

27-6-15

**To The Inquiry into End of Life Choices
The Victorian Parliament**

I am writing as a concerned citizen regarding the rights of the patients/ people who are in the terminal phase of a terminal illness, who are suffering unbearable pain and feel they have no dignity left in their lives.

I am a retired social worker and have worked in Port Adelaide Community Health Service, The Parks Community Health Service, Dale Street Women's Health Service, Alice Springs Community and Mental Health Service, Darwin Employee Assistance Service Australia, and a Social Work tutor at James Cook University Cairns.

I have worked in community development roles and as a counsellor for nearly 30 years.

I spent 4 years in 2006 to 2010 working and travelling right around Australia, hearing similar stories when it came to voluntary euthanasia.

I am now living back in Darwin working part time.

I have seen so much misery in families when they are forced to stay alive by the laws of this land.

I had taken it on my self to make comments on the legal language in the attempt to have the Voluntary Euthanasia Bill 2012 passed in the South Australian Parliament. I trust familiar language will be used in the Victorian inquiry into end of life choices.

There are many ambiguous and emotive / with religious connotations that should not be part of a legal document. I do not have any legal training but I have a keen eye on discrepancies.

I therefore submit my concerns around the language used to dispel the right to voluntary euthanasia.

Points to Consider Regarding the Victorian Parliament Inquiry into End of Life Choices. 27-6-15

1. Suicide

1.1 In no State or Territory in Australia is it a legal crime to commit suicide, yet it is deemed illegal to assist someone to suicide and a person can be charged with 1st degree or wilful murder.

The irony of this is that someone not necessarily restricted by disease, ongoing severe physical pain or incapacity are able to legally end their lives. Yet those who are seriously ill, suffering immense pain and are in need of help or assistance to end their inhumane life are made to endure their lives simply because they can no longer kill themselves.

Question A: If it is considered a person's right to self determination to suicide for what ever reason why does the state then punish those who are vulnerable, suffering and want to end their lives but cannot, due to their physical incapacity to do so? Why is it that Australia supports this injustice?

Question B: How is it that the suicide law did not allow religious and / or medical values and beliefs to interfere with the law of suicide?

Yet it appears both religious and medical values and beliefs are allowed to have influence over laws affecting the most vulnerable in our community when it comes to voluntary euthanasia?

2.. Dilemma's in the Euthanasia Debate

2.1 Question C: Quality of life; who has the right to say how each person must live, or what they should put up with in their lives?

Question D: Who knows better than the person themselves what quality of life they want?

Currently the medical profession are stating they want to have more patient centred care, if this is correct then surely the patient should be able to decide when there is no more quality left in their lives.

- Scare mongering tactics are always used to silence the vulnerable. Depression is often used as an excuse to not allow someone to die. Who wouldn't be depressed if they are in constant pain, unable to walk, talk or feed themselves, have to wear nappies, and can no longer do anything but stare at their loves ones as they continue to suffer also.

- Some doctors argue that it is not easy to judge if a person has really reached their threshold of pain! *Who are these doctors, how dare they play god and decide whether someone is suffering enough before they finally accelerate the patient's death. The patient is the one who knows when enough is enough!*

- We often hear how so called vulnerable patients are at risk of ending their lives because they don't want to be a burden on their families. Have these people ever thought that this is a reasonable belief. I don't want to burden my child or husband if it is unbearable for me to live for whatever reason. I see taking the option of death is my right. I love my family and I choose not to cause more pain to them than necessary. Death is part of life.

- Sometimes it is the terminally ill patient that keeps holding on for the family as they fear the family cannot cope so they continue to suffer and sacrifice for the family. No one ever seems to talk about this. I have seen so many people hang on to life even though they are suffering because they don't want to upset the family. I have witnessed, as soon as a family member tells the patient that it is ok to die and that the family will cope, they often die peacefully within a short time, within days in fact. Having more open discussions around death would be very beneficial for many families, educating them on looking at all options and respecting their family's decisions.

- According to the act a doctor must agree that a patient is of sound mind and is suffering from a qualifying illness. *How does anyone measure what constitutes a legal term of qualifying illness when it come to pain or illness that justifies taking one's life or assisting a person to end their life. The answer is you can't, again it is only an interpretation of the doctor. Some people cope better than others with illness, this is down to the individual and may have nothing to do with what the doctor perceives as being normal.*

Surely to simplify this it should be the patient that states whether they have had enough of what ever illness they have.

- In regards to sound mind, if an Enduring Power of Guardianship has been signed this should be upheld and the doctor's opinion or family members should not be able to interfere with a legal document. If no existing documentation has been signed a safe guard of having 2 Psychiatrists chosen by the patient and / or an accepted family member who has the patients' permission can assess the state of a person mind.
- There is uncertainty in law about what constitutes as a "reasonable response" regarding how a doctor may interpret a particular medical decision they may make. *If you can't define it in legal terms why have it in the voluntary euthanasia act? Set up clear written forms that every doctor has to ask their patients or the patient family members/ friend who have permission to speak on their behalf, what they want done in their circumstances. Make this a legal binding document so the doctor has proof of what the patient wants. Nothing should be left to the discretion of the doctor in regards to how a patient is to endure pain and suffering and cope with a debilitating illness. It is the patients' right to decide how their life should be.*

4. Opposition to Euthanasia Bill

4.1 The opposition states they affirm the dignity of each individual and their right to appropriate health care that is compassionate and caring according to the Christian Medical and Dental Fellowship of Australia executive officer Michael Burke. *This all sounds very fair and wonderful but my idea of dignity is not his idea of dignity so this should not be used in any legal discussion. There should be clear guidelines to discuss dignity as each person will have their own interpretation of this; hence it is up to each person's perception of dignity.*

4.2 Similar with compassion, what I believe is compassionate may differ greatly from what Mr Burke believes is compassionate; there should be as little ambiguous language as possible in any legal document.

4.3 When safe guards are discussed in any legal document who makes those decisions. Again I believe it is up to the person to decide what they want not some one else dictating what they should feel and do with their body.

It is so patronising of people to argue about serious lack of protection for patients. People die from wrong diagnosis, incorrect medical procedures, inappropriate medication, and lack of medical follow up or inconsistency already in Australia. That is life we cannot create a perfect system or world. When will we stop this shocking protracted ending of life that is simply in-humane?

5.0 Revocation A Request for Euthanasia

5.1 It stated in the presented Voluntary Euthanasia Bill 2012 in SA "that a written, oral or other indication of withdrawal of consent to voluntary euthanasia is sufficient to revoke the request even though the person **may not** be mentally competent when the indication is given" *This is ridiculous, biases religious dogma and this belief is being used in legal documents. The sanctity of life is behind this*

*statement. According to our laws as it stands now if you are believed to be **not mentally competent** you cannot request voluntary euthanasia. The law is not being objective, it can't have it both ways.*

6.0 Voluntary Euthanasia Monitoring Committees

6.1 Question E: Why is there no representative from the National Seniors or COTA on any VE Monitoring committee? Surely this group of people represents a large section of the community and needs to be included in discussing issues about what happens to them when they are incapacitated and dying.

7.0 Medical Concerns Regarding Health Outcomes

7.1 It is well recognised that people who smoke will have negative outcomes. Regular tobacco smoking will contribute to eventual death in many cases.

The same issue regarding regular and over consumption of alcohol will have negative affects on a person's health and can eventually lead to their death.

Both tobacco and alcohol are legally permitted, there are no legal restrictions to how much a person smokes or drinks alcohol in the privacy of their home. Yes, there are monetary restrictions and driving restrictions but in regards to what a person does in their own home this is left to the individual.

One does have to question why it is acceptable to slowly kill your self if you choose this path. Yet a person who may have been healthy all their lives and then get sick and can no longer fend for themselves is legally punished and their opinion or choice of death is not even considered.

7.0 Recommendations

7.1 The request for euthanasia must come from the patient and be entirely free and voluntary. Medical, religious and legal practitioners have no right to dictate how a person should live their life. If they are not doing harm to others this should be entirely their own decision, the law has no right to interfere with a person's choice on how they wish to die once they reach the age of 50 years old.

This policy could be incorporated within the health system or government by sending out a written form to every South Australian that reaches age 50 years old and asking them what they want to happen if they become;

- (i) In an event of a future illness or injury which leaves them in an incurable and irreversible mental or physical condition with no reasonable prospect of recovery.
- (ii) The terminal phase of an incurable life threatening illness
- (iii) Permanent unconsciousness (coma)
- (iv) Persistent vegetative state
- (v) Advance dementia

It would then have a clear description of what their wishes could be / such as ;

- (i) Do every thing to keep me alive and give me any medication and palliative care required to relieve pain.

- (ii) Use all treatment available to me under the palliative care act to keep me alive

or-

- (ii) Do not use cardio pulmonary resuscitation (CPR)
- (iii) Do not have mechanical ventilation (on a respirator)
- (iv) Do not give artificial (tube or intravenous) feeding or hydration

Then have a statement saying “unless required for my dignity and comfort as part of my palliative care”-

- (i) Do not want a surgical operation
- (ii) Do not want antibiotics
- (iii) Do not want to be admitted to hospital, provided that this does not place an unacceptable burden upon my carers, I give permission to my carers if necessary to make that decision. (The carers may have to make that decision.)

This proposal is no different then sending out bowel cancer testing kits to any person reaching age 50 years old. In this way every Australian will have the opportunity to have their say in how they wish to be treated when and if the situation arises that they can no longer fend or speak for themselves.

This will lessen the issue around being of sound mind as so many people wait until it is too late to say how they wish to die and what they want when they no longer have any dignity or quality of life.

People have the choice to not fill these forms out and to do nothing and wait and see what happens to them when their time comes to die.

A booklet on services available for any health and well being issues, including counselling and community programs could also be sent to the person so that they can also see what is available to them as they age.

There is no disputing that there will be people who may make decisions to please others but in reality how many, what are the statistics compared to the people who are very clear how they want their life to be and to how it should end.

There is no full proof system to stop abuse of a vulnerable family member, if there was we would not have such high statistics of domestic violence, child abuse and elder abuse. We can only make a system as fair, just and as transparent as possible. People have the right to determine their own lives and how they wish to control their aging process.

Recommendation

7.2 An Australia wide recording and monitoring system could be introduced on the computer systems similar to e-health.

The system would record what the person has requested and a red alert system would come up whenever a person's name is put into a computer in any health system, including doctor's surgery, nursing homes, retirement homes, ambulances and hospitals. The alert system would advise what the person has requested if the event of some serious illness or injury that leaves them in an incurable and irreversible mental or physical condition.

This would help the medical profession and safe guard the patient by making sure their wishes are made clear and that this document is legally binding.

I am aware that people under the age of 50 years old also have severe health issues and want the choice to have voluntary euthanasia. It will be far more complex issue because of their age. Nevertheless special considerations could be part of a

new policy regarding voluntary euthanasia. The strategy for me is that perhaps targeting the 50 year olds and over may have more of a chance of passing in parliament but then I am probably being optimistic!

Written By Tina Namow 27-6-15

[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]

[REDACTED]

My name and everything I have submitted can be published for the public

Personal story

I have seen both my mother and sister suffer a long and very painful illness before they finally died.

My mother had dementia of the body where eventually everything stopped working including able to swallow, she was like that for 5 years, begging me to kill her.

My sister died with bowel cancer suffering great pain. She also wanted to die with dignity but instead lay in a hospital bed slowly withering away to nothing and left with no self respect or humanity.

No one has the right to decide when a person has suffered enough pain, endured enough humiliation and loss of self and their dignity. No politician, no doctor or family member should have the power to say whether a person has a right to say I have had enough pain and suffering and humiliation, it must be up to the person concerned.

First step re legislation could be - People 50 years and over should have that right to decide if enough is enough. Counselling could be offered before the decision is made for Voluntary Euthanasia to ensure that they are not just depressed and that they may have some other options.

Palliative care can only help with pain and comfort to a certain level but they can't give a person a sense of dignity and some control over their lives. Let us become a compassionate society as if we don't more people will try suicide in terrible ways such as hanging them selves. One family member tried hanging herself but she was too weak to climb up onto a table.

Is this what we want for our sick family members this type of trauma?

Tina Namow