

Doctors for Assisted Dying Choice

(Formerly Doctors for Voluntary Euthanasia Choice)

respecting rational patient end-of-life choices

To
MS A. SANDERSON, MLA
CHAIR
JOINT SELECT COMMITTEE ON END OF LIFE CHOICES

Doctors for Assisted Dying Choice thank you for the opportunity to address unanswered questions and questions taken on notice as outlined below:

Questions taken on Notice:

1. Can you please outline the needless barriers you believe the Victorian legislation creates?

Please refer to the attached document.

2. Can you please provide the background details relating to the charts used in the slide on disease trajectory?

Studies about the time frames of progression of certain medical conditions have led to the graphs below. The typical disease course till death is plotted.

It indicates that cancer patients remain relatively high function until the last few months.

People with organ failure such as severe lung disease or heart disease typically show a gradual decline interspersed with acute exacerbations which are treated and partly reversed.

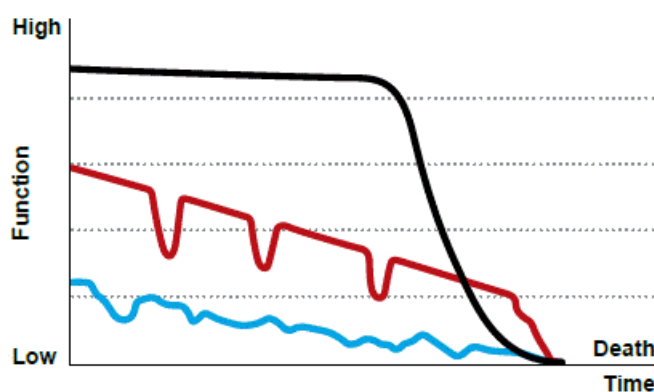
Neurodegenerative conditions such as motor neurone disease or dementia cause prolonged gradual decline and severe incapacity over years.

Reference:

Clinical Review :Illness trajectories and palliative care

BMJ 2005; 330 doi: <https://doi.org/10.1136/bmj.330.7498.1007> (Published 28 April 2005) Scott A

Murray, Marilyn Kendall, Kirsty Boyd, Aziz Sheikh



Source: Murray, S.A. et al¹

— Cancer
— Organ failure
— Neuro-degenerative conditions

3. Could you please provide the evidence (that you referred to on page 5 of the transcript) from other jurisdictions which shows that palliative care services actually benefit when voluntary assisted dying is introduced?

The Quality of Death Index ranks the quality of palliative care in 80 countries across the world.(see attached)

The 7 countries where Voluntary Assisted Dying is legal, rank in the top 15:

Australia 2nd, Belgium 5th, Netherlands 8th, US 9th, Canada 11th, Japan 14th and Switzerland 15th.

In Europe, detailed reporting and comparison of palliative care improvements have followed the introduction of euthanasia in the Netherlands and Belgium. We include the following paper :

Sciknow Publications 2014

State of Palliative Care Development in European Countries with and without Legally Regulated Physician-Assisted Dying

Jan L Bernheim1,*, Kenneth Chambaere1, Peter Theuns1,2, Luc Deliens1,3

They conclude that:

In Belgium, government expenditure for palliative care grew consistently by a yearly average of 10% over the 5 years following legal regulation of physician-assisted dying. As assessed in 2005, palliative care development in the Netherlands and Belgium did not lag behind Western-European countries without legally regulated physician-assisted dying, and was close to on a par with the UK, the benchmark country.

Palliative care improvements have also been monitored in the US.

A 2015 report which assesses quality improvement and access to palliative care in each state showed above average improvements in palliative care in states where VAD is legal:

—America's Care of Serious Illness: 2015 State-by-State Report Card on Access to Palliative Care in Our Nation's Hospitals, in the Journal of Palliative Medicine, shows that the 7 states where VAD is legal all received well above the national average on 66

Oregon 89, Montana 100, Washington 93, Vermont 100, Hawaii 70, California 74 and Colorado 75

We conclude that those jurisdictions where voluntary assisted dying is introduced, show at least equal or greater improvement to palliative care services than in jurisdictions where VAD is not available.

It is possible that this reflects a greater public demand for a good death and increased request for palliative care services in jurisdictions where the public debate and process of legislating voluntary assisted dying has taken place.

It also shows that a voluntary assisted dying option remains supplementary to that of conventional palliative care and not a replacement.

Questions and Responses End of Life Choices Inquiry

1. Given your experience and the findings of the survey above, in your view is it likely that only 1-2% of patients have refractory symptoms around the end of life?

From our experience in caring for patients who are dying, we estimate that at least 5 % of people die whilst experiencing unbearable suffering not manageable with palliative measures.

The exact figure is irrelevant.

Even if one person dies suffering severe distress, when a way to stop this suffering is available, it is one person too many. We cannot find that acceptable.

2.

a. Can you suggest any means by which more equitable access to palliative services might be secured?

After working closely with the Silver Chain Hospice Service, we recognise that this service is second to none in enabling a person to die at home.

We feel that there is need for an increased availability of community palliative care services and carer support programs particularly in outer metro and rural and regional areas.

GP 's provide the majority of palliative care in WA, especially in rural and regional areas. Improved medical practitioner awareness of the palliative care resources that are readily available including Web based clinical guidelines ,courses and learning modules and phone advice with specialists allows optimal management by GP's independent of the location of care.

b. In your view can access and quality of palliative care be maintained (and improved) in conjunction with a legal framework that provides for voluntary assisted dying?

Yes

There is evidence from other jurisdictions that palliative care programs continue to improve after an assisted dying law is implemented.

In Oregon 90% of people who die with medical assistance are enrolled in a hospice program This compares to 45% national average .(references)

Palliative care programs will remain the main providers of end of life symptomatic care.

Please also refer to question 3 above.

Terminal Sedation

3.

a. In your view is the practice of terminal sedation well-understood by medical practitioners in WA?

Regarding terminal sedation practice we make these observations:

Terminal sedation is Palliative Care's answer for refractory suffering at the end of life.

The medical protocols for terminal sedation are aimed to fit into the palliative care model by "Neither hasten nor prolong death" and are carefully and slowly titrated to appear to avoid hastening death.

In practice we know that these protocols are often not effective and we know that doctors regularly provided higher dose regimes to ensure suffering is stopped as soon as possible often hastening death in the process.

In some cases, difference between terminal sedation and assisted dying is often not clear and carefully kept secret behind closed doors.

This hidden practice is the elephant in the room.

Medically Assisted Dying already happens.

An anonymous survey by Neil *et al* in 2007 of 854 Australian doctors who work in end of life care showed that 35% have done exactly that.

Currently, there is no information about when and where this practice takes place and there are no safeguards nor consent protocols in place nor is the practice universally offered.

The major difference between terminal sedation and assisted dying is that in the former the patient is obtunded ie that is they are heavily sedated, barely, if at all conscious, often dehydrated and the process of the dying can be long and a trial for both them and their loved ones, who often remember the process of that death with guilt and horror.

With assisted dying, the patient has made a conscious decision to die while they still have their mental faculties and can say farewell to those who are or have been significant in their life. These deaths are remembered with reverence and thankfulness and are described by relatives as ‘a good death’, a fitting end for those who choose it that compliments and rounds off that person’s life experiences and achievements.

b. In your experience does the practice of terminal sedation ordinarily take place in circumstances where nutrition and hydration are also withdrawn?

Yes
We have not observed artificial hydration nor nutrition being provided when terminal sedation is instigated and evidence indicates that this is seldom provided during the process of terminal sedation..

c. In your experience is it always possible to determine whether a patient who has received terminal sedation still suffers with physical or psychological pain?

We concur with our specialist colleagues that there is no evidence that sedating someone will alleviate their suffering. External signs of distress may or may not be present.

A condition known as **“locked in syndrome”** illustrates that the lack of any physical response, does not indicate lack of awareness. These people are fully aware and conscious but appear to be in a complete vegetative state. Functional MRI neuro-imaging has revealed brain activity in patterns to external stimuli similar to those of a fully conscious person. Some people who recover relay complete awareness during their period in a coma.

d. In your experience are there occasions where terminal sedation is ineffective in some patients who regain complete or partial consciousness despite receiving sedating medication?

Yes
In our experience a partially sedated dying person is at high risk of developing drug induced side effects such as delirium and agitation.

Cochrane review about the practice of terminal sedation concluded that:
“There was insufficient evidence about the efficacy of terminal sedation in terms of a person’s quality of life or symptom control.”

e. In your view are the current laws adequate to protect doctors administering terminal sedation? If not, what change is required?

We have compiled a response to this question and several related questions regarding the doctrine of double effect as the issues raised are interlinked

One member of our group has experienced first hand that the law is not adequate. Legal advice has confirmed the subjective and grey nature of the current legal framework:

The current law relies on the apparent INTENT of the medical practitioner. An observer may not know this intent and may misinterpret the medication provided to relieve symptoms as an attempt to hasten death. Drugs used to sedate or relieve pain may also reduce respiration.

Once this observer has this interpretation, they can report the death to the police, which would spark a murder investigation and charge. Only during a court proceeding, would the doctor be able to use the doctrine of double effect as a defence.

The palliative care framework for terminal sedation, using the slowly titrated dosing regime **only serves** the purpose of safeguarding the doctor from this possible misinterpretation.

Neither the dying person nor the loved ones are served by this slow approach.

In contrasting terminal sedation (TS) and Voluntary assisted Dying(VAD), we make the following comments:

1.

With TS the outcome is prolonged and uncertain, as to timing (Unless a person suffers from end stage organ failure when there is no practical difference between TS and VAD)

The patient may linger in an anguished or comatose state, dehydrated and deteriorating - a spectre far from any conventional notion of care. Responsibility for this lies with the law of the land more than the medical and nursing staff.

With VAD the outcome is quick and certain. The patient chooses an earlier time in the dying process, when dignity and purpose are intact. This can be, and this is, both a rational and a mentally healthy choice. Many doctors will privately agree with that statement, for themselves. Why not then for our patients?

2.

With VAD deaths are remembered with reverence and thankfulness, and are described by relatives as 'a good death' - a fitting end, for those who choose it, that compliments and rounds off that person's life experiences and achievements.

With TS the process of dying can be a trial for both patient and loved ones. The latter often remember the experience with guilt and horror.

3.

With TS documentation is cryptic and statistical information impossible to collect. There is no regulatory framework or oversight.

With VAD documentation is clear, frank and open to scrutiny

4.

With TS the decision is made by the physician.

With VAD the decision is made by the patient.

Legal protection for doctors would allow less fear of prosecution and more appropriate dosing for severe end of life symptoms for their dying patients.

A person with end stage organ failure and who relies on their central respiratory drive to stay alive, may require only very small doses of sedatives for this drive to be interrupted and for death to follow. In those cases, the act of terminal sedation is indistinguishable from Voluntary Assisted Dying.

A very fragile person with end stage organ failure will likely succumb as soon as low dose sedating medications are commenced. This is our experience.

Observational studies about terminal sedation in cancer patients have shown that respiratory and/or circulatory suppression occurred in 20%, and was fatal in 4%. This percentage is likely to be much higher in those with end stage major organ failure.

On the other hand, a young person with healthy lungs and heart, who is dying from cancer and experiences intractable suffering, terminal sedation may be protracted. These persons may lie unconscious for weeks before they die from dehydration. This is extremely distressing for witnessing loved ones

One possible solution for the current legal uncertainty regarding symptom control in **when death is imminent** is for

The Criminal code be amended to exempt a medical practitioner, who acts on the specific request of the patient to administer optimal medication dosages to control symptoms even if this may hasten death. Appropriate consent would need to be obtained and recorded in the medical records.

Similarly,

Advance Health Directives could allow a person to state that they wish for "all treatment aimed to relieve their suffering even if this treatment also potentially hastens their death".

5. In your submission you indicate that some doctors' practice slow assisted-dying and others rapid assisted-dying. Would you please elaborate on what you mean by this?

NOTE we said rapid or slow terminal sedation.

Slow terminal sedation is the official slowly titrated dose regime of palliative care profession as described before. Hardly a way to ensure that suffering is stopped as soon as possible when a person who is already dying has severe refractory suffering.

Many medical and nursing professionals recognise this problem and will give medication doses which are high enough to ensure suffering is stopped quickly, often with the understanding that this also hastens death.

8. Do you think that there is a risk with titration that it can prolong the period of suffering for a patient at end of life before an effective dosage is identified?

The purpose of the gradual titration method is to ensure that all observers know that the aim is to relieve suffering, and not to hasten death.

The Committee has heard evidence from the palliative care profession that they specifically mention this to the patients and their loved ones prior to commencing the sedation process.

The doctor has an educated guess about the dose required to render the person sedated using a 24 Hour pump subcutaneous injection. Intermittent top up doses may be given for "breakthrough symptoms" The dose is reviewed after 24 hours. In some cases this process takes several days. The persistence of perceived suffering by the medical staff is a trigger to increase the dose.

There is no evidence that rendering a person sedated stops suffering. They may only become less responsive to their suffering.

Refusal of Medical Treatment

10. The refusal of medical treatment can include refusing artificial hydration and nourishment by patients who are reliant upon others for the necessities of life, as in the Rossiter case.⁸

a. In your assessment, is this issue now clear for GPs?

The General Practice Specialist education program includes aspects regarding patient autonomy, informed consent and decision capacity assessment. Most general practitioners would be well versed on the notion that a person can refuse any clinical intervention including artificial provision of food and water.

b. Would you say the practice is implemented consistently WA?

From our observations, unless a person specifically refuses, hydration and nutrition is always provided. This even occurs when this requires a severely demented person in the foetal position to be force fed. This may allow such a person to exist for many years despite not having any internal drive for hunger nor thirst.

Uptake and adherence to AHD in WA is suboptimal but could prevent such a situation.

Futility

11. Doctors are not under an obligation to administer medical treatment where treatment is futile

Do you believe the outcome would be different if a similar survey was carried out in WA today, and if yes, why?

Yes We have observed that there continues to be pressure by and on doctors to offer interventions even when these may not help or even harm their patients.

This pressure is caused by fear of litigation, doctors self imposed need to offer at least something and pressure by patient and relatives not to give up on them.

Whether this pressure is acted upon and intervention proceeds is largely based on the doctors personal view of their primary role as “healer ” “ or “reliever of suffering ” In general, doctors find it hard to say that they can do no more.

b. Can you suggest any means by which the value and enjoyment of life by elderly and potentially disabled or chronically ill people and their own preferences may be better able to be factored into considerations of the futility of medical treatment?

Suggestions:

1 Community awareness campaign to empower seniors and the chronically ill to be involved in all health care decisions rather than relying on “doctor knows best”

”Help your doctor know your health priorities”

2 Universal Advance health Directives and mandated adherence by health care staff.

Voluntary Assisted Dying (VAD)

12. In your submission you indicate that if VAD is introduced into Western Australia an assessment should not ordinarily require a medical specialist (in relation to the disease) nor a psychiatrist (in relation to capacity):

a. Why do you say a medical specialist should not ordinarily be required?

General practitioners are specialists in whole person medical care and are the coordinators of allied and specialist health care provision for their patients .

We have detailed information in the form of reports from specialists regarding the diagnosis, prognosis and treatments provided as well as investigation results.

It is very unlikely that a General Practitioner would not have sufficient information to ascertain the persons life limiting illness diagnosis or prognosis. Should this be the case, a phone call to the relevant specialist would clarify any doubt.

Mandated Specific review would make VAD poorly accessible.

b. Why do you say a psychiatrist should not ordinarily be required?

General practitioners provide the majority of psychiatric care in WA .

Only a small percentage of people who are mentally ill require specialist psychiatric care. GPs are experienced in the diagnosis of a depressive illness. And routinely use depression assessment tools to aid diagnosis and assess response to intervention.

General practitioners routinely assess decision making capacity and use a Standard Mini Mental State Examination for formal cognition testing(.SMMSE)

Capacity assessment is currently used prior to drawing up a will or in order to provide a report to the State Administrative Tribunal .

Specific Decision Capacity Assessment is carried out, with several open ended questions to assess understanding relating to their decision and the likely outcome of this decision.

Poor memory performance on MMSE does not, in itself, equate to inability to express wishes and understand consequences of decisions.

Reasoning ,in character decisions and consistency needs to be preserved however.

The general practitioner has a longitudinal relationship with the patient and is well placed to ensure the patients health care decisions are within the character of the patient and are consistent over time.

Mandated Psychiatric review would make VAD poorly accessible.

This view is shared by the Royal Australian New Zealand College of Psychiatrists.

13. In your submission you indicate that a time period until likely death is too prescriptive and may exclude some people from accessing VAD:

a. What diseases would result in patients being excluded from VAD if a time period was prescribed?

Please refer to “Amendments to Victoria VAD Act for WA” document.

b. Which patients should have access to VAD?

Those patients with a progressive terminal condition who experience unbearable suffering which is not amenable to other interventions acceptable to the patient.

The prognostic time-frame currently used in the end of life health care framework could integrate VAD eligibility into the palliative care guidelines:

The current End of life care framework is used to guide the focus of medical care during a persons terminal illness trajectory.

The surprise question “Would you be surprised if this person died in the next 12 months?” is used to recommend the focus on a palliative approach.

This be a good guide to indicate eligibility.

If the answer would indicate a prognosis over 12 months or there is doubt, as could be for those with a neuro-degenerative condition, we would recommend specialist input to ascertain that their death is **reasonably predictable**.

b. Why do you indicate that legislation should allow both self-administration and injection by a health professional?

1.

In line with respecting **individual autonomy**, patients should be offered all available options so they can decide their preferred method of VAD.

2.

In Jurisdictions where both self ingested and injection are available, the majority of dying people **prefer an injection**.

3.

Medication used for medically Assisted Dying via injection are freely available in Western Australia. Should Nembutal remain unavailable in WA, a health practitioner administered injection remains an option, which would allow access VAD.

4.

Self administered ingestion requires a person to be able to swallow a 100 ml volume of very bitter tasting fluid quickly without gagging or vomiting.

Some patients may fear that their disease progression may prevent self ingestion and **may take the medication earlier than if an injection were available**

5

In the Victorian Model the injection option is only available for those who are **physically unable to self ingest**. The medical practitioner makes this **assessment**.

This determination is open to **subjective** interpretation and **may not be clear** .(For example, if a person tells the doctor that they would gag from the bitter taste, would this mean they are able to opt for the injection?)

15. Submissions to this Inquiry have raised concerns that doctors' involvement in the intentional killing of their patients would compromise the patient-doctor relationship.

a. Do you think that there is any merit in trying to minimise doctors' direct involvement in the administration of the lethal medication?

No

Firstly we would like to clarify that the practice of providing a person with a life ending medication is intended to stop suffering We strongly object to use of words like killing and suicide. They are totally inappropriate in the context of the medical care of terminally ill and dying patients.

Far from compromising the doctor-patient relationship, the acceptance of VAD into medical care would be likely to enhance that relationship very greatly.

The ability for health care providers to openly explore the patients fears and wishes and accept the patient's lead in this process, allows a patient to feel respected and remain in control of their path right to the end of their lives.

There is no evidence in other jurisdictions that the doctor- patient trust relationship suffers as a result of the participation in medically assisted dying by some members of the profession as this GP from Canada writes:

“Report Dr Reggler:

I am a UK-trained GP now practising in British Columbia (BC), Canada.

I have provided over 20 medical assisted deaths for my own patients and those referred by other physicians. In my experience, one of the most remarkable consequences of the change of the law in Canada in June 2016 has been the immense anxiolytic effect that patients and their loved ones get from the knowledge that they, the patient, are in charge of when their suffering ends.

Not the disease, not the doctor: the patient.

This is powerful stuff and the medical profession should not stand in the way of what is one of the most significant improvements in the options available to patients suffering intolerably and irremediably, especially at the end of life.

Some may be concerned that patients will distrust their physicians because we are supposed only to help prolong life; in fact, Most patients are pleased to learn that we are more interested in their well-being and their autonomy than in our own rather narrow view of the role of the physician at the end of life. I get thanked on a weekly basis for being involved in providing Medical Aid In Dying.

13 February 2018

Jonathan G Reggler, Family physician, Comox, BC

Ref <http://www.bmj.com/content/360/bmj.k562/rapid-responses>”

We strongly advocate that Voluntary medically assisted dying is a legitimate medical intervention to stop suffering. Doctor administration of the medication is no different from any other method aimed to stop suffering.

b. In Switzerland an intermediary with requisite skills (Dignitas) plays a significant role
Would you be able to comment on any of the advantages or disadvantages of such a model?

The only Advantage we see in a non health care setting would be to reduce stress and burden on health care providers.

Disadvantages of such a system are that

- 1 It may cause some patients to feel abandoned by their health professionals.
2. Potential for fragmentation and lack of continuity of care.
3. No medical back-up in case there is an unexpected outcome.

16. You have indicated that legislation should provide for an End of Life Service. What role(s) would be undertaken by such a service?

We recognise that the current palliative care service providers work under guidelines which currently prevents them from participating in VAD.

Many palliative care providers have indicated to us, however, that they would continue their care of a person who requests VAD and refer them to a service provider who does offer VAD.

This would lead to a gap in service providers.

The establishment of the End of life service would aim to fill this gap by:

1 Establishing a mobile service with trained doctors, nurses, social workers and psychologists to guide a terminally ill person and their loved ones through the assisted dying request procedure as well as provide administration of the life ending intervention. Doctors who are linked to this service could function as assessing doctors.

2. Coordinate education and training for health care providers of VAD (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.)

2 Provide information for patients and carers about the care options available, including symptomatic care options as well as information on how to access an assisted dying option.

4 Provide a database of medical practitioners and health services who provide assisted dying care as well as those who state that they do not provide this care.

5 Establish a dedicated website which would ensure that information is readily available to both health care providers as well as the public.

17. If VAD is introduced what safeguards or protections should be built into the legislation:

Safeguards for patients?

We agree with most safeguards included in the Victorian Voluntary Assisted Dying Act 2017. We believe, however that some criteria intended as safeguards are in fact needless obstacles. Please refer to our suggested amendments.

.Safeguards for Doctors

- Any medical practitioner has the right to refuse to participate in any aspect to the VAD process.

They should however direct the patient to information which will guide them to Service providers of VAD ie refer to the End Of Life Website.

No person should be denied access to VAD as a result of lack of information.

-Freedom from prosecution under the criminal code provided all the criteria and protocols are adhered to.

Advanced Care Planning

18. Are you able to comment on why the **uptake of AHDs in WA is so low?**

Despite the fact that most seniors would choose to avoid life prolonging medical interventions and would prefer to focus of quality of life many have no ADH which can direct their health care team in line with their wishes.

Reasons could be

1 **Lack of community and GP awareness** of the availability of AHD.

2 **Lack of incentives for GP's** to instigate the discussion about planning for end of life decisions.

3 **Unpleasant topic** to think about and decide on.

4 **WA forms are not user friendly** (too open ended and not directed enough (compare with NSW forms)

5 **Aged care facilities and some doctors may have objections** to their residents having an AHD on religious grounds.

19. In your submission you indicate that at the 75 YO check-up patients should be offered Advance Health Directives (AHDs) by their GP.

a. In your view should the offer to assist with an AHD be mandated by law or professional codes of conduct?

No it should not be mandated by law but the WA RACGP could add ADH to the **guidelines for preventative** health practices for elderly.

Education workshops for medical practitioners already exist and may be mandated (similar to CPR updates)

Maybe a **birthday could trigger a letter** inviting them to see their GP to complete an AHD. Just like the breast/bowel cancer screen at the 50th birthday

b. In your view would it be useful if there was a central electronic registry for storage of AHDs?

YES

A central registry would allow AHD to be readily available for medical care staff at the point of care in the emergency room or even by ambulance officers.

The use of “medicalert type bracelets indicating that an AHD exists would prompt staff to check the registry.

This way ,when a person has an advance health directive they can be assured that it is available when needed.

20. In your view are AHDs understood and relied on by practitioners?

No

Some aged care facilities remain reluctant to abide by their residents ADH and continue to call for an ambulance to hospital even when the person has indicated they do not wish this.

This may be related to low staffing levels and lack of after hour medical staff who can attend to the resident’s acute care needs in the facility.

Once a person attends the emergency department little attention is paid to the presence of an AHD and acute care interventions are started as per routine.

Once a patient is stabilised, it is much harder to remove life sustaining intervention. This is the reason that up to 14% of us will die in ICU

Even when ADH is referred to, the wording that some patient may have used is ambiguous.

This may cause the health care provider to err on the side of caution and provide life prolonging intervention.

21. Are AHDs understood by the general community?

Most seniors know what they want, but find it difficult to complete the forms and do not know what words to use.

We suggest that the WA ADH forms are redrafted as per the NSW forms, which are much clearer.

Thank you for the opportunity to share our thoughts in this important matter.

We are available at any time for clarification or further information.

Yours Sincerely,

Dr Alida Lancee
EmProf Max Kamien
Dr Peter Beahan

Prof Richard Lugg
Dr Roger Paterson
Dr Ian Catto

WA State Convenor group for Doctors for Assisted Dying Choice

Western Australia and the Victorian Voluntary Assisted Dying Act 2017

A medical perspective by “Doctors for Assisted Dying Choice” Western Australia

Rationale for suggested amendments to Victorian VAD Act 2017 for WA

- Maintain appropriate safeguards.
- Remove needless obstacles to access VAD in account of WA's unique geography.
- Reduce needless time delays for access to VAD.
- Remove bureaucratic processes not aimed at safeguards and monitoring.

Introduction

The Victorian Voluntary Assisted Dying (VAD) Act is a well considered comprehensive legislation and would serve Western Australia well as a template. It seems logical to maintain a consistent legal framework across Australian states.

We agree that most of the criteria and safeguards are relevant to Western Australia.

However,

Western Australia is different from Victoria in that our state is 10 times larger at 2.6 million km² compared to 0.23 million km² and health services are centralised in the Perth metropolitan area.

This poses unique challenges for those who are terminally ill in rural Western Australia.

We feel it is essential that those who live outside the Perth metropolitan area have access to a Voluntary assisted dying option without having to travel to Perth for medical opinions or need to overcome undue bureaucratic obstacles.

For most Perth Metropolitan Western Australians, timely access to specialist opinions is difficult.

For those in Rural WA this is almost impossible. We agree with the local branch of the Royal Australian and New Zealand College of Psychiatry, that there may be significant practical barriers to psychiatrists carrying out mandated assessments of all patients seeking access to Physician Assisted Death in a timely way. The same applies to other specialists.

General practitioners are qualified to provide the required eligibility assessments and are more accessible.

A mobile health care team trained in end of life care may also be able to assist people who make a VAD request. Medical assessment may also be carried out through Tele-medicine as long as the assessing health practitioner has access to all the patients medical records.

2016 census data	Population	Distance from Perth
1 Perth	1,907,833	
2 Bunbury	71,090	175 Km
3 Geraldton	31,982	414 km
4 Kalgoorlie-Boulder	29,875	595 km
5 Albany	29,373	414 km
6 Busselton	25,329	222 km
7 Karratha	15,828	1500 km
8 Port Hedland	14,000	1750 Km

Relevant medical workforce in Western Australia

2014 medical workforce data	No in Perth metropolitan area	No in Rural WA
Oncology	36	1
Neurology	39	0
Palliative Medicine	18	1
Psychiatry	246	15
General practice	3381	934

Details

The Victorian VAD Act 2017 contains 137 pages including 143 sections and 8 forms.

In contrast, the Oregon Death with Dignity Act contains 12 pages.

The tendency for Victoria to over-regulate may be due to the perceived need for extreme caution and unfounded fears of inappropriate use of this Law.

We have the benefit of being able to draw from the experience with similar laws in other jurisdictions over several decades. There, the practice of VAD has seamlessly become a part of accepted medical practice without any evidence of mis-use.

To simplify the Act and to allow amendments to be made to address unforeseen practical problems without need to review of the act, several aspects of the Act could be referred to Regulations made under the Act rather than stipulating them in the Act. This also applies to the forms.

Suggested sections that could be reworded as

“ Health practitioner must follow the current regulations”

Section 4

Decision Capacity meaning.

Section 19 and 28

Information to be provided by assessing medical practitioners to the patient.

Section 31-33

Referral for another opinion and transfer of care.

Section 39-40,

Storage and Disposal of unused Substance.

Section 45-56

Prescription and administration of Substance.

Section 57-58

Information provided regarding Substance to patient or their representative.

Schedule 1

Forms 1-8

Suggested sections that could be amended/deleted to removed undue obstacles:

Section 7

Conscientious objection of registered health practitioner.

a. A health practitioner has a right to refuse to provide information about VAD

Addition; BUT the health practitioner MUST direct the patient to a source where information about VAD is available.

We agree with b-f

Rationale :

The lack of information should not be an obstacle to access to VAD. A dying person, who experiences unbearable suffering needs ready access to information and practitioners who can assist. No individual has the right to impose their personal views onto another. By withholding information, this imposition is enacted.

A dedicated Website with information about all options as well as a data-base of health practitioners and health facilities who participate and object should be readily available.

Section 8

~~Voluntary assisted dying discussion must not be initiated by the health provider.~~

The health provider must NOT DIRECT the patient to make a decision about VAD nor suggest this as an option in isolation from alternative management options.

Rationale :

Lack of information should not be an obstacle to access to VAD.

The health provider is able to provide information about all legally available options to manage the persons symptoms, including VAD and/ or refer the person to an information source about all End of Life health care options.

Section 9

Eligibility Criteria for access to a Voluntary Assisted Death.

(1)(d) (iii)

Person is diagnosed with a disease that is expected to cause death in the near predictable future but not exceeding ~~6 months~~ 12 months

Rationale

Prognostic time frames are not a reflection of severity of intractable symptoms in a terminal illness. A longer prognosis may reflect a greater need for an expedited death as suffering is expected to continue for a longer duration until eventual death.

Current Palliative care time-frame guidelines are already in use with the “Surprise question”.

“Would you be surprised if this person dies in the next 12 months?”.

The answer is used to guide management focus.

A “No” answer starts discussion about end of life care decisions and focus on palliative care.

The option of VAD would fit into these guidelines.

Identify patients:

Gold Standard Framework triggers

Three triggers for supportive/palliative care:

1. The surprise question: “Would you be surprised if this patient were to die in the next year?”
2. Choice/need: patient makes a choice for comfort care only, or is in special need of supportive/palliative care.
3. Specific indicators: clinical indicators for each of 3 main EOL groups (cancer, organ failure, frail elderly/dementia).



4

Research shows that health practitioners are reliable in estimating this question :

Journal Clinical Oncology 2015

The utility of the surprise question in identifying patients most at risk of death.

Judith B Vick, Nate Pertsch, Mathilde Hutchings, Bridget A. Neville, Stu Lipsitz, Atul Gawande...

Background: Understanding the cancer patient’s prognosis in all illness phases is important.

Evidence suggests that the “**Surprise Question**” (SQ) -- “Would you be surprised if this patient died within the next year?” -- may be useful in identifying those most at risk of death.

Methods: From July 2012 to October 2014, oncology clinicians at Dana-Farber Cancer Institute were invited to enroll in a randomized controlled trial on the impact of a structured intervention to improve conversations about end-of-life goals -- the Serious Illness Care Program. The SQ was asked about each patient seen by the enrolled clinician.

Results: 81 oncology clinicians enrolled in the study and we had complete data on 4617 patients: 3821 (83%) for whom the clinician answered “Yes” to the SQ and 796 (17%) for whom the answer was “No.” Propensity-adjusted 1-year survival for “Yes” patients was 93% (95%CI 91-96%) compared to 53% (95%CI 46-60%) for the “No” patients ($p < 0.0001$).

Conclusions: The Surprise Question identifies cancer-center patients at high risk of death within one year better than clinical variables such as cancer type, stage, patient age, or time since diagnosis.

(4) Despite subsection (1)(d)(iii), if a person is diagnosed with a disease, illness or medical condition that is neurodegenerative, that disease, illness or medical condition must be expected to cause death ~~within weeks or months but not more than 12 months~~ **in the predictable future, as determined by a relevant specialist medical practitioner.**

Prognosis is uncertain in many severely disabling progressive neuro-degenerative terminal conditions.

These condition can cause prolonged severe and progressive suffering for years prior to eventual death.

A time-based prognosis may not allow the option of an expedited death to those who need it most.

Section 10

Medical practitioner minimal criteria.

(3)

~~At least one medical practitioner must have relevant expertise and experience in the disease~~

That both assessing health practitioners must be in the possession of the patients full clinical records and be familiar with the persons disease and treatment options.

If either assessing practitioner is uncertain, the person should be referred to a medical practitioner who has relevant expertise and experience in the disease.

Rationale

Adequate clinical records are sufficient for any qualified experienced medical practitioner to be clear about the diagnosis, treatment options and prognosis.

The term “relevant expertise and experience in the disease” is open to interpretation and unclear.

For instance ,if a GP had treated a patient with breast cancer 2 years ago and read up on the disease, would this indicate that they have experience and expertise?

Considering the Medical workforce in rural WA, a mandated specialist review would make VAD inaccessible and be an undue obstacle for a patient to access VAD.

Section 13 and 23

(1) Medical practitioner must refuse or accept the request within ~~7 days~~ **24 hours**

Rationale

A medical practitioner should not delay the process of the patients request for VAD.

There is no reason for a medical practitioner to be able to refuse or agree to participate within 24 hours.

Section 35

Witness eligibility

(2) (c) ~~Not eligible to be a witness to the written request if that person is directly involved in providing health services or professional care services to the person making the declaration.~~

Not eligible if to be a witness to the written request if they are one of the assessing medical practitioners.

Rationale

Many dying persons in an institution rely on care personnel and may not have access to other witnesses.

Section 38

(1) (a)Final request at least ~~9~~ **7** days after the first request.

Rationale

Seven days is sufficient time to ensure a decision is enduring and a further delay would cause needless ongoing suffering.

Nine days is a random number and there is no logical reason for it's use. Seven days is a week.

Section 38

(2) if the medical practitioner considers that the persons ~~death is likely to occur~~ condition is likely to deteriorate considerably before 7 days, (1) (a) does not apply

Rationale

A faster process is allowed if suffering is expected to increase as a result of a delay.

Section 39-40

~~Appointment of contact person.~~

The Medical practitioner who certifies the death will discard any unused substance or return it to the pharmacy.

Rationale

Currently the medical practitioner or the Silver Chain Hospice service already do this with any unused narcotics or other Schedule 8 medications. This ensures that there is no time delay in the removal of any unused medication.

Any added stress to loved ones should be avoided at all cost.

Sections 45-56

~~Voluntary Assisted Dying Permit~~

We suggest the a permit is not required and is a needless obstacle.

Rationale

The process of obtaining a permit creates needless bureaucratic delays and does not add to safeguarding the patient. Our experience of Departmental approval systems is that the processing would be either too slow for the time scale needed for the humane operation of a VAD system, or (more likely) it would become a mere formality, defeating the purpose it was intended to achieve.

No other jurisdiction has such a system.

The Owler Panel introduced the concept as “similar to the current authorisation process for other restricted drugs,”

A full discussion is given at pages 133-34 of the Report. The Panel concedes that other jurisdictions rely on a process of review after the fact (which is to take place in Victoria anyway). It admits that in other jurisdictions, there is very little evidence of wrongdoing, citing confirmatory statistics from the Netherlands and Oregon. In our opinion, a satisfactory case for the imposition of this additional layer of bureaucracy has not been made out.

Contemplating hypothetical collusion between the two medical practitioners to report as eligible a patient who does not meet the criteria, the Panel says that “the Department [of Health and Human Services] and the Voluntary Assisted Dying Review Board would be able to identify irregularities or wrong doing before a permit for prescription is given” (Report, page 122). The statement is clearly wrong as the Board is not involved in the permit-issuing system.

The current system in place for prescribing restricted medications, such as the abortion pill or narcotics, involves a telephone approval process, whereby the medical practitioner describes the reason and criteria for the medications, with is then checked by an officer against the eligibility criteria. Once the criteria are met, an approval number is issued, which written on the prescription. Such a system is practical for monitoring purposes and does not create needless delays.

The person can opt for either a self administered oral substance or Practitioner administered injection.

The decision for preferred method of VAD should be that of the person only.

The medical assessment regarding the physical ability to self ingest is subjective and open to interpretation. This causes uncertainty for both the patient and the health practitioner.

For example:

If a patient tells the doctor that she would gag on the bitter liquid and cannot self ingest. Does this qualify that person for the injection?

If a doctor assesses the person as being able to self ingest, but the person drinks the liquid too slowly, or spills part of it, it may not be effective.

A failed oral ingestion attempt could be extremely distressing and should be avoided at all cost.

Section 65

Witness to administration request and administration.

(1) (b) ~~Witness is independent of the administering medical practitioner~~

Rationale

Any person who witnesses the provision of VAD should be trained and appropriately counselled.

The medical practitioner may have trained team members who can act as witnesses.

It is likely that the administration of VAD will occur with only loved ones present.

Any additional stress on loved ones to complete paperwork after the fact should be avoided at all cost.

Section 84

Offence to administer a VAD substance to another person after a self administered permit obtained .

Addition:

This does not apply to another person who provides reasonable assistance with preparation of the substance and provision of the substance to the person to enable them to self ingest under their guidance.

Rationale

A terminally ill person is likely to require practical help with a self ingestion due to mobility and agility constraints.

We thank to Committee for considering these amendments to allow those unfortunate Western Australians who need to make use of this law, ready access without undue obstacles.

Yours Sincerely,

Dr Alida Lancee
Em prof Max kamien
Dr Ian Catto

Prof Richard Lugg
Dr Roger Paterson
Dr Peter Beahan

Western Australian convenor group for Doctors for Assisted Dying Choice

Note; Also with input from legal practitioners.