

Admin, LACO

Subject: FW: dying with dignity and why the Dutch law should NOT be our example!!!

From: Wilma

Sent: Sunday, 8 October 2017 8:23 AM

To: Joint Select Committee on End of Life Choices <eolcc@parliament.wa.gov.au>

Subject: dying with dignity and why the Dutch law should NOT be our example!!!

To the Joint Select Committee,

Dying with dignity

As a society we have had no trouble deciding that ALL human life (animals are luckier here sometimes) should be saved if at all possible. "Do no harm" is the oath doctors have pledged. But is keeping anybody alive, simply because we CAN, regardless of their quality of life, really doing no harm? If we have so arbitrarily decided that initially all life should be saved, isn't the other side of that coin then, not forcing people to live on when they don't want to and have clearly expressed that?

From what I have heard and read (admittedly I am a lot more diligently following the Dutch developments than here in Australia) it seems that 80 % of the Australian populations think Assisted death should be an option. If this is a democratic country how come the minority have their way!?!?

Let's start with the 1st group of people that should have access to this program of Dying with Dignity.

Those who can **APPLY** for themselves; foremost the group of elderly people whose health deteriorates to such a degree that they express time and again they do not want to be on the planet anymore. I live in a retirement village and know quite a few people who are at this stage NOW.

Of those in care how many TRY to commit suicide I don't know; I have heard 2 per week succeed!! The situation is unfair to both the patient and his or her carers who may be held responsible for their lives... or deaths.

The Dutch law on euthanasia has often been touted as an example but in the Netherlands the struggle to get some good laws passed is ongoing to THIS DAY!! What is in place is NOT adequate for either patient or doctor so lets not take that as an example for the moment. Let's take advantage of learning from THEIR mistakes/learning curves, rather than making the

same ones here and then finding it almost impossible to rectify down the track as is the case over there.(I may be Australian but I am Dutch born and bred, and ALL my family are still there. My family has had to deal with euthanasia or the refusal of euthanasia !!! time and again)

We need to find a way to make assisted dying a task that is a normal, integral part of the medical profession's education and practice and one with which they are as familiar (if uncomfortable), at least, like vets, though it is the worst part of the job, they CAN deal with it.

How can we as a society help achieve this?

The points below are taken from the viewpoint of the people who have/want to APPLY (I deliberately use the word 'apply' as the word 'request' does not always seem to register) for assisted death.

- Would it be easier for a doctor if a legal professional were involved in the whole process instead of having to deal with it afterwards and sometimes be found wanting?(as is the case in the Netherlands)
- Would it be easier if more than 2 doctors were involved so one does not bear the weight of having given the final say so to end that life or prolong suffering? These days with smart phones that should be manageable.
- And NO veto (as is the case in Holland) and make it an uneven number so there cannot be a 50 -50 situation. (I am thinking 5 people, 4 medical professionals and one legal representative; 3 minimum incl a legal professional)
- - Would it be an option to include nurses and palliative care professionals in this group of 5 ?
 - What needs to change in the medical educational system for this to be a part of the normal educational and thinking processes and not as an taboo subject?
 - What needs to happen in society at large ?(maybe it is happening already? We just are not as loud as the minority (apparently 20% only!!!) that claim it is against their faith or simply 'not on'?
 - Should there be 2 different procedures and laws in place? Where one application is done some time in advance, while in case of a sudden change another rule would apply, especially if that person already had applied earlier and been refused that time?(see my mother's story below)
 - The patient should not be dependent on ONE (1) doctor to start the process, who may simply ignore/not bother to start anything (see my father's story below) Instead, the application/request should be to a medical board of some kind.*

What has the law given people who have been granted the right to die who then don't take advantage of it (or not for a long time) that is so important?

This: YOU have the POWER back, YOU have the CHOICE and that is a huge RELIEF in itself and most days you then say;

I don't want to die TODAY; maybe tomorrow, but not today! (And so are much happier than they have been for a long time to boot.)

Who should be allowed **to apply**?

I think everyone, young and old should be allowed to **apply** (not receive necessarily!!!) and be seriously considered/ looked at. This includes young suicidal people. There needs to be a **suicide prevention program running alongside** the DWD (dying with dignity) program. (as is the case in Switzerland with Dignitas) This is a good way to catch those who really want help and a reason to live rather than to commit suicide, but at the same time those who truly, truly, truly, don't want to live then don't have to throw themselves under a train or hang themselves or whatever method they believes is their only option. This may sound very callous, but both for the suicidal person and their families it would be preferable if they could die with dignity and be able to say their goodbyes and not leave family and friends behind with absolute devastation and guilt.

Another law (at a later date) would have to be made to deal with a situation in which someone cannot apply for themselves:

- very premature babies with disabilities as a consequence, where parents CAN (not necessarily do so) apply to have the baby euthanized (in Holland the law covers up to 1 year old babies. The child itself can request, in tandem with a parent, to have its life ended from age 12 and from age 18 independently)
- serious accident victims
- there may be other situations where this could be a consideration.

The Netherlands (Holland) pioneered these laws, but remember, pioneers are just that and are on a learning curve. Let's take advantage of their pioneering and learn from them rather than making the same mistakes. The problem is that now they are stuck with a law that is woefully inadequate. And they are still trying to improve their laws (3 or 4 new political parties have been set up with first on their agenda changing the laws for euthanasia/ assisted dying) as the dilemma is this urgent there STILL)

In my family, 2 uncles and 1 aunt were granted euthanasia. All 3 had cancer.

2 aunts were refused euthanasia in spite of the fact that they were crippled with arthritis, (wheel)chairbound (in 1 case for 20 YEARS!!!) and in their 80s. But since the condition was not considered 'life threatening' (as if old age isn't a cause of death!) they were refused! In spite of Dutch claims that suffering IS the main consideration!!!

My mother had asked to be euthanized when she still had her mental faculties to make this decision but had been refused; she was passed 80. She was healthy physically, but very depressed. Eventually her mental faculties deteriorated and she went into care in 2013.

She had a massive stroke June 2015. She was 87. She had a fall when that happened and was in so much pain she would vomit. She was no longer able to speak. It took weeks for her to be x-rayed and a cracked hip (the cause of the pain) was detected. No speech, so no ability to 'request euthanasia'. Not that that would have helped: once refused never allowed to re-apply!!! So she refused food and treatment and starved herself to death. It took 2 months of suffering!!

My father 89, who was also in care, had a heart attack 7 weeks later and while still able to talk, lost most of his other faculties. He requested euthanasia. **His doctor didn't even bother to start the process.**

Like my mother, my father decided to refuse treatment and food. He was short of breath and in so much pain for weeks; eventually the staff decided he had only a few weeks to live and gave him high doses of morphine. He died within 2 hours with the family around him. Only in these last few hours was he painfree and his old happy joking self.

My parents died 3½ months apart, both having to starve themselves.

This in the country where Euthanasia is legal!!!!!!!!!!!!!!!!!!!!

The problem

- Only 2 doctors (and 1 psychiatrist when doctors request this) have a say in this.
- If 1(ONE!!!) doctor gives the 'no' vote, it's over. S/he has the VETO vote; the opinion of the other is then no longer taken into account. Nor does the patient have recourse to another team of doctors to review the matter. And as in my mother's case, still no recourse when the situation has drastically changed for the worse!!
- The doctors have to fill in the legal papers **after** the fact and may be found wanting.

In august 2017 I heard on the Dutch news that to ease the stress on doctors (who all dread an euthanasia request) they are now proposing a new law

<p>Mensen die hun leven voltooid vinden, zijn meestal niet ongeneeslijk ziek. Wel kunnen ze lichamelijk aftakelen, afhankelijk worden van anderen en te maken krijgen met het verlies van regie over het leven, het wegvallen van het sociale netwerk en het verlies van doel en zingeving. In combinatie kunnen dit soort factoren leiden tot levensmoeheid. Of iemand het leven voltooid vindt, is altijd een persoonlijke afweging. https://www.nvve.nl/wat-euthanasie/euthanasie-bij-voltooid-leven</p>	<p>People who considered their live to be complete are often not terminally ill. They may face deterioration of body and become dependent on others; and face loss of control of their lives and loss of social networks as well as loss of purpose and usefulness. All these things combined could lead to 'tired of life' (levensmoeheid)feelings. Whether people find their life is complete is always a personal thing.</p>
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To date, in Holland, two thirds of the requests for euthanasia are refused. I have been informed by Dutch relatives that half the cases of people who have been refused euthanasia end up starving themselves to death. (as both my parents did)

How often does that happen here; the only recourse open to those who wish to die? (My Australian partner's mother did the same thing once she went into care and died within 4 months.)

A side effect of euthanasia being refused to so many people in Holland has been that the whole country has ended up in an untenable position with their elderly.

They are now beginning to implement the following:

- Retirement villages are now being turned into **high care facilities only**, while
- the rest of elderly and disabled, (low care and independent living with home help) will have to find assistance from family, friends and neighbours, living in their own homes. Services will no longer be provided. I am talking about things like Silver Chain etc. There simply aren't the finances available.

There is no doubt that laws on assisted dying will eventually be passed. Not only the law where people can apply for/request assisted death but also where people have to decide for others. Let's hope we have the guts to slog it out and make it good ones.

I can only hope this letter will make you think twice about what the law should look like and not merely copy an inadequate one
Kind regards

Wilma Brass

*Footnote:

To my knowledge the Dutch doctors do not leave the patient with the means to end their lives themselves but are present providing the drink/injection at that time.