

# Response ID ANON-UWBD-ARR9-G

Submitted to **WA Voluntary Assisted Dying Legislation Consultation**

Submitted on **2019-05-23 13:40:00**

## Demographics

### 1 What is your name?

**Name:**

Pip Brennan

### 2 What is your gender?

Female

### 3 What is your age?

45-54

### 4 Do you identify as:

None of the above

**Ethnic demographic:**

### 5 Where do you normally reside?

Western Australia

### 6 Are you providing your views as an individual or on behalf of a group / organisation?

Group / organisation (please specify below)

**Group / organisation:**

Health Consumers Council (WA) Inc

### 7 What best describes the circumstances in which you provide your submission today?

Consumer representative

**Comment:**

### 8 Do you wish for your feedback to remain confidential? (Submissions will be published unless you request it be kept confidential)

No, you can publish my feedback on your website

## Introduction

### Guiding principles

### 9 Are there other guiding principles that should be considered for the Bill?

Yes (please specify below)

**guiding principles open:**

People with a disability may be more vulnerable to coercion due to societal attitudes to disability and voluntary assisted dying. People with a disability need to be assisted to live before they are assisted to die.

## The person

### 10 Should there be a specified period during which someone has to be continuously living in Western Australia in order to be considered 'ordinarily resident'?

No

Not Answered

## The decision

## 11 What safeguards should there be to ensure that a request is voluntary?

### Voluntary decision:

Independent advocacy may be a useful mechanism to ensure that the wishes of the consumer are not unduly influenced.

As noted above, people with a disability suffer many day to day barriers to being supported to live, in terms of housing, income, access to services etc. People with a disability in particular would benefit from independent advocacy from an agency such as People With Disabilities WA

Key insights from the Health Issues Centre 2015 report highlighted that "whilst older people may be concerned about being 'kept alive' with no quality of life, they may be equally concerned about being 'written off' as an older person of no value, and that

"The choice to die should not be driven by a perceived need to avoid poor or

inadequate care." <https://www.healthissuescentre.org.au/images/uploads/hic-publications/HIC-submission-end-of-life-inquiry-2015.pdf>

The report also states this key principle that underpins safeguards: "Patients should be asked about their goals for treatment. Health professionals need to assist the person to translate their values and priorities into specific treatment decisions. Definitions of a 'life not worth living' need to be explored, not assumed. The value of efforts to build trust cannot be overestimated."

## 12 Should the assessing medical practitioner be able to refer to other health practitioners with relevant competency to assess that the decision is voluntary?

Yes

## 13 Should health practitioners be able to discuss voluntary assisted dying with their patients in the same way they raise and discuss other health or medical decisions and care options?

Yes

## 14 What are the cultural and linguistic considerations in relation to how people may be informed about voluntary assisted dying?

### CALD considerations:

There is a policy mandating that interpreters must be used for those who don't speak English, but we know this often does not happen.

In this context, it's an absolute must (we would contend it is always a must, but our constant advocating on this issue has not been able to overcome internal barriers of cost of interpreters and lack of time/ unfamiliarity of staff members using interpreting services).

The principle noted above of people being able to articulate their values and be supported by a clinician to match those values with treatment options is exactly the same here.

Much of this is not about a checklist, or toolkit or framework - it is about a caring health professional taking the time to build a trusting relationship. Again, independent advocacy would support this process of trust and relationship building.

The above comments relate to people other than Aboriginal and Torres Strait Islander peoples. Pat Dodson commented that "Health statistics are so bad that it is irresponsible to create another avenue to death." Again, the plea to be assisted to live before being assisted to die is relevant here.

Another key principle is people are supported to access the care they want, with independent support to make the right decision for their circumstances.

## 15 What, if any, additional initiatives should be considered to ensure people are properly informed about voluntary assisted dying and supported in the decision making process? For example: should there be a role for navigators?

### Additional initiatives:

Navigators/ advocates who are independent from the system, yes. I prefer the use of "advocate" in the sense of pure advocacy, where the wishes (or values) of the consumer can be articulated and support can be provided to match this with what is on offer. Navigation may be a very similar role, but infers finding the right service rather than having their consumer rights protected.

## 16 How should capacity be determined?

### Capacity determination:

The reality that capacity is "specific, contextual and can vary over time" is important. We have advocated for people who have been put under the Public Trust (who are manifestly inadequately resourced to do this well, and in our opinion can at times show the heartless face of bureaucracy in carrying out their role) and who have had access to a second opinion which has supported consumer capacity to manage their own affairs. We are very concerned at the complexities of the State Administrative Tribunal processes and how little support there is for consumers to navigate this system.

I agree with the Joint Select Committee that a GP can usually determine capacity and when this is not possible, a specialist can be consulted. We would advocate for the opportunity of a second opinion if the consumer requests this.

No

## 17 Should the assessing medical practitioner be able to refer to other health practitioners with relevant competency in capacity assessment (e.g. a neuropsychologist) instead of a consultant psychiatrist or consultant geriatrician?

Yes

## 18 Should there be particular consideration given to people who lose capacity after they have started the process?

Yes (please specify below)

### Considerations for loss of capacity:

If there has been a written values statement that may be something that could be taken into account. This reflection in the previously noted HIC Submission

succinctly highlights the challenges for the substitute decision maker:

"Substitute decision-making is ethically complex and can be a difficult process. Carers and family members are not medical experts and need information and guidance throughout the process... They may need support to identify and act in accordance with the person's values or best interests. More attention and resources need to be directed to supporting carers and family members through the entire end of life trajectory. "

<https://www.healthissuescentre.org.au/images/uploads/hic-publications/HIC-submission-end-of-life-inquiry-2015.pdf> page 8

## 19 Should there be a minimum timeframe to enable reflection on the decision to access voluntary assisted dying?

Yes

Yes

### Under what conditions:

I am thinking of symptoms of physical pain which cannot be alleviated particularly, and also note the discussion document's comments on impending loss of capacity or death.

## 20 Between which points in the process should the minimum timeframe be measured? (Refer to the Process flow chart on page 19)

### Timeframe between points in process:

The Canadian standard of 10 days between signing of written request and day of medical assistance in dying seems sensible.

## 21 What should the minimum timeframe be?

### Minimum timeframe:

This should be determined on a case by case basis.

## Eligible conditions

## 22 If voluntary assisted dying only applies to an illness or disease that is terminal, is specification of a timeframe either desirable or necessary?

No

## 23 Would a timeframe help or hinder access to voluntary assisted dying? From the perspective of the person? Or medical practitioner?

### Is a timeframe to death beneficial:

Due to the complexity of disease processes, it would seem difficult to have a "one size fits all" timeframe. Imagine for example someone with Motor Neurone Disease and they likely have two years or thereabouts between diagnosis and the condition taking their life after taking their capacity and faculties bit by bit. Surely there should be an individual choice in that parameter for say six months could cause great suffering to someone who wanted to die earlier in the disease's progression. (noting Victoria's extension of the timeframe to 12 months for those with neurogenitive conditions)  
Canada's interpretation of this to ensure a person-centred element is important.

In truth, VAD is going to be accessible to very few people. Case by case decisions on elements of VAD seem to support a more person-centred approach to VAD.

## 24 If a timeframe is to be specified should it be defined as:

### What should timeframe be:

Reasonably foreseeable outcome for this person

### If other, please specify:

Noting the discussion paper's noting that "an illness or disease can be influenced by the person's individual context and not only related to the condition."

## 25 Must a person's suffering be 'grievous and irremediable' to be eligible?

No

### Comment:

Agree with Canadian and Victorian approach of "suffering that cannot be relieved in a manner acceptable to that person."

## 26 Must the person's suffering be related to the eligible condition?

Unsure

### Comment:

The public may expect VAD to be available to many but in reality there are likely few people who will access it. As noted in Kathy Eagar's excellent presentation at the recent Palliative Care WA breakfast, in Oregon around 1.6K people may have been benefited from VAD whereas 158K would have benefited from Palliative Care. I wish Palliative Care could be renamed "Quality of Life Care" or Comfort and Quality Care" so more members of the public felt it was something they wanted to access...

But getting back to this, there is a risk that without a line in the sand about eligible conditions, there will be too much scope creep. Conversely, those not eligible

will feel a very existential suffering as a result of a policy decision.

## The process

### **27 How should the process take community, linguistic and cultural beliefs and practices into account whilst also ensuring human rights, personal autonomy, privacy and choice? What approaches or initiatives would assist in achieving this balance?**

#### **CALD practices and beliefs:**

As a health rights advocacy agency, the Health Consumers Council believes in the importance of independent advocacy to ensure all the safeguards are in place - interpreter access, healthy literacy divide bridged, power imbalance addressed.

### **28 What other ways are there to appropriately enable access to voluntary assisted dying?**

#### **Access to VAD:**

Provide web based information for the public and support them to make their own decisions.

Noting also the importance of telehealth to ensure equity of access to VAD for people in rural, regional and remote WA. Telehealth may also be a positive option for someone in Perth, again depending on the context.

### **29 Should a medical practitioner or health service that conscientiously objects have an obligation to refer the patient to a practitioner or service that has no objection?**

Yes

#### **How to find out who will provide VAD:**

This happens in a range of health areas, such as pregnancy termination. The key principle is access for a consumer should never be hampered by the beliefs of a medical practitioner or health service.

#### **Comment:**

My assumption is that this information would be available to medical practitioners, e.g. through Health Pathways, their professional association etc. Medical practitioners have an obligation to understand services and how to refer their patients.

### **30 What should the purpose and timing of the written statement be?**

to formalise the request once the person has been informed of all of their options, including palliative care, and is approved as eligible (and thus occur after the assessments)

### **31 Should the assessing medical practitioners have practiced for at least five years after completing their fellowship or registering as a GP?**

Yes

#### **> 5 years for both GPs:**

At least one (as in Victoria)

### **32 What should be included in the training for health practitioners involved in voluntary assisted dying?**

#### **To be included in training :**

Mainly the art of communication, i.e. listening to a patient and understanding their values, meeting them where they are and treating them with "unconditional positive regard" and kindness.

I also think it could be prudent to include the proposal of Nurse Practitioners as being part of this process.

### **33 Should the completion of approved training be mandatory before a medical practitioner is able to undertake the process for voluntary assisted dying?**

Yes

### **34 Should there be a separate approval and permit process for voluntary assisted dying (over and above any that may relate to the prescription of the medication)?**

Yes (please specify below)

#### **Please provide details:**

It would be important that the medical practitioner committed to a process of evaluating the experience of the dying person throughout the process, and their loved ones afterwards. Transparency of these evaluations may assist in supporting the public in choosing VAD options.

### **35 Should a medical practitioner only be permitted to administer the medication if the person is physically incapable of self-administration?**

Unsure

**Comment:**

Again I think it is something that needs to be decided in context. Agree on the importance of autonomy and agency, but what if a consumer is able to physically but just wants the medical practitioner to administer?

**36 What is the safest approach to returning any unused medication after death?****Approach to unused medication:**

This is not my area of expertise. The contact person to be responsible for unused medication as per Victoria seems sensible, however if it is a loved one, this may be a burden to undertake in a grieving period. I would assume the medical practitioner would be the responsible person.

**37 How should the public be protected from the loss, misuse or misdirection of medication?****Protections against misuse of medication:**

I am not clear how big a risk this could be. It seems minimal.

**38 Are there other safeguards to consider in relation to medication?****Medication safeguards:**

Not that I can think of. Today many people will be discharged from hospitals with way too many opioids and on the road to a prescription-drug addiction, so really I can't see this needs to be much of a focus?

**Death certification****39 Should it be required that voluntary assisted dying is listed as a contributing cause of death on:**

Yes

No

**Comment:**

Agree it is very important to track this and also important to protect privacy of the person who has died.

**Oversight****40 What types of members should form the oversight body? (e.g. qualifications, relevant experience)****Members for oversight body:**

I think the clinician, lawyer and ethicist is good and would also argue for a community member.

**41 What information should health practitioners be required to report to the oversight body?****Required info for reporting:**

Person's identity  
Disease or condition  
AHD/ACP/ EPG/ EPA - Values document etc.  
Time of death  
Medications used  
Medications disposed of  
Arrangements for removal of body

**42 What data should be collected about voluntary assisted dying?****VAD data:**

De-identified demographics, ensuring CaLD status is noted where relevant  
Disease or condition  
Time taken to go the whole processes from first appointment to death  
Evaluations of consumer (during) and loved one experience (during and after)  
Short reflection from practitioner

**43 How should community information and education be provided?****Community info and education:**

Community information needs to be co-designed with the community.  
Potentially a social marketing approach - where the arts of marketing are used for good - to build the health literacy and capacity of the public - could be adopted.  
Griffith University in Queensland <https://www.griffith.edu.au/griffith-business-school/social-marketing-griffith> have done some very interesting work through their school of social marketing.

A key feature of the projects they undertake is that they co-design messages and interventions with the different segments of the people they are trying to educate. For example, anti-drinking messages need to be tailored for the sporty adolescent, the sitting on the fence about alcohol adolescent, and the heavy drinking adolescent. There could be a different or innovative approach to the leaflets/website etc initiatives that may assist in raising public awareness about VAD.

#### **44 How should health practitioner training and education be provided?**

##### **Health practitioner training:**

Ideally the training would be co-designed between a college/university/training body and consumers and carers to ensure the non-technical aspects of this care - the quality of the conversations, the compassion of the practitioner - are valued and developed through the training.

#### **45 How should complaints about voluntary assisted dying be handled?**

##### **Complaints:**

I would like to see the Patient Opinion platform as another option for people to provide feedback. While we do have HaDSCO, our experience as an advocacy agency is that issues that have been addressed by a letter from the provider but have not ameliorated the concerns of the consumer or family are not usually progressed. The output of a letter is often mistaken for the outcome of a consumer and carer being heard, or the system learning from feedback and making changes.

The opportunity of Patient Opinion also allows for the whole system, and the whole community to learn.

#### **Conclusion**

#### **46 Are there any further issues related to the Joint Select Committee's recommended framework that require the Ministerial Expert Panel's consideration? (Refer to Appendix 3 on pages 49-52)**

##### **Comment:**

It will be very interesting to see the outcomes from the Panel's community consultations.

#### **Written feedback**

#### **47 Please provide in the box below your written feedback, or any additional comments, for the WA Voluntary Assisted Dying Legislation consultation.**

##### **Written Feedback:**

The Health Consumers Council sees the benefits and wisdom of Advanced Care Plans, however these have been difficult to enact for a number of reasons. We note with interest the My Values website <https://www.myvalues.org.au/> as a means for consumers to record what they are confident to do so - their own values and wishes. The "tick list" of interventions approach to advanced care planning is highly problematic.

We look forward to seeing this whole area continue to advance as both clinicians and the public become more familiar and adept at having end of life conversations.

And, as a health consumer advocacy body, we know that what will enhance the patient experience for many many more people than VAD, is palliative care. Or, as we like to think of it Comfort and Quality of Life Care!

##### **Upload:**

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