

Doctors for Assisted Dying Choice

(Formerly Doctors for Voluntary Euthanasia Choice)
respecting rational patient end-of-life choices

Drs4assisteddyingchoice.org

Submission to the Western Australian Inquiry into end of life choices from a medical perspective

Introduction

We represent a group of medical practitioners “Doctors for assisted Dying Choice” who, through extensive clinical experience, recognise that the current care options for our dying patients are not always sufficient for us to fulfil our duty of care to our patients, which is to relieve their suffering when cure is not an option.

We believe it is our role to help our patients to attain a good death as described by the Australian Grattan Institute research paper (2014):

What is a good death?

To know when death is coming, and to understand what can be expected

To be able to retain control of what happens

To be afforded dignity and privacy

To have control over pain relief and other symptom control

To have choice and control over where death occurs (at home or elsewhere)

To have access to information and expertise of whatever kind is necessary

To have access to any spiritual or emotional support required

To have access to hospice care in any location including home, not only in hospital

To have control over who is present and who shares the end

To be able to issue advance directives that ensure wishes are respected

To have time to say goodbye, and control over other aspects of timing

To be able to leave when it is time to go, and not to have life prolonged pointlessly

We recognise the limits of medical and psychosocial treatments in alleviating certain types of unbearable end of life suffering.

We recognise that only the dying persons themselves can determine if their suffering remains unbearable and that, on occasion, a patient is quite rational to request for death to come more quickly rather than that unbearable suffering should continue.

We believe that members of the medical profession have a duty to respond to those patient's needs as we have the means and skills to provide a gentle death.

We believe that as well as attempting to relieve suffering we also have the duty to ensure that the duration of this suffering is as short as possible.

We are aware that under the current legal framework there is uncertainty regarding the legality of some medical treatments aimed at alleviating end of life suffering.

We have experienced that under this legal uncertainty, some doctors work in various ways to circumvent these legal obstacles to help those patients. This leads to an unspoken, unregulated, non- universal clinical practice without adequate safeguards.

Some doctors avoid potential conflict and may not offer adequate medication leading to continued patient suffering.

We further recognise, that there is resistance among some groups of our medical colleagues to assisted dying.

In this regard, it is relevant to note that some medical practitioners, notably geriatricians, resisted the introduction of Palliative Care into WA in the early 1980's, on the ground that there was "no need" as their services already provided for adequate symptomatic relief at the end of life and one should never be seen to "give up" on the patient.

Many doctors have difficulty in giving up the fight to keep patients alive and in accepting that illness has won meaning that the doctor has been defeated. In time, those doctors have come to accept that we do what we can as healing professionals but there comes a time when we can do no more and the inevitability of life's end comes to pass.

But this gives doctors a new role – the palliative role, relieving suffering right to the end.

The doctor's role is to heal mostly, but relieve suffering always.

Forty years on, the resistance to palliative care by geriatricians has now shifted to resistance to the introduction of assisted dying, this time mostly by palliative care specialists.

It is now acknowledged that the doctors role can shift from healer to symptom reliever. Palliative care is now an integral care model for patients with a life limiting illness.

There is still no universal acceptance within the palliative care profession, however, that medical care cannot relieve all suffering associated with dying in a manner acceptable for the patient.

In the face of unbearable pain, a patient's request for an expedited death is quite rational. This is sometimes felt, on the part of some doctors, as a failure of their care.

This represents a denial of the limits of their abilities.

Surveys show that the majority of Australian medical practitioners, however, do recognise the limit of their ability to ease end of life suffering and support an assisted dying law.

It is recognised that all medical practitioners have autonomy with respect to their clinical practice. Some may choose not to be involved with assisted dying care.

Palliative Care Australia as a group promotes the mantra that: "We will neither hasten nor prolong death". This prevents palliative care specialists being involved with the assisted dying process. We are aware, however, of many palliative care specialists in Perth who would be happy to refer their patients to another medical practitioner for an assisted dying option and continue their care until the patient has deceased. This would allow cooperation and a seamless hand-over of care during the patients last phase of life. Furthermore, some specialists already practice a form of slow assisted dying under the banner of palliative sedation.

It is also recognised that there are wide ranging beliefs with respect to whether there is some value in end of life suffering. This exists both among the medical profession and the general population.

We believe that it is only dying persons themselves whose views are paramount.

The medical practitioner has no role in determining that end of life suffering is valuable or otherwise in the dying process of the patient.

Apart from the problems with the Western Australian legal framework and the limits of medical management of end of life suffering, we recognise several other obstacles for Western Australians to achieve a "good death":

The lack of universal Advance Health Directives and the lack of mandated adherence to these directives by doctors can result in futile medical intervention and attempts to prolong life against the patients wishes thereby increasing the duration of suffering.

Palliative care services are mostly based in major hospitals and most Western Australians will die in hospital despite the fact that most people would prefer to die at home. There could be major benefits to the quality of the dying experience for both patients and their loved ones by improving community palliative care options and improving carer support services.

We have reviewed the thoroughly researched report by the Victorian Inquiry into end of life choices 2016 as well as the provision of the Victorian Assisted Dying Bill . We concur with the report findings that “there is overwhelming evidence that the current legal and medical system is not adequate to deal with the pain and suffering that some people experience at the end of life.” We also agree with the report finding that “people want genuine choice about how they die and would like to be able to plan for their death.”

We agree that the conclusions drawn and recommendations made for Victoria are largely applicable to Western Australia with a few exceptions, mainly resulting from Western Australia’s unique geography.

Summary of main points

We concur with the recommendations of the Victorian Inquiry that:

1. There is a gap in end of life care options currently available and patient’s needs at the end of life.
2. This gap is created by uncertainty within the current legal framework that doctors work in, as well as the inability of modern palliative care options to relieve all unbearable suffering at the end of life.
3. This gap cannot be filled purely by improving palliative care access.
4. This gap leads to intolerable needless end of life suffering for some and fear for this suffering by most.
5. Current medical practices to manage patients with unrelenting suffering at the end of life differ widely and are related to the doctors personal views. Some doctors practice assisted dying some by slow means some by rapid means; many will not offer this option.
6. Currently there is no uniformity, no safeguards and no accountability for these practices.
7. The current law fails to protect doctors who provide end of life care, as terminal care may be interpreted by a third party to have the intent to hasten death.
8. Currently, patients are vulnerable due to of the lack of universal access to assisted dying, the lack of safeguards and the lack of assurance that optimal symptom relief will be used to control their suffering.

Regarding any proposed Assisted Dying Bill, we agree with most safeguards and criteria that are included in the Victorian Assisted Dying Bill. On account of it’s vast size and certain differences in it’s public hospital system, Western Australia has unique needs. Taking this into consideration, we recommend that:

1. Expert specialist review (for the patient’s medical condition) is not needed unless the assessing medical practitioner is uncertain and requests such review. Access to specialist opinion is very limited especially in rural and remote areas.

2. Psychiatric consultation is only needed where either of the assessing doctor is uncertain about the patient's competence or mental state. For a suffering dying person to prefer to die quickly rather than slowly is no basis to question his or her mental health. A mandated psychiatric assessment belittles the individual's autonomy. Decision making capacity assessment is a skill all medical practitioners have. Access to psychiatric opinion is very limited and if mandated would limit access to assisted dying.

3. If a medical practitioner's moral conviction conflicts with that of the patient with respect to an assisted dying request and if for any reason, the medical practitioner does not wish to be involved in the process, that medical practitioner should make available, to the patient, information and/or a referral to a medical practitioner or health service whose moral convictions better align with the request and wishes of the patient.

Regarding implementation of any proposed assisted dying law we recommend:

1. The method of assisted dying to be either by self-administered ingestion of Nembutal or by injection by a health provider, in accordance with patient preference and clinical practicality. This protects patient autonomy to decide their preference, removing the "grey area" regarding patient ability to self-administer. It concurs with observation that in jurisdictions where people have a choice, the majority chooses a health practitioner's injection.

2. Practice procedure protocols should be implemented, based on best practice in jurisdictions where assisted dying is available. This includes the use of Nembutal as a recommended substance for self-ingestion.

3. The implementation of an End of Life Service in WA which would coordinate education and training for health care providers, provide information for patients and create a database of medical practitioners and health services who provide assisted dying as well as conscientious objectors. This would include a website for public information.

Discussion

- A. Constraints on care choices as a result of legal uncertainty
- B. Practical consequences as a result of legal uncertainty.
 - 1. Medical practitioners may be hesitant to use adequate doses of medication to alleviate symptoms for fear that using higher doses may be misinterpreted as an attempt to hasten death.
 - 2. Medical practices vary widely in the ways they manage intractable suffering at the end of life.
- C. Medical care options are unable to alleviate all unbearable end of life suffering
- D. Proposed Assisted Dying legislation for Western Australia

A. Constraints on care choices as a result of legal uncertainty

Doctors, whether palliative care specialists or otherwise, generally recognise a duty to assist their patients in exercising their preferences for the way they want to manage their end of life when experiencing chronic and/or terminal illnesses, within the constraints of the law, their own moral convictions as doctors, and the practical circumstances of each patient.

We agree with the AMA position that doctors have an ethical duty to care for dying patients so that death is allowed to occur in comfort and with dignity, through the provision of good quality end of life care that:

- strives to ensure that a dying patient is free from pain and suffering; and
- endeavours to uphold the patient's values, preferences and goals of care.

The AMA also recognises the right of all dying patients to receive relief from pain and suffering, even where this may shorten their life. As in Victoria, there is much confusion as to whether this right is protected by law, resulting in sub-optimal control of pain and distress for many dying patients.

On the face of it, this right is not recognised at law. On the contrary, the Criminal Code makes no distinction between a doctor and any other person who “does any act or makes any omission which hastens the death of another person who, when the act is done or the omission is made, is labouring under some disorder or disease arising from another cause” (section 273). Under that section, hastening the death of a person in such a way amounts to killing that person, and could lead to a charge of manslaughter, or even of murder.

And yet this is something that many doctors have done and continue to do. It has been known for centuries as the doctrine of double effect. But its practice in medicine is unregulated and undocumented, providing no protection for either doctor or patient. The risk of prosecution is not just hypothetical – in 2001 a Perth doctor was indicted for murder by the Director of Public Prosecutions over the death of a patient who had been suffering from a terminal cancer of the kidney. The case arose because a whistleblower on the staff of a local hospice had a conscientious objection to the doctor's management of his dying patient.

Since this indictment was brought, section 259 of the Criminal Code has been amended to exempt from criminal responsibility anyone who administers, in good faith and with reasonable care and skill, surgical or medical treatment to another person for that other person's benefit. The Victorian Inquiry considered that this provision codified the doctrine of double effect in WA law, but it is far from clear that such is the case.

Under the above-mentioned Position Statement, the AMA believes that reform of the existing law is needed to ensure that a doctor responsible for the treatment or care of a patient in the final phase of a terminal illness, or a person participating in the treatment or care of the patient under a medical practitioner's supervision, incurs no civil or criminal liability by administering or prescribing medical treatment with the intention of relieving pain or distress:

- a) with the consent of the patient or the patient's representative; and
- b) in good faith and without negligence; and
- c) in accordance with the proper professional standards; even though an incidental effect of the treatment may be to hasten the death of the patient.

If there is no introduction of voluntary assisted dying legislation in WA, the above reform should proceed, even though such treatment would remain essentially unregulated and undocumented. However, should voluntary assisted dying legislation be introduced in WA, that would be the appropriate place in which to provide for the reform sought by the AMA.

Another practice seen in the care of dying patients in WA, as in Victoria, is that known as terminal sedation, or as the Victorian Inquiry described it, “continuous palliative sedation.”

This refers to an induced state of decreased or absent awareness (unconsciousness) in order to relieve the burden of otherwise intractable suffering, and which is intended to continue through to the patient’s death. Continuous palliative sedation is dealt with at length in the Report of the Victorian Inquiry.

Like the doctrine of double effect, it has been unregulated and undocumented, and has provided no protection for either doctor or patient.

For this reason, it was a major focus of the WA Acts Amendment (Consent to Medical Treatment) Act 2008, which introduced advance health directives (called advance care directives in Victorian legislation) and enduring powers of guardianship (called enduring powers of attorney with power to make medical treatment decisions, in Victorian legislation).

A key feature of these directives and powers is that they are put in place when the person concerned has the legal capacity to make them, and usually long before he or she is afflicted with a terminal illness. Unless previously revoked by that person, they remain in place during the dying process, and whether legal capacity has been lost or not.

The provisions of the above WA Act are intended to circumvent section 262 of the Criminal Code, which imposes on every person having charge of another, who is unable to provide himself with the necessities of life, the duty to provide for that other person the necessities of life [i.e. food and drink].

Providing food and drink is not medical treatment, but for a person in continuous palliative sedation, nutrition and hydration can only be provided by artificial means, bringing such provision within the definition of a “life sustaining measure”, which is defined in the Act as “a medical, surgical or nursing procedure directed at supplanting or maintaining a vital bodily function that is temporarily or permanently incapable of independent operation ...”

As a medical procedure, artificial nutrition and hydration can be lawfully refused by a patient through an advance health directive, or by the guardian of a patient through an enduring power of guardianship. It remains a matter for the judgement of the attending doctor whether a patient should be placed under continuous palliative sedation, but if the doctor elects to do so and a properly documented refusal of artificial nutrition and hydration is in place, then death is only a matter of time, although its timing will remain uncertain.

Under an amendment to the Criminal Code made by the above WA Act (to insert a subsection (2) to section 259) the doctor is not criminally responsible for a death resulting from continuous palliative sedation, if it is administered in good faith and with reasonable care and skill, and its administration is reasonable, having regard to the patient’s state at the time and to all the circumstances of the case. However, in the event of a complaint being made, there remains an element of doubt as to whether the administration of continuous palliative sedation in a particular case will be held to be reasonable by the relevant authorities, such as the Police, the Director of Public Prosecutions, the Medical Board of Australia, or the State Administrative Tribunal.

In 2016 a Perth doctor, Dr Alida Lancee became the subject of a police murder investigation after she described her management of a dying elderly woman suffering with end stage lung disease using terminal sedation. To date, the investigation remains open but no charges have yet been laid.

The consent of the patient is no defence (section 261 of the Criminal Code). However, should voluntary assisted dying legislation be introduced in WA, that would be the appropriate place to ensure the protection of the doctor, the patient and their loved ones.

B. Practical consequences as a result of legal uncertainty.

The aforementioned legal uncertainties gives rise to widely differing medical practices in managing patients with intractable suffering at the end of life.

Management is largely based on the personal views and concerns of individual medical practitioners and other health care staff.

1.

Medical practitioners may be hesitant to use adequate doses of medication to alleviate symptoms for fear that using higher doses may be misinterpreted as an attempt to hasten death.

The stories below illustrate the reality of this dilemma in practice. There are, unfortunately, hundreds more stories of similar events, which happen every day all over WA.

We point out that in all these cases, the patient has no control over their care choices and as a result, may suffer needlessly.

One of the doctors in our group describes the last days of his father:

“My father died 10 years ago in a Perth Palliative Care Unit. He had terminal bowel cancer and was admitted for terminal care, knowing he would not be coming out – short of breath, emaciated, great discomfort. After a few days, it was decided to relieve his pain via subcutaneous morphine. This essentially put him to sleep, and he was not given any intravenous fluids.

After 24 hours, he was clearly very dehydrated and I enquired of the treating Palliative care specialist as to whether the morphine could be increased as he seemed to be suffering – restlessness, gasping, dry as a chip. He made it clear that this would be seen as hastening death and was not allowed. We therefore plodded on for another 24-hours before eventually he succumbed.”

A doctor describes this event which caused her to stop working in palliative care:

“An elderly lady in a nursing home became distressed during her dying process from end stage chronic disease. I commenced a subcutaneous morphine pump to allow her to settle. When I reviewed her the next day, she had remained restless and distressed and had needed several top up doses overnight. I prescribed an increased dose of morphine in the pump. The nurse refused to administer this increased dose saying she thought it would kill the patient. I was concerned the patient would remain distressed if the dose was not increased and decided to change to syringe myself. The nurse then threatened to call the police if I did this. I had no other options than to leave the dose unchanged. The patient died 48 hours later with ongoing restlessness and distress. I felt helpless and furious at not being able to help this lady. From that day on, I felt unable to work in palliative care with the constraints of the law as it stands.”

A doctor describes the care of a senior palliative care doctor which she witnessed in August 2017:

“I was in a meeting with a senior palliative care specialist. She had just completed a ward round in the palliative care ward. She received a call from the ward nurse that a dying patient in her 90’s had reduced breathing rate and had become unresponsive after the morphine injection, which she had administered 20 minutes prior for severe pain. The palliative care specialist asked the nurse to administer an injection of Narcan (a morphine antidote) to reverse the effects of the Morphine. I asked the Specialist why she had asked for the Narcan as this is known to potentially lead to severe rebound pain and distress and the patient was very elderly and dying. She replied that she did not want the family to think that she had caused the patient to die with the morphine. She agreed that in her opinion the woman was better off not having the Narcan and be allowed to die comfortably, but she did not want any trouble for her or the hospital.”

2 **Medical practices vary widely to manage intractable suffering at the end of life**

It is currently entirely up to the doctor to decide if they will offer a dying patient with intractable suffering terminal sedation or not. It remains a controversial albeit acceptable practice.

It is also entirely up to the doctor as to the rate of sedation induction and the dosages of sedatives used. Some will use very slowly increasing doses over days to weeks, others provide a rapid sedation.

Both these practices are indistinguishable from Assisted Dying as to the eventual outcome but may in themselves not guarantee to alleviate suffering.

There is no evidence that ongoing suffering is not present during sedation with the current medication protocols for terminal sedation. The aim is that the patient “appears” comfortable. In reality, however, the fact that the patient cannot respond is no guarantee that they are not suffering.

Many reports from people who have witnessed their loved ones being slowly sedated over days to weeks to their deaths attest to the uncertain nature of the “comfort” that people experience whilst sedated with reports of restlessness, dry cracked lips, gasping and crying out not uncommon.

An anonymous survey of Australian medical practitioners indicated that 35% of doctors have, at the request of their patient, provided medical treatments with the aim to hasten death and shorten the duration of suffering for their patients.

Because under the current laws, these doctors could face criminal charges, these practices remain hidden and are unspoken.

There is no information available regarding who these doctors are, who the patients were, whether they were terminally ill, what medication was used etc. In other words there are currently no safeguards, no transparency, no universal availability nor accountability for assisted dying practices by doctors.

There are many doctors who do not offer terminal sedation to any of their patients for their own religious or moral reasons. A senior Palliative Care Specialist in Perth, told one of the doctors in our group that he would never provide terminal sedation as he was opposed to this practice and saw no need for this practice in his patients.

Other palliative care doctors, however use this treatment option, some even when death is not imminent as the following stories illustrate:

"I spent three months working in the Palliative Care Unit at a Perth Hospital. People in the last days/weeks of their terminal illness would be transferred from nearby hospitals. They would have their malignant ascites drained, or an excruciating bone metastasis irradiated, and would die, more comfortably, a few days or weeks later. The situation however was different for one lady. She had pancreatic cancer, was stick-thin, had no pain, no appetite and no energy. She paced the ward (slowly), a quiet but frustrated observer. Toward the end of my placement, she tearfully implored the consultant "when is my time?" With the permission of his patient (of course) and her family, the head of the unit commenced terminal sedation, and his patient died a day or two later. Two nurses objected strongly to what he had done and threatened to report him. I don't know whether or not they did, as I left the unit shortly afterwards"

And

"My sister died last month, by age 69 years she had severe emphysema and was prescribed continuous oxygen. Despite the best management that could be offered, her breathing difficulties were such that the simplest physical activity would make her extremely breathless. She went from talking about assisted dying to being quite insistent on seeking help in that regard. Her family was supportive, however, it was not something that could be planned legally and it caused a great sense of helplessness, concern and frustration that there was no one to turn to on the matter. Until she was seen by a palliative care specialist who acknowledged her wishes and a plan was outlined. She was admitted to a Palliative Care Unit. She was told she could take her time in coming to a decision to end her life, and that if she wished to change her mind she could return home at any time, and come back at a later date. Her mind was well made up. When the time came she removed her oxygen and was fitted with a subcutaneous catheter through which was administered standard sedation. By midnight she was unconscious and by 11.30 a.m. the next day she took her last breath aged 74."

C Medical care options are unable to alleviate all unbearable end of life suffering

Western Australia, like Victoria has an excellent palliative care service. The Western Australian medical service provision is not significantly different from Victoria.

Even though palliative care provision and access could be improved in Western Australia, this will not mitigate the fact that some pain and suffering at the end of life cannot be alleviated with medical management, no matter how modern and expert the care.

Australia ranks No 2 out of 80 countries in the world for Quality of Death Index. This report examines the quality, accessibility and affordability of expert palliative care in 80 countries. All jurisdictions in the world who have legalised assisted dying are ranked in the top 11 in the world for accessibility and quality of palliative care services.

The call for an assisted dying law in these countries was not driven by inadequate palliative care options, but rather by a dawning awareness that palliative care options are inherently not always effective or sufficient.

Despite expert multidisciplinary palliative care, a significant number of Western Australians experience intolerable suffering whilst dying. It is estimated that 4% of patients under expert palliative care have intractable symptoms. This equates to several hundred Western Australians each year.

Some suffering associated with dying is not amenable to medical or even psychosocial interventions. Severe lethargy, malaise, the indignity associated with incontinence, inability to communicate or inability to experience any quality of life are but some forms of suffering that doctors have no answer for.

This is called existential suffering, which is entirely subjective and individual to the patient. Currently, there are no management options available for these patients.

This is however, no excuse for undermining patient autonomy by passing judgement or belittling such suffering.

One doctor writes of her mother's death:

“As doctors at the coalface who care for terminally ill patients, we face the fear of being charged with murder for helping patients who are dying already. Palliative care doesn't always relieve terrible, intolerable and never-ending pain. That is the harsh reality. This is how my mother died: My mother always supported euthanasia, she was intelligent, articulate, beautifully groomed an avid reader with a wide circle of friends and a wicked wit.

A past smoker, she developed carcinoma of the tongue. Over time, more and more of her tongue was cut out. She was reduced to eating mush, people couldn't understand what she was saying and it was agony for her “like having barbed wire in her mouth all the time”. She was not depressed, but could not find any quality in her life any longer. She had her stash (of medication) and she took it. My sisters found her, in her nightie, collapsed on the cold white tiles in the hall. My mother suffered the indignity of dying alone on a cold hard floor. She should have died in bed with her loving daughters by her side. She died in pain and alone.

A terrible death marked by terrible suffering for those left behind. The legislation needs to change to avoid these sorts of endings. It is unfair to those who are dying and to their families forced to live with the guilt of not being there when they are needed the most. We need compassion and common sense not fear and falsehoods. My story is one of many. We are the silent suffering majority. It is time for change.”

D. Proposed Assisted Dying legislation for Western Australia

The aim of the proposed legislation is to allow a person the choice to reduce and shorten the duration of their end of life suffering, but with adequate safeguards to ensure this law is only accessed by those it intends to help. Experience in Northern American jurisdictions over the past decades, shows that this is an achievable aim. None of the problems that some fear have become evident in these jurisdictions.

The framework of the proposed Victorian legislation is largely suitable for Western Australia. The one difference is that our state is very large with the majority of expert medical services located in the Perth CBD. Wait times for specialist appointments can be very long even in the Perth region.

With this in mind, we recommend the following:

We recommend that the proposed criteria for medical review in an assisted dying request do not require specialist input unless the general medical practitioner is uncertain and requests such input.

We feel it is imperative, that to the maximum extent possible, people are able to access assisted dying care at the place of their choosing and not have to relocate to Perth for medical consultation or care. Access to specialist medical services is very limited even in the Perth CBD with the average wait for an appointment with a Neurologist 12 months, Gynaecologist 6 months and Psychiatrist 3 months.

Very few specialist medical practitioners provide home visits, which would require a dying suffering patient to attend a clinic. This is not possible for most patients who would request assisted dying and would significantly add to suffering.

Specialist services in rural areas are even more scarce.

General practitioners are the cornerstone of our health care system. They have completed four years post graduate training and are highly skilled professionals with specialist recognition.

General practitioners are the coordinators of care for patients with chronic and terminal conditions within our health care system. They often the first to make the diagnosis of a potentially life limiting condition and have referred the patient to a specialist for expert management. Information about the patients test

results, diagnosis, treatments and prognosis are shared with the general practitioner who remains involved in patient care during their illness trajectory.

General practitioners should have adequate information and skill to determine the patients diagnosis and prognosis including being able to advise the patient about their treatment options.

General practitioners are best placed to assess the patients mental state and decision making capacity due to their longitudinal relationship with the patient and the routine use of this assessment in all health care decisions that patients make. There should be no need for a mandated psychiatrist review.

Such a requirement may make access to assisted dying impossible due to the poor availability of psychiatrists. A mandated psychiatrist review would undermine the patients autonomy to make such a decision. It implies that one is mentally ill to request an assisted dying option until proven otherwise. When death is near and the patient is experiencing unbearable suffering, a request for help to die quickly is perfectly rational.

Another point to make is that general practitioners provide the majority of palliative care services in the community, with specialist palliative care doctors acting mostly in an advisory role and in the hospital setting.

Access to assisted dying option may unfairly exclude some groups.

The Victorian eligibility criteria requires a person to have less than 12 months to live.

We recognise that a group of patients who suffer greatly in the last years of their lives are patients with chronic progressive conditions such as motor-neurone disease, huntington's disease, multiple sclerosis and other progressive degenerative conditions.

Unless the law is drafted with great care, these patients may not qualify for assisted dying unless they refuse life sustaining treatment such as (artificial) nutrition or hydration. The current laws allow a person to choose this option, either by direct communication or through an advance health directive.

We find it appalling that a patient would need to starve themselves prior to becoming eligible for assisted dying.

We ask the committee to examine ways to allow people with debilitating progressive conditions to choose to die with medical assistance when their suffering remains unbearable.

Method of Assisted Dying care.

To allow a patient full autonomy over their end of life choices, we feel that all options for the method of assisted dying should be available to the patient. This includes self-administered oral Nembutal solution, or for a health care practitioner to administer an injection, either by preparing the infusion which the patient can commence or by injecting it under verbal instruction of the patient.

We see no reason to withhold the option of a doctor administered or prepared injection unless the patient cannot self-administer. In jurisdictions where patients have this choice, the majority choose the injection. The determination of a patient being unable to self-administer is a subjective one and this is open to debate. Even though the Victorian Bill indicates that the patient is not physically able to self-administer before injection can be offered, this physical inability may be caused by psychological factors. The assessing doctor needs clarity on this issue.

We recommend that the patient should be offered the choice whether to self-ingest, commence an infusion or be provided with an injection independent on their capacity to self-ingest.

The use of best practice protocols is essential.

In certain jurisdictions, assisted dying care has been practised for over two decades. Detailed best practice protocols are available regarding the medication that is reliable. Nembutal solution is the gold standard for oral use and should be made available. There is no alternative orally ingestible medication combination available to provide a reliable peaceful death.

These jurisdictions have systems in place to monitor and oversee the Assisted Dying Practices to ensure that the law is upheld and that vulnerable groups are safeguarded. Detailed public reporting has allowed transparency and accountability.

Establishment of an End of Life Service in WA.

Prior to implementing any assisted dying law we recommend the establishment of an End of Life Service. This service would coordinate education and training for health care providers in optimisation of symptomatic care options, assessment procedures of the patients, interpretation of the law, psychological support for patient and loved ones and the use of medication protocols.

This service would also provide information for patients and carers about the care options available, including palliative care options as well as information on how to access an assisted dying option. This would be made possible by a database of medical practitioners and health services who provide assisted dying care as well as a database of health services and practitioners who do not provide this care. We feel it is important that this information is readily available to the public and would recommend the development of a website for this purpose. A survey of medical practitioners shows that just over half would be willing to offer assisted dying care to their patients when it becomes legal.

Patients whose doctor refuse to be involved with an assisted dying option, need to be able to access a doctor who provides this without barriers.

There is some merit for doctors to complete a training course prior to being able to offer assisted dying care. In the same vein extra training is already required prior to being able to prescribe certain medications.

Advance Health Directives.

In Western Australia, Advance Health Directives are legally binding, however as yet not universally offered nor universally adhered to.

We recommend that Advance Health Directives (AHD) be offered to all who visit their GP for their 75 YO health assessment as well as those who enter assisted living residences. This would be enabled by providing a separate Medicare rebate for implementation of an Advance Health Directive. Although this is not a state responsibility it is recommended that WA join Victoria in requesting such provision by the commonwealth.

A central database of AHD's would allow emergency department health care workers rapid access information about a patient's wishes, potentially avoiding unwanted medical intervention. A medic-alert bracelet could alert medical staff of the existence of an AHD.

We also recommend that a patient be able to request in their AHD that all necessary treatment to control suffering be used, even if this treatment may also hasten death. This would continue to apply and could be referred to if a patient loses capacity after their first request for assisted dying, to allow the assisted dying process to continue.

We hope that the information and recommendations in this submission are of value to the committee. Reference are available on request.

We also attach the Evidence-Based Fact Sheet regarding Assisted Dying, which we mailed to all members of the Western Australian Parliament.

We are available at any time to meet with the committee to clarify or expand on issues raised in this submission and would appreciate a hearing.

Yours faithfully,

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and the WA working group members,

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End of Life Choices : Evidence Based Facts

In Australia people are free to hold their personal beliefs regarding end of life care choices.

However

There are many aspect regarding end of life care that are factual and not open to opposing beliefs.

Fact 1

Palliative care cannot control all severe suffering at the end of life.

Palliative care specialists agree that about 4 % of their dying patients are still in severe distress despite all her efforts.) This means that several hundred Westerns Australians die badly each year.**

Good modern palliative care can reduce end of life suffering, but many symptoms associated with a terminal illness have very limited medical management options.

For instance, nerve pain from compression by a tumour remains difficult to control and can be agonising.

Breathlessness is also very difficult to manage and is not uncommon in terminal illness .

There are many other distressing symptoms other than pain that can not be managed medically, such as the loss of dignity associated with incontinence, as well as the increasing exhaustion associated with a slowly dying body. Some people find these existential symptoms intolerable.

Palliative treatments themselves can lead to distressing side effects not tolerated by all.

Fact 2

Medical practitioners are not best placed to make end of life decisions

Death and dying are not medical matters, they are a normal aspect of the human experience. Every person has their own moral and belief structure around this issue and should be able to have a choice in what their dying experience should look like.

Medical practitioners in our modern society are but one member of a patient-centred health care team. The treating team acts in an advisory capacity to the patient enabling him or her to make choices regarding treatment options.

Fact 3

The current Legal framework fails to protect doctors who provide palliative care

The current practice of terminal sedation is a slow form of assisted dying and can hasten death in a physically weakened patient.**))

This treatment option may be illegal unless the doctor can prove that the intent was to relief suffering and that a hastened death was a side effect.

Most doctors do not wish to have to defend themselves in court and face possible life jail time for murder.

This leaves terminally ill patients vulnerable to the personal stance of their doctor.

Some doctors will help, risking legal ramifications (polls of medical practitioners have indicate that up to 25% of doctors have given patients possibly life shortening treatment at their patients request**)) Some will not help, leaving patients to die a slow painful death.

Currently there are no safeguards, no transparency and no uniformity in end of life care.

Fact 4

Palliative care funding and research does not reduce when assisted dying becomes legal.

There is good evidence that the opposite is true.

Oregon has had legislation for medically assisted dying for the past 20+years.**))

Detailed data about the availability and quality of hospice palliative care since the introduction of this law has been kept.

In Oregon 90 % of people approved for an assisted death are enrolled in Hospice care program.))**

This compares to only 45% people dying in the whole of USA. Comparative analysis of Quality of palliative care improvement across EU countries over the past decade has shown that Belgium and the Netherlands are on par with their EU counterparts who do not have assisted dying laws.

Fact 5

Over 80 % of Western Australians want the choice of medically assisted dying .

Reference: survey of 100,000 Western Australians in 2016 *) WA Speaks

Fact 6

Legalising assisted dying for the terminally ill does not lead to expansion of legal assisted dying for non dying persons. (NO Slippery Slope evidence)

Oregon has had an assisted dying law specifically for the terminally ill for over two decades. The percentage of deaths attributed to assisted dying have remained stable over the past 20 years in Oregon and other US states at less than 0.5% of all deaths.*) There has not been a public demand nor attempt to expand these laws to include those who are not dying .

The laws in the Netherlands and Belgium do not specify that the person should be terminally ill to qualify, but rather that they have unbearable suffering. A very different legislation to what is proposed for Australia. Any concerns raised from these jurisdictions are not relevant to the debate in Australia, as the proposal for the current Bill will specify that the person is terminally ill with a limited prognosis to be eligible.

Fact 7

Assisted dying legislation does not lead to increased risk of suicide.

The message with the proposed legislation is one of **choice for the dying**.

Currently too many terminally ill people attempt to kill themselves in order to have this control, often in very violent, lonely and distressing ways.

These people are not suicidal and do not want to die, they are suffering whilst dying.

This is totally unrelated to depression related suicide where a person rejects life through a mental illness. The word suicide is not relevant to assisted dying.

Fact 8

The majority of Australian Medical Practitioners support an assisted dying law.

A survey in October 2016 showed that 65% of Australian medical practitioners support assisted dying law for patients with a terminal illness. Only 30% of doctors are members of AMA.*)

Over 50% would agree to participate in assisted dying for their patients should it be legalised.

The establishment of an End of Life Service could provide education for health care practitioners in symptomatic care for the dying (palliative care) , training for health practitioners who are willing to assist patients in dying and information to the public.

Any doctor who does not wish to be involved can refer to doctors in this service at the patients request.

Fact 9

End of Life Choice legislation with safeguards is achievable.

A carefully drafted workable legislation is possible to both give choice to people who are dying and protect people from possible mis-use of such law.

The Oregon law mandates reporting to a Review Committee by both doctors involved. There have been no cases where these doctors were found to be breaking the law nor cases where a person was placed under external influence to request assisted dying.

Statistics in Oregon indicate that the majority (around 80%) of assisted deaths have involved people dying from cancer and this has remained stable over 20 years.*)

Fact 10

There is no evidence that people with disability, mental illness, or the very elderly have become vulnerable as a result of an Assisted Dying Law.

It is not possible for a non dying person to have access to medically assisted dying under the proposed law in Australia. Experience in Oregon shows no adverse effects for vulnerable groups.*)

For more information please contact:

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***) references for statistics or reports available on request.**