntary Euthanasia Party was registered in 2014 and currently has over 1750 members. This submission is produced on behalf of the VEP (NSW).

We are pleased that the ‘Inquiry into End of Life Choices’ will examine all aspects of end of life choices, however, we strongly believe the most important consideration for your committee must be the legalisation of voluntary assisted dying. If individuals facing an inevitable death are not given the choice of a peaceful and dignified death at a time of their choosing, we will never remove their fear and these individuals will never be able to make the most of whatever time they have left. As a society, if we do not legalise voluntary assisted dying, we can expect to see an increasing number of people committing suicide, often prematurely and violently, in order to avoid the terrible end stages of their illnesses.

Members of VEP (NSW) believe it is important to create a bill that includes all the necessary safeguards, however, we also believe that any new law should be workable so that the intention of providing choice and dignity for terminally or incurably ill Australians can be achieved and individuals can gain more control over the manner and timing of their deaths.

Like most advocates for voluntary assisted dying, VEP (NSW) supports the provision of high quality palliative care, however, even the best palliative care cannot guarantee that some patients won’t be forced to endure unrelievable suffering at the end of their illness. For this reason we believe both options should be made available and see no reason why they can’t be compatible.

While Advanced Health Care Directives have gone some way in assisting a person to exercise their preferences for the way they want to manage their end of life, without the option of an assisted death being included in AHCD’s, they cannot ensure there won’t be suffering at the end of life.

Over the past two decades there have been many bills introduced into state parliaments across Australia, yet none have passed into law. With respect, we would like committee members to be aware that some submissions from opponents of voluntary assisted dying, during previous inquiries, and even some of those already submitted to this inquiry, have included statements based on data that has been misrepresented. We would like to recommend that any reports or data that is referenced in submissions should be independently interpreted and verified.

In this submission we have endeavoured to provide a comprehensive overview of the issues surrounding the legalisation of voluntary assisted dying. We have provided references to recent reports and outlined the most recent developments from overseas.

Finally, we appreciate the opportunity to make this submission and as representatives of the Voluntary Euthanasia Party (NSW), Dr David Leaf and myself would be happy to appear at a public hearing if invited.

Ms Shayne Higson
Voluntary Euthanasia Party (NSW)
State Convenor
**Addressing the Terms of Reference**

(1) Assess the practices currently being utilised within the medical community to assist a person to exercise their preferences for the way they want to manage their end of life, including the role of palliative care.

While a number of practices have been implemented to assist a person to exercise their preference for the way they want to manage their end of life, one important preference continues to be denied and that is, the preference to have a dignified and peaceful death without suffering, at a time, place and manner of your choosing. To allow this preference would be consistent with the modern approach in medicine of Patient-Centred Care.

Like the vast majority of Australians, we believe that if someone is dying from a terminal or incurable illness, with no hope of recovery, is experiencing unacceptable pain or suffering and has decision-making capacity, they should have the right to request medical assistance to end their life. In other words, we believe they should have the choice to go a little earlier, in order to achieve a peaceful and dignified death surrounded by the people they love.

**Reasons to legalise voluntary assisted dying**

There are many reasons why voluntary assisted dying (VAD) should be legalised including:

1) **Palliative care cannot always alleviate all suffering.**

We definitely support the provision of high quality palliative care, however, even the best palliative care cannot guarantee that some individuals won’t be forced to endure unreleivable suffering at the end of their illness.

In June 2014 the NSW Health Minister, Jillian Skinner, said on the *7.30 Report* that, “there would be no need for voluntary assisted dying if people just have access to good palliative care”. However, this is simply not true.

In 2013 the Council on the Aging (COTA) conducted a survey of people aged 50 years and over. As part of this survey respondents were asked to communicate their views about a range of end of life issues, including palliative care. Just over a quarter (26.3%) of those who knew or had known someone receiving palliative care did not feel that it provided enough comfort towards the end of the person’s life. This is a significant proportion and it shows that palliative care, with its current practices, should not be the only option.

In May 2015, Palliative Care Australia (PCA) released data from its own survey. According to PCA President, Professor Patsy Yates, the survey showed that while almost 70% said they were satisfied or very satisfied with the standard of care, almost a third (31%) were ambivalent about or unhappy with their loved one’s care. According to Professor Yates, ‘that would translate to about 50,000 Australians each year who feel they did not receive satisfactory care’. She went on to say, “Our survey also illustrated a generation gap when it came to concern about care. Younger people were more likely to be unhappy with the care their loved one received, with more than half saying they were not satisfied with care”.

The results from both these surveys demonstrate that despite the best of palliative care, the truth is, there is some suffering that cannot be alleviated.

These surveys do not, of course, capture the opinions of patients and their carers who did NOT participate in Palliative Care. For many of them, the choice was clearer - make other arrangements, such as DIY suicide or quietly allow a sympathetic doctor to assist them. That means, of course, that the 26% - 31% dissatisfaction rates are likely to be higher in reality.
Palliative Care Australia (PCA) has, on a number of occasions, acknowledged the limitations of palliative care and that is presumably why they have taken a neutral stance when it comes to the issue of voluntary euthanasia.

In a policy statement from 2006 they said;

"While pain and other symptoms can be helped, complete relief of suffering is not always possible, even with optimal palliative care."

Policy Statement (2006), Palliative Care Australia

In 2011 Dr Scott Blackwell, the CEO of Palliative Care Australia said,

"Palliative Care Australia neither supports nor opposes voluntary euthanasia. In some ways I think let's legislate it and let it just find its place." (August 2011) 3.

In their current position statement on Euthanasia and Physician Assisted Suicide, PCA states that ‘Euthanasia and physician assisted suicide are not part of palliative care practice’. 4. This is true in Australia because it is currently illegal, however, it doesn’t have to remain that way.

In the European countries and American states, where voluntary assisted dying is legal, palliative care and assisted dying are closely intertwined and are certainly not mutually exclusive. 5.

In Belgium, the advocates for legal voluntary euthanasia have been amongst the strongest supporters of palliative care and the two are bound together in legislation and regulations. 6.

In Oregon, where voluntary assisted dying has been legal since 1998, the vast majority of individuals who use that state’s dying with dignity legislation are enrolled in hospice care. In 2014, 93% were enrolled in hospice care and 89.5% of them died at home. 7.

There is no medical specialty that can have all the solutions, for all patients, all of the time. Palliative Care is no different, yet this is what many opponents of voluntary assisted dying try to claim. Experienced clinicians know that some patients do not want to be FORCED into the palliative care pathway, preferring to manage their own death, without the dependency and indignity that the final months or weeks demand. For them, death is not the worst outcome.

2) Offering voluntary assisted dying is compassionate.

Like most Australians, we believe it is cruel and inhumane to force people to endure pointless suffering at the end of their lives and so voluntary assisted dying should be legalised on compassionate grounds.

One of the most vocal organisations to oppose voluntary assisted dying, The Australian Christian Lobby (ACL), has in its vision statement that they aim to ‘foster a more compassionate, just and moral society’, yet they continue to block law reform. 8.

Unfortunately they have a different view on suffering to most. If you access the ACL website you can listen to audio and read articles and comments about voluntary euthanasia. In one report Bioethicist and Palliative Care Specialist, Dr Megan Best said;

"You have to look behind the mentality that accepts euthanasia and they just don’t think that suffering is something that should be tolerated and they don’t see that there is any benefit in someone suffering."

When asked by the interviewer what the benefits of suffering were, Dr Best went on to say;
“For the Church there are lots of benefits to suffering such as strengthening faith and developing perseverance which of course are not going to be at all impressive for the general public.”

Dr Best is probably correct in assuming that the general public would not be impressed because we believe most people would struggle to see any benefit from prolonged suffering.

But the Australian Christian Lobby does not speak for all Christians. All recent polls show that a significant majority of practicing Christians (between 70% - 88%) support giving a terminally ill patient the choice of a medically assisted death. An organisation called Christians Supporting Choice for Voluntary Euthanasia was formed in 2009 and its Statement of Belief says:

“We are Christians who believe that, as a demonstration of love and compassion, those with a terminal or hopeless illness should have the option of a pain-free, peaceful and dignified death with legal voluntary euthanasia.”

We know that family members and medical staff can be deeply traumatised when someone who is experiencing unrelievable suffering begs for relief when none can be provided. As a compassionate society, we need to offer the choice of voluntary assisted dying to prevent this needless suffering at the end of life.

3) Legalisation of voluntary assisted dying is associated with an improvement in palliative care.

In overseas jurisdictions where voluntary assisted dying has been legalised, there have been improvements in the provision of palliative care. In Oregon, for example, nurses who were asked to rate doctors on their palliative care skills before and five years after the legalisation of voluntary assisted dying, noted significant improvements in care on five of six rated dimensions. The sixth one was unchanged.

Research has also shown that both Belgium and the Netherlands have good palliative care by international standards and are among the countries with the best availability of palliative care in Europe. A 2008 study concluded that the movement to legalise doctor-assisted dying in Belgium had promoted improvements to end-of-life care more generally, and that the existence of good palliative care made legalisation ethically and politically acceptable.

In the most recent study (Feb 2015) titled ‘Does legal physician-assisted dying impede development of palliative care? The Belgian and Benelux experience’, Chambaere and Bernheim, once again concluded that palliative care had been ‘boosted’ and ‘furthered’ in these jurisdictions.

Some opponents of voluntary assisted dying argue that, if the practice is legalised, it should be kept outside medical practice, however, we believe this would be a mistake. Australia has a well-established medical discipline that specializes in the care of individuals who are dying. If these palliative care specialists truly care about their patients, and respect their autonomy, they should be willing to support the choice of a voluntary assisted death, if the patient reaches a point where they would prefer a peaceful and dignified death on their own terms.

Studies from overseas support this view. For example, in 2009, the College of Physicians in Quebec released a report entitled Physicians, Appropriate Care and the Debate on Euthanasia, calling for an open discussion on the question of euthanasia in the context of end-of-life care. The report stated that if voluntary euthanasia is to be permitted (which it will be in 2016 in Canada), it should be conducted in the context of care and considered a medical act.

We are confident that there would be plenty of palliative care professionals willing to provide the option of voluntary assisted dying if it were legalised, and far from undermining the doctor / patient relationship, we believe it would actually enhance it.
4) Voluntary assisted dying laws work safely and effectively.

There is now a large body of evidence from overseas that demonstrates that voluntary assisted dying laws work safely and effectively. In Europe voluntary assisted dying is legal in Switzerland, the Netherlands, Belgium and Luxemburg. In America, it is currently legal in five states - Oregon, Washington, Montana, Vermont and New Mexico.

The Death with Dignity Act has operated in Oregon since 1998 and there has been no evidence of abuse over that 18-year period. Former Oregon Governor, Barbara Roberts has said; “Oregon has proven what happens when you make the law and compassion come together.”

Opponents try to argue that it is impossible to protect the vulnerable and that these laws could be abused but we strongly disagree. All the bills that have been introduced over the past two decades, in the various state parliaments across Australia, have all included stringent safeguards.

Opponents often point to jurisdictions, such as Belgium and the Netherlands, to claim that these laws can be abused, however, what they fail to point out is that the criteria for accessing voluntary assisted dying varies in different jurisdictions.

The Belgian Act on Euthanasia of May, 28th 2002, for example, does not require that a patient has a ‘terminal illness’. It states:

“the patient is in a medically futile condition of constant and unbearable physical or mental suffering that cannot be alleviated, resulting from a serious and incurable disorder caused by illness or accident.” 17.

The same is true for the Netherlands, where their law states that the patient’s suffering has to be ‘lasting and unbearable’.18. Both these European laws include a number of safeguards and, like Oregon, there have been no prosecutions for abuse of their laws.

The most recent report from the Federal Committee on Oversight and Enforcement in Belgium, covering the years 2012-2013, revealed that, just like in the previous 12 years, the Commission has not sent a single suspected case of abuse to the courts.19.

5) Control gives peace of mind, and sometimes that is all that is needed.

Voluntary assisted dying laws provide reassurance to people with terminal or incurable disease that they will not be left to suffer the pain and indignities of a traumatic death. Having control gives peace of mind and as the experience from Oregon has shown, sometimes that is all that is needed. Of the 155 patients for whom Death With Dignity Act prescriptions were written during 2014, only 94 (60.6%) ingested the medication.20.

We have also seen this demonstrated here in Australia. Last year, Peter Short, a terminally ill Victorian, was able to make the most of the last months of his life because a compassionate doctor, Rodney Syme, had agreed to supply him with the drug Nembutal, if it was required to achieve a peaceful death at the end stage of his oesophageal cancer. Not only did Peter live life to the full without fear, he also used his final year to advocate for voluntary assisted dying law reform. In the end, Peter did not use the Nembutal, however, knowing he had control meant he had a better quality end-of-life experience than those without that choice.21.

Jay Franklin is another Victorian who now has control, having qualified for an assisted suicide through Dignitas in Switzerland. Although he is still suffering terribly, being given the ‘green light’ by Dignitas has made Jay more resilient. He too is now an advocate for voluntary assisted dying and he even ran as a candidate for the Voluntary Euthanasia Party in the last Victorian state election.
6) Legalising voluntary assisted dying does not threaten the weak and vulnerable.

Opponents of voluntary euthanasia often muddy the waters with words and concepts that evoke really bad connotations. For example, at a recent presentation in Sydney, titled 'Death Talk', Professor Margaret Somerviille continually referred to the ‘killing’ and argued that the disabled, the frail, the elderly and even the lonely would be at risk of being euthanased without consent if assisted dying laws were introduced. To support this type of scaremongering, opponents often use wilful misrepresentations of the facts, however, if you investigate the original reports the truth becomes apparent.

Numerous independent audits of existing voluntary euthanasia laws from several jurisdictions have shown them to be safe. The “slippery slope” does not exist. Vulnerable people are less likely to take advantage of voluntary assisted dying.

Rates of assisted dying in Oregon and in the Netherlands showed no evidence of heightened risk for the elderly, women, the uninsured (inapplicable in the Netherlands, where all are insured), people with low educational status, the poor, the physically disabled or chronically ill, minors, people with psychiatric illnesses including depression, or racial or ethnic minorities, compared with background populations. The only group with a heightened risk was people with AIDS.22.

In Canada the Royal Society of Canada Expert Panel reported: “There is no evidence from the Netherlands supporting the concern that society’s vulnerable would be at increased risk of abuse if a more permissive regime were implemented [in Canada] . . .What has emerged is evidence that the law is capable of managing the decriminalisation of assisted dying”. 23.

7) Rates of assisted dying without an explicit request go down when VAD is legalised.

Opponents of voluntary assisted dying often try to imply that there is widespread ‘killing of patients without their explicit request’ in countries such as Belgian. However, all the data shows that not only are the rates of ‘life-ending acts without explicit patient request’ continually dropping in Belgium, they are also much lower than in countries without legalised voluntary assisted dying, including New Zealand 24 and Australia. In 1999, an Australian survey showed that more than a third of surgeons surveyed reported giving drugs with an intention to hasten death, often in the absence of an explicit request. 25.

Opponents often seize on the reports from Belgium, that quantify the number of ‘life-ending acts without explicit patient request’ trying to imply that these patients are being ‘euthanased’ against their will, when, in fact, ‘these acts predominantly involved the use of opioids’ which are rarely used in euthanasia’.26. In other words, these acts are the same as those that are carried out in Australian hospitals and nursing homes everyday and are done on compassionate grounds.

8) There is a more humane way to die.

Under current Australian laws there are limited options available for individuals wanting to avoid an unpleasant, painful or undignified death.

Some choose to obtain medication illegally, risking confiscation or prosecution and at significant personal expense. If they are successful in obtaining their Nembutal, they then have to die alone for fear that loved ones left behind could be prosecuted for assisting.

Others are so desperate they resort to more violent forms of suicide, which is an absolute tragedy. Traumatic for the individual but also for the others involved - police, paramedics, onlookers and, of course, family and friends.
Even under medical care the proper relief of suffering does not always occur because doctors fear they will be prosecuted for assisting if someone complains.

Even, terminal sedation, that is sometimes possible within a palliative care context, cannot compare to voluntary assisted dying when looking for the safest or most effective way to relieve suffering at the end of life and provide a peaceful and dignified death.

We don’t need to imagine what it would be like if a voluntary assisted dying bill was passed into law because we have plenty of evidence from overseas.

An article published in Oregon in 2014 told the story of a man named Ben Wald who chose to hasten the end of his life with a doctor-prescribed lethal medication through Oregon’s Death with Dignity Act. The doctor who prescribed the medication, Dr David Grube said that after practicing for many years, he had seen that in some cases doctors cannot prevent suffering and he said:

“In medical ethics, the top value is patient autonomy. The patient should be allowed to choose what they want, not what the doctors want.”

It is worth reading some of the article on Ben Wald’s death under the Death With Dignity Act to see that there is a more humane way to die.

There was nothing maudlin about Ben Wald’s death at home in Kings Valley.

“Once he learned that he was going to be given the choice to end his life, he relaxed,” his wife Pam says.

Ben and Pam invited 10 of their closest friends, along with the Compassion & Choice volunteers, to join them on the evening of Friday, May 4, 2012.

“He was in bed,” Pam says. “Prior to taking the medication, he spoke to each of them individually. We sang songs.” And one of the friends read a poem.

Riggs, the volunteer Compassion & Choices nurse, gave Ben medication to prevent vomiting.

Then Riggs mixed the powdery lethal medication — 1,000 milligrams of the barbiturate pentobarbital — with orange juice and handed it to Ben. He drank it himself, as the law requires.

“His last words to everyone,” Pam says, “were ‘Thank you.'”

Ben fell asleep within five minutes. Two hours later, as Pam was holding his hands, Riggs tapped her on the shoulder to say that Ben had died.

“I’ll never forget the experience,” Pam says. “Anybody who is at that point in their life has a right to explore this and not be denied the opportunity to take advantage of it.

“Making this happen for Ben allowed me to give my husband my last gift of love.”

9) Many jurisdictions around the world are moving forward with VAD law reform.

There have been a number of developments around the world so far in 2015 in the campaign to legalise voluntary assisted dying.

- Canada - In February 2015, the Supreme Court of Canada overturned a 20-year ban on physician-assisted suicide and said it would allow voluntary assisted dying ‘in the case of consenting adults who are suffering intolerably from a severe and incurable medical condition, though the illness does not have to be terminal’. The decision was suspended for 12 months to allow politicians an opportunity to enact new rules surrounding the issue.
• **Colombia** – In April 2015, 18 years of legal limbo ended as physicians got the final go-ahead for voluntary euthanasia with a new regulatory protocol. Colombia is the first country in South America to legalise voluntary assisted dying.  

• **South Africa** – In late April 2015, an order was granted by the High Court in Pretoria allowing a terminally ill cancer sufferer to commit suicide with a doctor’s help, acknowledging that continuing to live in pain and suffering infringed his constitutional right to dignity. Judge Hans Fabricius then recommended that Parliament now seriously consider introducing a bill to legalise voluntary euthanasia.  

• **America** – In June 2015, the *End of Life Option Act* was passed by the California Senate by a vote of 23 to 14. If the measure wins approval by the Assembly and Gov. Jerry Brown, California will join five other states in legalising assisted suicide for dying patients. Draft bills, ballot initiatives and court cases are progressing in 20 more American states in 2015.  

• **Britain** – In June 2015 a Private Member’s Bill on assisted dying was tabled in the House of Commons. This Bill will essentially be the same as the *Assisted Dying Bill* introduced by Lord Falconer, which made historic progress through the House of Lords last year, but ran out of time before the 2015 General Election. Rob Marris MP, came top in this year’s ballot for backbench legislation, which means that a Second Reading debate for his Bill is due on the 11th September 2015. With an influx of new, enthusiastic MPs, *Dying In Dignity* in the UK are optimistic that there is greater support in the Commons for assisted dying than ever before.  

10) Australians and others around the world want change.  

Repeated polling over 25 years has consistently reported overwhelming support for the legalisation of voluntary assisted dying. According to a Newspoll (December 2012) survey, 82.5% of Australians are in favour of allowing voluntary euthanasia.  

In June 2015, the well-respected British magazine, *The Economist* asked Ipsos MORI to survey people in 15 countries on whether doctors should be allowed to help patients to die, and if so, how and when. Out of the 15 countries surveyed only Russia and Poland showed minority support. Overall, the survey found strong support across America, Western Europe and Australia for allowing doctors to prescribe lethal drugs to patients with terminal diseases. In 11 out of the 15 countries they surveyed, most people also favoured extending doctor-assisted dying to patients who are in great physical suffering but not close to death.  

![Survey Results](image-url)
11) Support for voluntary assisted dying has increased in jurisdictions where it has been legalised.

Support for voluntary assisted dying has grown within jurisdictions that have legalised the practice. According to a recent study in Oregon, 80% of registered Oregon voters support the law — an increase of 20% from the 1997 referendum on this legislation.\(^{35}\)

According to a report from Belgium, acceptance of euthanasia amid medical professionals has increased from 78% in 2002, when their law was introduced, to over 90% in 2009.\(^{36}\)

The evidence has shown that once the choice of a voluntary assisted death is legalised, individuals realise that their fears were unwarranted and support increases.

12) The religious beliefs of some should not be imposed on all.

Australia has a diverse faith, and non-faith, community and is increasingly a secular society. Strong opposition to voluntary assisted dying by religious groups, or religious politicians, based on their belief in the sanctity of life, is not a justification for denying choice for those who do not share that belief.\(^{37}\) To deny voluntary assisted dying for all, on the belief of some, is extremely unfair.

According to the *Australia 21 Report* titled ‘The Right To Choose An assisted Death: Time For Legislation?’ (2013), ‘there is now wide acceptance that human life is not an absolute good and that notions of compassion and autonomy can carry greater weight in some circumstance.’\(^{38}\)

As has been pointed out in the submission from ‘Christians Supporting Choice For Voluntary Euthanasia’, many Christians are moving away from the more traditional position and are advocating for a more humane approach to voluntary assisted dying. Even high profile religious leaders, such as Archbishop Desmond Tutu and the former Archbishop of Canterbury, Lord Carey, have changed their minds and now support law reform.

Those who fervently reject religious faith should not be exposed to suffering in the expectation of a last minute conversion.
13) People are suffering now.

Whenever this issue is discussed in a public forum hundreds, and even thousands, of Australians tell their personal stories of having to watch loved ones die in traumatic circumstances.

During the debate on the *Rights of the Terminally Ill Bill 2013* in NSW in May 2013, Getup ran an online survey of its members. A few weeks later they released the results and sent out this email:

"We have been overwhelmed by your responses. More than 13,000 GetUp members shared their feelings, thoughts and stories on this deeply personal issue. Of the 13,549 responses, 94% of you voiced support for humane assisted dying legislation provided rigorous safeguards are in place. A huge majority, but those are just the numbers talking.

We have spent the last three weeks pouring through your responses. The thoughts and stories you shared were illuminating, confronting, beautiful and they were heartbreaking. Many times, we were moved to tears.

*Thank you so much for having the courage to share your stories with us.*"

If after reading all these reasons for legalising voluntary assisted dying you are still in any doubt, please read this comment that was posted on the Channel 7’s Sunrise Facebook page following an interview they did with Richard Di Natale talking about the *Medical Services (Dying with Dignity) Exposure Draft Bill* last year.

They asked whether medically assisted dying should be legalised and Denise Kapernick answered:

**YES. YES. YES.**

Anybody who disagrees and considers this murder has obviously not sat there and watched a loved one die a slow, painful and cruel death. They have not seen them cry in pain when the morphine isn't enough. They have not seen them gasp for air as they drown in phlegm. They have not sat and watched as their limbs swell with fluid from being bed-ridden and even cutting their fingernails bringing them to tears. They have not watched as their loved one is reliant on others to spoon feed them, wipe their noses, roll them over to attend to the bed sores, to clean their faeces, to wipe their tears away.

*They have not watched a once-proud and self-reliant man lose all his dignity and control and become bed-ridden as his body has failed him.*

*It is not murder to give a terminally ill person the option of ending the pain earlier.*

*RIP Dad. Love you always.*


(Denise Kapernick has given permission for her post to be reproduced in this submission)
2) Review the current framework of legislation, proposed legislation and other relevant reports and materials in other Australian states and territories and overseas jurisdictions.

We assume that this inquiry has partly come about as a result of out of date laws relating to the practice of assisted dying. It seems clear, that here in Australia, the legal uncertainty surrounding doctors hastening, or assisting the death of their patients, has resulted in inequitable access to humane end-of-life choices.

This was highlighted in a recent story in *The Age* (July 8, 2015), in which Associate Professor Neil Orford, director of Intensive Care at University Hospital Geelong and director of Critical Care Services at St John of God Hospital Geelong, described the end-of-life experience of his father. In this story he explained how, at his most vulnerable, his father suffered, while at the same time, his family were treated clumsily.

“I have learnt it is easy not to get good end-of-life care. Although there is growing recognition at all levels of the health system that it is better to provide end-of-life care that focuses on people rather than just disease, it is still easy not to die well,” he wrote.

Professor Orford explained that it was only after he identified himself in his professional role, that things changed.

“By the end of the day the doctors involved in his care had spoken to me, understood our concerns, and agreed to our requests for care that concentrated on comfort. When the palliative care team arrived they listened to us, and delivered clear, effective comfort care, lifting a burden of anxiety off our shoulders,” he wrote.

Although Professor Orford acknowledged that our healthcare system is full of caring health professionals, he believes it is also full of ‘vulnerable families’ and ‘we need to do better.’

“If we don't, only those lucky enough to know the system, know someone, or stumble across a hospital that is really good at this, will be given the choices we all deserve.”

The Voluntary Euthanasia Party (NSW) trust that legal experts and committee members are best placed to review the current framework of legislation, however, we would like to stress that the current legal situation should not continue.

When it comes to proposed legislation, the priority for members of VEP (NSW) is to see legislation, somewhere in Australia, that would allow an individual suffering from a terminal or incurable illness to choose the manner and timing of their own death through appropriate medical assistance.

The *Inquiry into End-of-Life Choices* will no doubt look closely at previous voluntary assisted dying bills introduced across Australian over the past two decades, as well as the laws that currently exist in overseas jurisdictions. There is also valuable information in comprehensive reports, such as *The Royal Society of Canada Expert Panel: End-of-Life Decision Making 2011* and the *Australia 21 Assisted Dying Report 2012*.

Once again, the Voluntary Euthanasia Party (NSW) trust that, following extensive consultation, lawyers and committee members will be best placed to formulate the most appropriate scope and wording of new legislation to meet the needs of our society.
3) Consider what type of legislative change may be required, including an examination of any federal laws that may impact such legislation.

The Voluntary Euthanasia Party (NSW) is made up of members with a range of views in relation to the scope and wording of any proposed voluntary assisted dying legislation. As we have not yet held our first AGM, we are reluctant to commit to a fixed position on the detail of a proposed bill, however, we can safely assume that all our members would be united in the belief that any competent adult with a terminal or incurable illness deserves the right to receive assistance to end their lives peacefully, at a time of their choosing.

Definition of ‘illness’ or ‘eligible medical condition’

In any proposed bill we support a definition of ‘illness’ that is broad enough to include progressive conditions such as multiple sclerosis and motor neuron disease, not just ‘terminal illness’.

We would prefer the term ‘Eligible medical condition’, along the lines of the Tasmanian Voluntary Assisted Dying Bill 2013, that refers to an ‘Eligible medical condition’ and defines this as:

**Eligible medical condition**

(1) For the purposes of this Act, an eligible medical condition is an incurable and irreversible medical condition, whether caused by illness, disease or injury –

(a) that would result in the death of a person diagnosed with the medical condition and that is causing persistent and not relievable suffering for the person that is intolerable for the person; or

(b) that is a progressive medical condition that is causing persistent and not relievable suffering, for a person diagnosed with the medical condition, that is intolerable for the person –

and that is in the advanced stages with no reasonable prospect of a permanent improvement in the person’s medical condition.

Safeguards

The VEP (NSW) would support the following pre-conditions or eligibility requirements:

- the person is at least 18 years of age;
- the person is an Australian resident; and
- the person is mentally competent with capacity and the decision to end his or her life has been made freely, voluntarily and after due consideration;
- two medical practitioners have confirmed that the person has an eligible medical condition;
- the secondary medical practitioner is not a relative or employee of, or a member of the same medical practice as, the primary medical practitioner;
- that, in reasonable medical judgement, there is no medical measure acceptable to the person that can reasonably be undertaken in the hope of effecting a cure; and
- any medical treatment reasonably available to the person is limited to the relief of pain, suffering, distress or indignity with the object of allowing the person to die a comfortable death.

Voluntary Assisted Deaths Review Panel

The VEP (NSW) believes it would be advisable to set up an independent, Voluntary Assisted Deaths Review Panel so that annual reports can be prepared and presented and any new law can be monitored.
Conclusion

We acknowledge that palliative care is, and should be, an important medical service offered to terminally or incurably ill Australians. However, in reality, sometimes the process of dying includes periods of intense and intolerable suffering, which neither medication nor medical staff can control.

The current legal situation leads to enforced suffering, which some have even described as torture. To force a helpless, dying individual to endure pain, discomfort, indignity and fear for days, weeks, months or even years, against their will, is cruel and inhumane and it should no longer be acceptable.

We need healthcare that integrates a peaceful death into the care options available to terminally or incurably ill adults. Doctors need to talk to their patients about end-of-life plans and, most importantly, respect their patients’ dying wishes, even if that means providing or allowing a voluntary assisted death.

We believe good laws should reflect the values of society and with a clear majority of Australians in favour of voluntary assisted dying, politicians need to act.

We hope that as a result of this inquiry, a voluntary assisted dying law, with all the necessary safeguards, will be passed in Victoria and then hopefully other states will follow Victoria’s lead.

As indicated earlier, we appreciate the opportunity to make this submission and as representatives of the Voluntary Euthanasia Party (NSW), Dr David Leaf and myself would be happy to appear at a public hearing if invited.

Ms Shayne Higson
Voluntary Euthanasia Party (NSW)
State Convenor
Phone: 0403 625 456

State Foundation Executive Committee of the Voluntary Euthanasia Party (NSW)

Shayne Higson – State Convenor
Brian Beaumont Owles – Deputy State Convenor and Treasurer
Gideon Cordover – State Party Secretary
Dr David Leaf - State Committee Member
Judith Daley – State Committee Member
Sandi Steep - State Committee Member
Footnotes


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