

Paul & Lisa Byl

22 October 2017

Attention: Principal Research Officer
Joint Select Committee on End of Life Choices
Legislative Assembly
Parliament House
PERTH WA 6000

RE: INQUIRY INTO THE NEED FOR LAWS IN WESTERN AUSTRALIA TO ALLOW CITIZENS TO MAKE INFORMED DECISIONS REGARDING THEIR OWN END OF LIFE CHOICES

Dear Madam or Sir:

Please note our comments in relation to the above mentioned Inquiry. For the sake of clarity, in our letter the term "euthanasia" also means "physician assisted suicide" and "medically assisted suicide".

In 1996, at the age of 23 and almost 10 weeks after our wedding, I (Paul) sustained a high level incomplete spinal cord injury which has had a profound effect on the life of my wife, as well as myself. In an instant our lives were changed forever.

For me it meant a loss of independence in many areas of daily living, requiring assistance with simple tasks of personal care, including emptying my bladder and bowel. I also need assistance in dressing, and while I can feed myself, my food needs to be prepared for me. It also meant using a wheelchair for mobility. Going out together would never be the same. Holidays would never be how they were previously. A decision to go out would need to account for toileting and access issues, meaning spur-of-the-moment outings are few.

For my wife, it also has been a huge adjustment. The strain of attending to all of my personal care and showering is too great for my wife. As a consequence, we employ carers to help with this. Over the years I've had a number of carers and I've taken the opportunity to ask these ladies whether or not they would support euthanasia for those who are ill or don't have quality of life. Some have answered in the affirmative, that yes, they would support it for those who are sane and don't have quality of life. I then ask them what they think if I were to say that tomorrow I would like to be killed (euthanased). Interestingly, they exclaim "But you've got a lovely wife and a beautiful son". My response then is, "Exactly, but having a lovely wife and beautiful son doesn't cause my bladder, bowel and other functions to function normally. They don't cause the spells of pain and discomfort to turn into pleasurable sensations. Further, I feel a burden on them. Because of me they can't go out and about freely like other able-bodied people. My wife can't experience intimate moments as females in other relationships can. Further, as I age, I will need increasing

assistance. As for our son, he can't play cricket / soccer / football with me, fly a kite, or surf like other boys can with their dads. So not only is my quality of life diminished, so is theirs!"

Having said that, we wish to be absolutely clear that we in **no way** see euthanasia as an answer to life's challenges. So it is with great concern to us that we have political leaders (and others) promoting euthanasia. Should euthanasia be legalised here in WA, we enter dangerous territory. Because even with safeguards in place, people with disabilities will, either inadvertently or not, feel pressure to have themselves killed. Note too, that you will **never** be able to legislate to prevent further widening of the safeguards/laws.

And thus euthanasia is a dangerous option. It undermines society's responsibility to protect its most vulnerable members. Instead of affirming the value of **every** person, legalising euthanasia entrenches the idea that if you are disabled, elderly or chronically ill, you are 'better off dead' and your life is not worth living. Over the years since my injury, I have met patients who had experienced a traumatic injury resulting in paralysis, and who had lost the will to live. Legalising euthanasia is not going to help these people or their families. People with disabilities have a role to play in society, and **are** able to contribute.

Further, why would we (the state) spend large sums of money on suicide prevention? Why would it be ok to assist somebody to legally end their life (euthanasia), but not the other (suicide)? And why would it be ethical to legalise and fund euthanasia while there are disabled, elderly or chronically ill people who struggle to or can't access the services they need?

Another important consideration is the effectiveness of palliative care. Instead of funding euthanasia, the state ought to focus on and promote the effectiveness of palliative care. How many people know that the standard of *Australian Palliative Care services, whether in the home or in the medical setting, is currently rated second in the world?* (see Appendix 1) And as 105 Palliative Care health care professionals write in their letter (see Appendix 1):

Our work is a good news story that should provide the public with great confidence.

Instead, in the current debates on euthanasia and assisted suicide, we frequently observe that public confidence in Palliative Care is being actively and deliberately undermined. Assertions include that Palliative Care doctors either cannot or will not relieve suffering and that assisted suicide, and in some cases euthanasia, is needed to address this.

This is simply false.

Current Australian data indicates that no more than 2 in every 100 Palliative Care patients would be in moderate or severe pain at the end of life. In these unusual cases where when all other methods of palliation for pain and other symptoms is inadequate, and if the patient agrees, palliative sedation therapy is available to provide adequate relief of suffering.

This is not just a 'pharmacological oblivion' as some have claimed. It is the careful management of pain and other severe symptoms through individualised medication plans at therapeutically recognised doses, and with dignified personal care, delivered by experienced doctors, nurses and allied health workers. Family and carers are also supported with emphasis on a holistic approach.

No one is abandoned and everyone can be assisted or supported in some way.

Further, these same health care professionals write:

As defined by the World Health Organisation and re-stated by the Australia and New Zealand Society of Palliative Medicine, the discipline of Palliative Care aims “to improve the quality of life of patients and families facing problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual.” Good end of life care, supported by the skills and expertise of Palliative Care professionals, also enhances a person’s choices, including the individual’s choice to refuse life-prolonging, or other medical treatments unacceptable to that individual.

All Australians should have the confidence that their care and support in their time of need will be defined by this approach, and not by the ill-advised and erroneous observations of those who are rushing to legalise assisted suicide.

Dr Marion Harris MBBS FRACP in Medical Oncology and Cancer genetics¹, writes (see Appendix 2):
The critical issue is that assisted dying has implications that extend far beyond any one individual and his or her right or choice. These extend to that person's family, community and to society as a whole. To grant a few the right to euthanasia means that the rights of many vulnerable others are compromised.

If assisted dying is legalised and becomes normalised in our society, over time people with incurable cancer and other terminal illnesses will be conditioned and pushed towards it.

Faced with another option, they now have to choose to burden their family with their care. Stories of bad deaths, hopelessness, of being a cost to society, and of having a completed life will combine to suggest that they should choose an assisted death.

Another factor to consider is that as Christians we believe that human beings are made in God’s image and have an eternal soul (Genesis 1:26-27). For this reason Christians speak about life having ‘sanctity.’ Psalm 139 teaches that human beings are “fearfully and wonderfully made.” Humans have been given special rules and laws which distinguish them from the animal kingdom and hold them to a higher standard of behaviour. Humans are distinct from animals, which are legitimately euthanised when in pain. Animals are not made in the image of God and do not have an eternal soul. The Bible, in both the Old and New Testament, only ever condones intentionally ending a person’s life in the context of legitimate war, self-defence or – in some instances - capital punishment; murder is condemned (Exodus 20:13).

Because human life is sacred, the Bible contains numerous encouragements to care for those who are sick and suffering. Acts of charity, including the establishment of hospitals and healthcare facilities, has long been a feature of Christian ministries. The weak and infirm should be treated with dignity, honour and respect by the generations that follow them (2 Timothy 5:4).

Please don’t misunderstand us by thinking we are imposing our beliefs on the rest of society. This disingenuously dismisses a portion of the population who have the right to have their beliefs reflected in the democratic process. Furthermore, the strategy of dismissing religious arguments from the public sphere simply because they are religious fails to properly acknowledge the role that religious beliefs have in forming both personal opinions and the moral views of societies as a whole. It is based on a misunderstanding of the separation between church and state. While church and state must be institutionally separate, any state and the citizens within it depend on a

¹ Dr. Marion Harris http://www.monashhealth.org/page/Marion_Harris (accessed 22 October 2017).

system of morals and ethics. For thousands of years, religious beliefs have formed the basis for morals and ethics.

All people, atheists and secularists included, have a system of ethics and none of the underlying belief systems, including those which are faith-based, should be dismissed out of hand. There are numerous moral beliefs in a democratic society which are justifiably 'imposed' on a population; for instance, the moral belief that violence and assault are wrong. To dismiss religious arguments from the euthanasia debate because they represent an 'imposition of beliefs' is disingenuous.

In summary, euthanasia is both unnecessary, and unsafe. If legalised, it will reduce the choice of care and support of those in need. We already have the answer to end-of-life choices / suffering, Palliative Care, but it needs more promotion and better funding.

We urge the Committee to take the opportunity to inform and educate Parliament and the public of the benefits of Palliative Care, and why euthanasia is an unnecessary and dangerous option, undermining society's responsibility to protect its most vulnerable members.

Finally, we inform the Committee that we are willing to appear before it should it wish us to do so.

Yours truly

Paul Byl

Lisa Jayne Byl

Dr Maria C Cigolini

Clinical Head **RPAH Department of Palliative Medicine**

Clinical Lecturer **University of Sydney**

Sydney Cancer GH6,

Royal Prince Alfred Hospital

Dear

I am writing on behalf of 105 Palliative Care health professionals who are concerned and opposed to the present euthanasia and physician assisted suicide bills before the Victorian and New South Wales parliaments.

For some time, one strategy of the proponents of the bills has been to downplay, obfuscate and corrupt the intentions and effectiveness of Palliative Care. The aim of the strategy seems to be to create fear in listeners that Medical, Health Care and Palliative Care professionals cannot help people with terminal illness, increase or prolong peoples' suffering and, conversely, that Palliative Care hastens patients' death in a covert way.

This letter has been written to refute these claims, to present a factual account of Palliative Care, to call for rejection of medically assisted suicide legislation, and increased commitment to Palliative Care services in Victoria and New South Wales, in order to address the needs of those nearing their last years of life.

These bills are a most serious threat to the wellbeing and safe care of people with terminal illness, and to those with severe, chronic and disabling conditions, who may feel they have become a burden to others. Both the NSW Auditor General's report on Palliative Care service provision and the Victorian enquiry into end of life choices have emphasized the need to address inequity and shortfalls in service, and for better service delivery.

Yours sincerely,

MBBS(Syd) FRACGP FACHPM Grad.DipPallMed(Melb)

An Open Letter to the Members of Parliament by
Australian Palliative Care Professionals

We, the undersigned Australian Palliative Medicine professionals, do not support the introduction of medically assisted suicide or euthanasia in the states of Victoria and New South Wales. We are also writing to address claims made about Palliative Care by assisted suicide advocates, including Mr Andrew Denton, to the public and in the media. We do not intend this response as an attack on Mr Denton, and wish him well with a good recovery in his present illness.

We work every day with people who are seriously ill and dying, to support them and their families and carers when burdened by their illness or condition, and in their time of need.

Although the standard of Australian Palliative Care services, whether in the home or in the medical setting, are currently rated second in the world, this is not widely known in our community, and these services and our care are not well understood.

Our work is a good news story that should provide the public with great confidence.

Instead, in the current debates on euthanasia and assisted suicide, we frequently observe that public confidence in Palliative Care is being actively and deliberately undermined. Assertions include that Palliative Care doctors either cannot or will not relieve suffering and that assisted suicide, and in some cases euthanasia, is needed to address this.

This is simply false.

Current Australian data indicates that no more than 2 in every 100 Palliative Care patients would be in moderate or severe pain at the end of life. In these unusual cases where when all other methods of palliation for pain and other symptoms is inadequate, and if the patient agrees, palliative sedation therapy is available to provide adequate relief of suffering.

This is not just a 'pharmacological oblivion' as some have claimed. It is the careful management of pain and other severe symptoms through individualised medication plans at therapeutically recognised doses, and with dignified personal care, delivered by experienced doctors, nurses and allied health workers. Family and carers are also supported with emphasis on a holistic approach.

No one is abandoned and everyone can be assisted or supported in some way.

Mr Andrew Denton also claimed at the recent 'Communities in Control 2017 Conference' in Victoria, that because Catholic thinking holds that suffering can sometimes be of benefit to the person, Catholic Health Care service providers and Palliative Care professionals are deliberately under-medicating symptomatic patients at the end of life. This false assertion implies that professionals in these services are deciding that their patients should experience pain and suffering because it is somehow good for them.

It is contrary to fact that any Palliative Care service or its employees, of any faith or secular belief, would behave this way. The approach to Palliative Care across all

Australian and New Zealand services is held to professional standards, with rigorous and transparent quality control and benchmarking, contributing to our high world ranking.

One has to question the targeting of services and professionals providing the majority of the care and support of those who are terminally or chronically ill, and their families.

Ironically, Mr Denton and others simultaneously claim that Palliative Medicine sets out to end peoples' lives in the guise of giving pain relief. Both claims are false. Research has shown beyond doubt that therapeutic doses of opioid medications and sedatives in palliative care settings do not shorten life. The often-repeated claim that Palliative Care professionals purposely shorten the lives of patients with medication and other practices is untrue, and risks discouraging terminally ill and vulnerable patients from seeking the assistance of Palliative Care, or from taking the very medication which would ease their pain.

As defined by the World Health Organisation and re-stated by the Australia and New Zealand Society of Palliative Medicine, the discipline of Palliative Care aims "to improve the quality of life of patients and families facing problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual." Good end of life care, supported by the skills and expertise of Palliative Care professionals, also enhances a person's choices, including the individual's choice to refuse life-prolonging, or other medical treatments unacceptable to that individual.

All Australians should have the confidence that their care and support in their time of need will be defined by this approach, and not by the ill-advised and erroneous observations of those who are rushing to legalise assisted suicide.

For the sake of public confidence, we ask that all sides of the current debate respect the role of Palliative Care services and the dedication and competence of all the professionals that staff them.

If assisted suicide or euthanasia laws are ever considered by our parliaments, that consideration should not be based on the false belief that we cannot assist or support those with pain and suffering in a professional and ethical manner.

If there is a problem facing Palliative Care in Australia it is that access to high quality services is not yet universal. We therefore warmly welcome the commitment of the New South Wales government to provide an additional \$100M to the sector focussing on rural and regional service delivery. We call on the Victorian Government to support the call by Palliative Care Victoria for \$65M recurring funding to assist the service to provide care for those in need.

It would be unethical for any state jurisdiction in Australia to move to legalise for assisted suicide or euthanasia whilst many ill, aged and disabled Australians cannot yet access the support that they need. Such a move would not enhance choice, but instead reduce choice around the care and support for those in real need..

We call all Victorian legislators to recommit to Palliative Care and the other services needed to better benefit all Victorians, and not to let others' agendas undermine more pressing Health Care and Community Service priorities.

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I won't intentionally help my patients to end their lives

Marion Harris

Published: October 9 2017 - 11:45PM

Most patients with incurable cancer battle to the end. They exhaust all evidence-based active treatment options and clinical trials before being told that supportive care measures are now best.

A request to die is uncommon, and is often driven by poorly controlled pain or nausea, as well as fear, loss of function and hopelessness. Usually when pain and other symptoms are under control, good nursing care is on hand, and psychological support has been provided, patients no longer want their death to be hastened.

For family members watching a loved one die, the experience can be agonising. However, with appropriate involvement of palliative care, the preparation and education of family members about the normal processes of dying (such as irregular breathing and fluctuating consciousness), and with the administration of pain relief, there is minimal physical suffering.

When a patient seeks assisted dying, it is often when they are first told they have a limited life expectancy and before they are truly unwell. They are so distressed by such difficult news that they anticipate what is to come and can be consumed with fear and an urge to regain control. They may respond by seeking assisted dying at a time of their choosing. In overseas jurisdictions where this is legal around 80 per cent of those who access it have cancer.

Under the assisted suicide model proposed for Victoria, no psychiatric assessment or specialist palliative care assessment of intending patients are required. There is no need to involve the patient's treating doctors as two new doctors with no mandated end-of-life expertise assess and authorise lethal medicine without any follow-up care.

Informing family members is optional. The entire process can be completed and drugs taken within 10 days – little time for change of mind about an irreversible act. Everyone is presumed to have decision-making capacity unless they obviously don't. Determination of a patient's life expectancy involves an educated guess by doctors and the confidence intervals can be wide.

The critical issue is that assisted dying has implications that extend far beyond any one individual and his or her right or choice. These extend to that person's family, community and to society as a whole. To grant a few the right to euthanasia means that the rights of many vulnerable others are compromised.

If assisted dying is legalised and becomes normalised in our society, over time people with incurable cancer and other terminal illnesses will be conditioned and pushed towards it.

Faced with another option, they now have to choose to burden their family with their care. Stories of bad deaths, hopelessness, of being a cost to society, and of having a completed life will combine to suggest that they should choose an assisted death.

Elder abuse for financial gain is already well documented as a growing problem in Australia. Expansion of indications for assisted dying with time is inevitable – just ask Alzheimers Australia. In addition, doctors are complicit in this act as they intentionally provide the ill with the means to end their lives – a new and not so welcome addition to their job description.

Two people on average each day in Victoria tragically take their own lives, and almost all of these do not have terminal illnesses. It is a mixed message to campaign to prevent suicide in some, while providing the means to others.

Thousands of Victorians die each year without access to adequate palliative care services. Provision of well-resourced palliative care services statewide is the best way to reduce suffering at the end of life – not a lethal substance.

The Australian Medical Association as well as most other international medical bodies do not support assisted dying laws. The American College of Physicians has this month published its position statement reaffirming its strong opposition to this practice on many levels. Even doctors who do support this are reluctant to provide scripts or perform euthanasia themselves.

These are the reasons why I – along with 100 other Victorian cancer specialists – have put my name to an appeal to Victorian MPs not to pass the legislation.

Regardless of any change in the law, I won't intentionally help my patients to end their lives, nor do I personally know of any doctor who will. It is not the solution to the complex problems people face at the end of life, and it creates more problems and injustices than it solves.

Marion Harris is a consultant medical oncologist at a major public hospital in Melbourne.

If you are troubled by this report, or experiencing a personal crisis, you can call Lifeline 131 114 or beyondblue 1300 224 636 or visit lifeline.org.au or beyondblue.org.au

This story was found at: <http://www.smh.com.au/comment/i-wont-intentionally-help-my-patients-to-end-their-lives-20171009-gyww7j.html>

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Position Statement: Euthanasia and Physician Assisted Suicide

Preamble

There is current societal, academic and parliamentary debate in Australia on the topic of legalisation of euthanasia and assisted suicide for people living with a life limiting illness who are experiencing unbearable suffering. Euthanasia and physician assisted suicide are currently illegal in all Australian states and territories.

Background

Palliative Care Nurses Australia Inc. (PCNA) is a national member based organisation for nurses working with people who are living and dying from progressive illnesses and their families. The vision of PCNA is to promote excellence in palliative care nursing for our community, through leadership, representation and professional support. The World Health Organization (2002) definition of palliative care underpins our work.

Palliative Care Nurses Australia believes that:

- Palliative care does not include the practice of euthanasia or assisted suicide; and that the intent of palliative care is to neither hasten or postpone death;
- Nurses play a key role in minimising the patient's suffering and maximising their function and access to support and comfort. Optimal palliative care nursing involves:
- advocating for and ensuring all patients have access to palliative care in accordance with their needs;
- impeccable assessment and management of the physical, psychological, socio-cultural and spiritual needs of the person and their family in accordance with the best available evidence;
- discussing and supporting a patient's choices to withhold or withdraw treatments where the potential harm outweighs possible benefit or is against their expressed wishes;
- considering the complex and multi-dimensional nature of suffering and acting to prevent and alleviate it where possible by seeking and utilising the best available evidence and interdisciplinary advice;
- respectfully and compassionately acknowledging a person's desire to die statements or requests to hasten death in the context of a life limiting illness, and seek to understand the origins of the request; whilst acknowledging that for a small proportion of people pain, distress and/or suffering can persist despite the provision of best palliative care;
- responding to a person's request to hasten death in accordance with: the law, professional codes of conduct, ethical health care principles, best available evidence, and the unique needs of the person and their family; and
- fostering informed and respectful communication with patients, their families, other health care professionals and the wider community about death, dying and end of life care, including the topic of euthanasia and physician assisted suicide.

Definitions

Palliative Care as defined by the World Health Organization (2002) is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care provides relief from pain and other distressing symptoms, and:

- affirms life and regards dying as a normal process;
- intends neither to hasten nor postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Euthanasia is a physician (or other person) intentionally killing a person by the administration of drugs, at that person's voluntary and competent request (EAPC, 2015).

Physician assisted suicide is a physician intentionally helping a person to terminate their life by providing drugs for self-administration, at that person's voluntary and competent request (EAPC 2015).

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1 August 2017

To all Members of Parliament in Australia

The Asia Pacific Hospice and Palliative Care Network promotes access to good-quality hospice and palliative care for all in the Asia Pacific region. We value every moment of life and do not support any action that has the intention of shortening a person's life. Restoring dignity and enhancing quality of life is the basis of palliative care.

We do not support the deliberate ending of life and we view with concern moves in certain jurisdictions in the region to legalise physician-administered euthanasia and physician-assisted suicide. Licensing doctors to administer or supply lethal drugs to seriously-ill patients has no place in the practice of health care. Such moves devalue the dying and undermine society's responsibility to protect its most vulnerable members.

Australia and New Zealand are acknowledged leaders in fostering palliative care development in the Asia Pacific region. In much of this region, pioneers are struggling to establish good end-of-life services in the face of little political and financial support. Eighty percent of the world's dying has little or no access to morphine for pain relief.

The United Kingdom, Australia and New Zealand have been ranked as the top three countries worldwide in the 2015 Economist Quality of Death Index . The eyes of the world are on these nations and on how they discharge their responsibilities to dying people.

For those of us trying to improve end-of-life care, licensing doctors to provide or administer lethal drugs to patients poses serious risks of sabotaging efforts around the globe to convince governments that pain relief and good end-of-life care are basic human rights.

The Asia Pacific Hospice and Palliative Care Network appeals to you therefore to recognise your responsibilities on the world stage when considering any proposed legislation before you.

Yours faithfully

**Associate Professor Cynthia Goh
Chair, Asia Pacific Hospice Palliative Care Network**