

Submission to Victorian Standing Committee on Legal & Social Issues

Inquiry into End of Life Choices

Thank you Colleen Hartland - Victorian Greens spokesperson for Health

- I would also be willing to attend the public meeting.

I have been deliberating putting "pen to paper" - for the the first time in my life to, actively fight for a cause which has been growing within me as a passion on a daily basis, Voluntary Euthanasia including advocating rational suicide.

In the past I haven't had the time or energy to contemplate any cause other than to work all my life and try to exist on a daily basis. I have felt quite apathetic at times that I couldn't manage more in my daily life to assist society in some way. I also consider myself to be a very private person and by shouting to the world my opinions would only be exposing myself too publically. Can I defend myself and should I continue with this passion?

But the time has come. So here goes.

My story....as brief as I can be.

I'm a relatively new mature nurse. I am nearly 54 years of age.

My head is spinning, from what I see. I see death and dying every day. Do I turn my back? I feel like I don't have a voice and if I do I could make my working life extremely difficult - for myself! The consequences scare the living crap out of me. So here I sit with racing heart, anxiously writing my thoughts. Is it right that I sit here in the comfort of my own humble kitchen, at the table, feeling threatened by the unknown possible consequences of my opinion?

So I prefer to remain very silent, however, in my mind I will quietly do everything I can to assist myself and my partner, to die as we would prefer, as circumstances determine and in the interests of our loved ones. In short, a dignified and pain free death, special time with our loved ones in our last moments with them – if we are granted time to do just that!

Everyone has a RIGHT to voice their opinion whatever that maybe. Freedom of Speech without ridicule. We are not to judge, we have no right when it comes to dying.

I am also proud to say that I have become a member of Exit International for the past two years, whatever that may entail!? This is complete reassurance for me at this point in time. Life is short and precious and we all know it can change oh so quickly!

I have just finished reading all submissions on my day off and my heart is bleeding, now more so than ever, for people like Lawrie Daniel! (submission No:3) who has "hit the nail on the head" when describing his daily living hell and who can find no relief!? I am moved to the core, speechless, numb, and in mild shock as I sit at my kitchen table crying inside and for the tragic plight of others - Graeme J, Greta A Lindenmayer, Mr Sumner Berg, Christine Maree Gray, Carolyn King, Coralie Richmond, Terri Eskdale, Christine Hamann, Mr Paul Scherek, Mr Ed Lewandowski, Mr John Brandenburg, Mrs Beverley Greenwood, Mr Lucien Boryslowski, Nancy E Wood OAM JP (retired), Alan Coleman, Edward S. Robinson, Mrs Elaine Roberts, Ms Michaela Samman, Bill Alcock, Robert Peters, Pauline Clegg, Hon Rod MacKenzie, Robert Cava and Miss Clare Phillips, to name only a few. I have read all your words and those of anyone else who is "on the same (VE) page!".... you know who you are! all of you have inspired me to finally write. I thank you all for sharing so much personal life changing experiences!

I too don't want my life strung out, or ever enter a nursing home! That option is out of the question for many reasons and I don't have the money! and I refuse ! I have two gorgeous sons in their mid 20's and I would not want them to see me as a vegetable. This will not be the case if I am fortunate enough to have the time to plan my passing.

I see too many elderly people dying without any relief and dignity!

and I have no voice!

They want to die and they tell me so. Yet sadly they have no choice other than to die a lingering death and when they die and in so doing subject themselves and their loved ones to an undignified and "painful" experience. Where is the humanity in all of this?

Sadly, in my experience, I see so many instances in my role as nurse where appropriate and legal medication are just not charted. Drs are under extreme pressure for many reasons.

We need to educate the world and tell them!?, especially family members, that it's ok to die!...to let "them" go!

We need to do this via adverts on TV and social media!?

Life has a beginning a middle and an end, planned or unplanned, or however one wants to do it. Sure some dying people and families don't want to intervene, fine! That is their business!....just like abortion is (unfortunately) the woman's business! How come VE cant be passed but abortion has been!? Thanks for the mercy of God that abortion has been passed! that's one step in the right direction! but a little contradictory when VE is so difficult to pass!?

I have been asked quite a few times “Will my (95 year old) mother get better!?”
OMG! I think to myself hasn't anyone ever sat with them to talk with them!?

We need to educate people on the dying process, gently but firmly, before it happens! someone has to have the guts. I have had many discussions with family members surrounding the coming of death of a loved, they sit beside the bed looking scared not knowing what is going to happen next!?

One story always comes mind

Handed over on afternoon shift..... that a very elderly man is probably going to pass very soon....(maybe on my shift?)....hasn't eaten or consumed fluids or passed urine for 3 days.....on going respiratory complications...very weak.....I go check on him....make sure he is comfortable.... he is all by himself..no family!?(or otherwise mentioned)..nurses are too busy to really check.... room is dark....dreary...depressing....I keep a close eye on him.....thinking to myself that time is drawing near.....I think too of my father who passed over 14 years ago....he is never far from my thoughts!.....

Next time I check..... there is a youngish woman..... looking flushed.....anxious.....siting beside him....out of breath.....I thought it may be a grand daughter!?(in fact it was his daughter! (40ish?)).... she slipped into the facility somehow unnoticed...staff weren't informed!?...she had driven up the highway 125kms from home....she has 2 young children....one was ill....her partner had recently been diagnosed with prostate cancer....her mother had been diagnosed with lymphoma.....she blurted out that her brother had suicided as a teenager.....her partners brother had died in an accident!...also as a teenager.....she was beside herself!

Daughter was "unaware" that her father was so ill!?(....was he dying!? she asks....with fear in her eyes....I asked if anyone had spoken with her!?(....someone more senior perhaps!?(....nothing!?(...I wasn't a regular at the facility.....I gently asked her how close she was to her father.....extremely!.... OMG! I think to myself.....and draw upon everything inside me!?

Experiencing the death of my father 14 years previously in a very similar situation was going to help. I too wasn't told my father was very close to dying after a very long illness. I had absolutely no knowledge of the dying process! The nurses didn't tell me anything. I too had driven 125km the other way! With two small children on board. I entered the hospital looked into my father's eyes and an hour later he was dead! Thank goodness I had that time to hold him for that brief moment. My father knew I was coming. He held on for me and then let go.

Perhaps I was able to help this woman! psychologically/emotionally!? something!?

I'm thinking to myself "OMG! I'm just a new nurse!" I hope I say the right thing!? I'm not an expert!? but she looks at me as if I am! that I have all the answers!? At the same time I think there's no one to really help me!! Time is running out!

I sit beside her and tell her how wonderful it is that she is here to hold her fathers hand....sit close...that's the way.....talk to him....he can hear you....you know.....I get her a cup of tea.....my time is limited!?.....I was pressured to get back on the floor to work.....co-workers were literally "eyeballing" me!?....spending too long with someone who was dying!? Just another one!.....it was late Friday afternoon....time was ticking away.....the place was busy and noisy.....I spend a bit more time...reassuring the daughter that presently her father is very comfortable..(thank God! for him and me!))...see he is sleeping peacefully.....at the moment...and his breathing is calm and relaxed...but if he wakes...becomes restless and looks distressed call out to me....

"Oh by the way", I ask "Where are you going to be staying!?....what are your plans?".....she tells me she is going nowhere!?.....by that she means.....she is not moving until her father has passed.....I gently explain that it could be a drawn out process.....as such...but if we are lucky it will be sooner rather than later!.....she smiled slightly..she was extremely adamant that SHE was not leaving!.....and I mentally supported her in her decision!....it was her right!... "I'll let management know"....as I slipped out the door again. I felt pressured that I would need to tell someone!.....eventually.. of the daughter's intentions....when I got a spare second...my mind was racing ahead..

"I'm close by".... I reassured her....the look in her eye was so sad...heavy and anxious..... "and I'll check on you and your father every 10 minutes or so to see how you are getting along!?" ..that's how quickly I thought his death may come!?!..it was in my gut!?!....I head towards the room again to check... only minutes have passed.. perhaps 15?....this was start of shift!..Daughter is distressed because her father is now awake and distressed.....restless.....terminal restlessness..... breathing laboured.....I've seen it before.....but the daughter hadn't.....I continue to reassure her....Ill be back in a couple of minutes....Ill go and check his drug chart for any orders and see what can be done!....at the same time I'm very aware that....shit I'm a new nurse!...in a relatively unfamiliar facility.. this is sort of not my job!?!...I could tread on toes here....look like an upstart...I approach the nurse in charge...who is a casual.....she is very busy and stressed out working out what she is going to do next....I ask her politely if I could check a chart.... "Sure go right ahead".....phew! ...while she is totally immersed in organizing her shift with a medication trolley.....my heart is racing....thinking....this is Friday afternoon!....if there isn't anything in the chart to help this (obviously) dying man! what will I do next!?!.....and how will I handle it!?!...with limited experience and knowledge and time!!.....I had worked in Hospice and seen it there!?!...Thank God! such a wonderful experience to watch "those" nurses in action! I had also been taught by a very inspirational/switched on palliative care teacher during my course!....whom one day I dreamed of being just a fraction like!

Drug chart checked!.....fear has crept into me!.....no prn orders!.....nothing!....I remember looking at the clock...shit 430pm on a Friday afternoon!..this is bullshit!....why hasn't anyone done something sooner!?!.....its easy to pass the buck!...in nursing!....I've seen it so often....Drs rooms will be starting to shut down for the weekend.....the head nurse is too busy to scratch herself.....but I have to gently tell her what is happening.....and could I please get some sort of order!?!...anything!?!...this man is dying?....he hasn't eaten or passed urine in 3 days!!!.....now restless!!!!!!.....daughter is anxious....very

anxious.... she has come along way from home....she loves her father....daughter has BIG family issues happening!!...its 430pm on a Friday afternoon....if we have no order....night shift will struggle if this man is still alive! and the daughter told me she is NOT leaving until her father has died!. that means the daughter could be here for the next week!?!...I stand back waiting for the nurse to respond....she rushes down to his room..... comes back and tells me “This man is not dying!??? yet!?!?”.....OMG I think to myself!....this nurse is mad!?!.....but I can’t say a thing!....I don’t know enough!?!...this is the start to my nursing career!....or the end of it!?!..I think of the daughter.... distressed!.....I think of all the consequences!....a distressed death!....with the daughter looking on!.....night staff....time ticking away.....finally I ask the head nurse again.... “Ummm...well maybe we should cover ourselves over the weekend!?”...I say.....

“Yeah, ok....I guess,” she says..... “See what you can do!?”..... “Does that mean I can call the Drs rooms!?”...I ask ever so tentatively!?!.....almost cringing, “Yes” comes back the answer!.....next step complete!...I think to myself!.....

OMG! now I have to ring through and convince the secretary at the surgery!..... I run back to the daughter....reassure her that I think I can get some morphine/maxolon!.....just in case!?!....father is still very restless/agitated!.....relief partially spreads through me that I may be able to assist in some way! The nurse in charge didn’t even guide me as to which drug to order!?! And I now know in hindsight that there are perhaps a better combination of drugs to prescribe and try....if there was more time!

I run to nurses station.....find phone....number....breathe.....and make sure I speak with conviction to secretary of surgery!.....heart pounding.....pause.....Yes!.....yeah...yippee....success....I got my first order.....and it was to arrive shortly!?!.....

Meanwhile I rush back to my nurse buddies....and get to work.....

A short while later head nurse tells me order has arrived!?!?.....surprise!...surprise!!!!.. “But does he really need it now!?!?.....since he is not dying!?!??”.....I am reeling inside my head!..... I explain very politely to the head nurse that I have been watching the dying man continue to be very restless and agitated...don't you get it!?!? I want to scream!...

“Well maybe I’ll draw up 1/2 the order!?!.. I don't want to cause unnecessary respiratory depression!?”

“Whatever”..... I think to myself!....then add quietly.... “I'd be drawing up the whole lot for this man.....it's not such a big order!....and this man is struggling to breathe as it is.....isn't morphine supposed to help with difficulty breathing”..... I mumble to myself....as the nurse walks away to draw up the syringe to the full amount... “Yeah!” I think to myself.

I go back to daughter to tell her what is going on.....reassure daughter plus plus plus... “The nurse in charge is going to administer to morphine any minute!”...daughter is now smiling slightly....a little....relieved.....”Thank God” she breathes not taking her eyes off her distressed father.

We turned our backs for just a moment and her father passed!!....at the same time head nurse enters the room with loaded syringe..... “Well I never would have believed it!?” and off she rushes again!

Now I was left to console the poor distraught daughter!.....I shut the door.....we sat down again....I got some tissues....I told her to let it all out....start the grieving process.....and she did...daughter was in deep shock really....had never seen anyone die before..... I also told her how wonderful it was that her father had passed so quickly....and that she had made it in time to be with him.....I made her another cup of tea.....and we talked some more.. I told her it may take some time...but eventually it will get easier...the grieving....it will be raw and shocking.....and you'll think you'll never get over it!....remember your father lived to a ripe ole age!.. and that is a blessing!?...Boy did I feel her grief!....it was almost a true re-enactment of when my father died, I managed to keep a stiff upper lip somehow!

I packed her father's clothes. Numerous brown paper bags had been given to her by another nurse at this stage!?...in passing!?...daughter looked even more shocked and I was too! But didn't show it. I said that I would pack!.. “Sit down, this is my job!....you can't pack your fathers clothes when you have been through so much already”. Daughter was shaking.

When she was ready, I eventually helped her to her car... “But what is going to happen to my father now!?”.... “He is safe with us....we will look after him! and we will call you and let you know the rest later”.....was she ok to drive?..... “Yes”, she said.....her partner was going to meet her halfway along the highway and guide her back.....I told her to take care.....on the road..... and get back to her family..... she hugged and thanked me... with sincere gratitude...

I was relieved when it was time for me to go home.....exhausted....I felt like I had done a good job.....but I was also disappointed.....that my co- workers were obviously not as empatheticwas that because they had become "hardened?"...to this day no one knows what actually happened that day....and my team members appeared oblivious.....aged care places can be so harsh!? (and expensive!)

We can't prolong agony!...and lack of dignity!

Forcing people to eat and drink!?

I am so settled at the moment in regards to how I want to die! I feel at peace! I do not fear dying. As long as I don't experience a traumatic accident, cardiac arrest/CPR or stroke!? all I pray for in that instance is that I can speak coherently and tell my Dr and my loved ones to get the syringe driver going!

I will do everything I can to assist myself on how I want to die!

I hope that I die peacefully in my mature years, in my sleep! But hey that's like winning tattslo to!.....get real!

In the meantime if I am diagnosed with a terminal illness tomorrow I will embrace my life! Terminal illness gives us "some" time!.....as apposed to sudden death!....we have a say!....and how great is that!

I want to die while I am still of sound mind! still physically abled!....there will be a small gathering...everyone will hold hands....sing!...pray....dance...laugh.....drink and be merry...it will be my birthday!...if I can plan it like that!?...and I will pass....I will make sure no one is sad!.....before I go.....

Currently I have a very close girlfriend dying of cancer....that has been a recent shock and life changing experience for both of us!.....putting per imminent death into perspective....we live and embrace the moment.....she can still smell the roses.....

I also have a partner 17 years my senior! with a complex medical history! (We have a great Dr!). John could die at any moment! I met him 18 months ago on an internet dating site! and we moved in together within a month!? Nothing to lose!? Bite the bullet! It's been a life changing time for me! and him! We talk openly about death! and everything else under the sun! and if anything happens he would want to die quickly! so would his very supportive family! including his gorgeous ex-wife.....and I would want the same!....

That's it!....I'm passionate about my right to die!....Paise the Lord for Dr Nitschke!

Go! Cannon Rosie Harper!.....I just got to know you today on YouTube! WOW!.....what a day it has been!

God Bless you all!
Karin Lubitz