



LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON END OF LIFE CHOICES IN THE ACT

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Submission Cover Sheet

End of Life Choices in the ACT

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I can understand for most changes to legislation it a politician's job to understand problems, find facts and provide solutions with minimal emotional involvement. However, for something like euthanasia, which is so deeply personal to both people for and against legalising the service, the emotion needs to be heard, and **empathised**, not just sympathised. Anyone can feel sorry that someone's loved one will die, thus remaining distant to the fact. However, as a politician, to truly represent the people who have chosen to elect you to a position where you are able to facilitate changes, finding problems and generating solutions based on fact alone, misrepresents both sides of the argument.

Gaining perspectives from both sides of the argument is necessary to be aware of the community's feelings on such legislation. To add my perspective, I have added in my facts as well as my feelings to help the reader fully empathise with not only having a loved one diagnosed with a terminal illness, but also wanting to make a choice to end his life the only way he could. I understand it's a bit of a read, however to fully empathise with the situation, I believe it's necessary to hear the history behind my reasoning of legalising euthanasia.

Should you choose to want to discuss further, I am happy to be contacted using my above details. I'm passionate in wanting euthanasia to happen, as I believe it is truly beneficial to those who choose to utilise its services. I also note that as with abortion services, no one is FORCED to utilise it, it is simply a choice made available to those who meet the appropriate criteria.

My History

I was a carer (in addition to my mother) of my late father, [REDACTED]. He was diagnosed with Parkinson's disease in 2006. Parkinson's disease has over 100 different presentations. My father had slow, stiff movements in addition to the typical cramping and freezing of Parkinson's. It was a slow progression at first, he still continued to work his 2 full time jobs at the Dickson or Belconnen Woolworths petrol stations and in the timber department in Belconnen Magnet Mart. He used to be a Builder and he built the home I still live in today.

He got slowly worse and had a slight limp in his leg but it wasn't until I returned home from a 2-month holiday overseas when I was 12, when I realised how quickly the disease spread. His limp was suddenly much more pronounced even as he took my large suitcase down to our car. The disease progression continued until he had to ask me, his then 13-year-old daughter, to complete his paperwork as it was becoming hard for him to write with a pen. His words started to slur and the saddest memory I have, apart from his death,

was when I asked him to sing to me in his big beautiful baritone voice, and his replying being; "I'm sorry Cherry, I can't sing anymore".

The disease again progressed until he had to quit both his jobs as he no longer had the dexterity, nor the speech capability to handle wood or press buttons on machines. By this point, it was increasingly difficult for him to drive our automatic car, but he still had the responsibility to drive me to school. He refused to let me take public transport, so he kept pushing through the pain until I was finally able to get my Learner's permit at the first possible chance. I drove myself to school every day, but he still had to drive home which became more difficult day by day. By the time I got my Provisional licence, he had the opportunity to rest, so he then became chair bound. He needed my mother's help to lift him up off the bed every day, he needed help to be showered and changed, then eventually he became incontinent and needed help to change his pads.

He would still try to grasp onto his last sense of independence and would try to get out of bed or go to the toilet by himself. Each day would be a gamble for me and my mum, will he still be on the couch in the exact same position as we left him before school or work? Will he have fallen in the kitchen? Will he have fallen over midway through trying to use the toilet? All of which and more we have both had to endure, pick him up, and get back on the couch. At times, he didn't even have the strength to stand on his own two feet. But simultaneously, he wanted to put ski boots on and go down the slopes.

Imagine, bring at your peak fitness and then in the span of ten years having everything you can do, and everything you enjoy being taken away from you. Your ability to walk, talk, move, swallow, have a shower, go to the toilet, eat, but just as important, hug your children, console them when they're upset, deliver income to the family, feel of service to your community, maintain friendships or simply play chess at his peak "Grand-Master" level. Each and every one of these things and more got slowly stripped away from my dad. He would try so hard to get words out of his mouth to communicate, but all it would end up was some mix of a mumble and gargle which would finally turn into a mixture of laughter and tears when he realised he couldn't be understood. He was completely cognitively present, so he grew distressed whenever he couldn't use his body to communicate the words he clearly understood. Imagine, understanding everything, formulating replies in your mind to whatever was asked, but your body absolutely refusing to move your mouth in a way to let out coherent words, turning everything into a mumbled mess. As his daughter, I spent the most time with him before and after he got sick, so I was the person that could understand him the most. When it came time to doctors appointments or nurse visits, when they didn't understand him, I had to tell them what my dad said. Even if his words were a jumbled mess, I could make clarity out of them when most people would give up, which was both a blessing and a curse as a 16-year-old. A curse at the time, when you were always being dragged away from doing things that you wanted to do, but a blessing over time when realising that doing these things was special and made you closer together.

His independence finally slipped. He was not allowed to eat solid or minced food, a liquid only diet through a PEG tube directly into the stomach. His words were far too mumbled for even me to comprehend, so either iPad writing or pointing to a chart was the way to go which took a painstakingly amount of time.

The ONE thing he thought he could control, his life, wasn't even his to make a choice with. The law as it currently stands, wouldn't allow for people like him to make a choice to end his life. Where others in more healthier positions may choose to end their lives in more violent or painful ways such as drug overdose, self-inflicted gunshot, some mixture of poison, hanging etc, my father chose to push to the end and completely trust that the doctors would be able to help him in his last moments. A trust, that although was well meant, was unable to come to the execution that my father had hoped for; painless, peaceful relief.

We were lucky enough to be well supported by nurses, occupational therapists and carers, however it came to the point that my father needed 24-hour care. The NDIS, being the new organisation that it was, although had the necessary means to help us, were not able to help us in a timely manner. Which led us to not having the funds or accessibility to afford a full-time carer.

At a time when my mother was at work, and I had to be at university, a community nurse came to see my father. It was at this time, where he later spoke with my mother and said "you can't leave him alone anymore. It's negligent and there may be a legal case involved." This of course freaked my mother out to the point of tears, which I had rarely seen before. If she wasn't able to work, we would lose our house. It was not an option. It was at that point in time where I spoke to one of the main nurses and OT's that went well above their calls of duty, [REDACTED] and [REDACTED]. They had suggested that in the case where we needed emergency support, we could take him to the hospital where they could take him in and look after us while we tried to contact the NDIS for around the clock care.

One week into his stay at the hospital he expressed his wishes to me that he wanted to die. My mother and father had both talked about it many times in the past but wanted to protect me by not talking about it. I had discussed with him that a euthanasia injection was not legal. The closest thing he could do was to not eat, or drink water. So that's when his "self-euthanasia" began, he chose to not eat food.

It's here in the hospital that I have one of the happiest moments with him. My boyfriend of 5 years at the time wanted to ask my dad's permission for my hand in marriage. My father, although "promising" to not say anything to my then-boyfriend, couldn't contain himself. As he pointed to each letter on the chart making out the sentence, he was laughing and crying happy tears when he finally spelt the words "Kyle wants to marry you".

He spent a total of 3 weeks in hospital until he was ready to be moved into palliative care. The Palliative unit had some of the most well mannered, lovely nurses, doctors and volunteers I had ever met. They made every step so seamless and tranquil. But in this point

in time, I started to have my doubts on how "well" his treatment was. The doctors and nurses were perfect, doing everything by the book. But does that mean that the book is currently right?

Every day, more and more morphine and medications were injected into my dad, making him more "numb" and less of my dad.

He eventually couldn't open his eyes anymore; every breath was laboured and painful. He rarely had the energy to open his mouth to breathe. You could hold his hand and ask him questions, at which he could respond with a squeeze. Any time his breath was more laboured, we would ask him if he wanted more pain medication. If he squeezed once, it meant yes.

When the doctors say things like "be careful what you say around him. He is still conscious and can hear you, even though he may not be responsive, and his eyes are closed like he is sleeping." I questioned whether what they were doing was actually treating him and minimising his pain or if they were silencing him by morphine. Essentially locking his mind in an unusable body, still feeling everything, but paralysed from movement.

A recent comment made by Tony Abbott on the Euthanasia topic had led me to really think about my dad's situation which is reflective of others with terminal illness. The comment states: "people who are gravely ill should have their pain relieved, not their lives ended."

From spending time with my father on his deathbed, I rarely saw moments of "relief". I saw my father, breathless with pain or my father too sedated to respond. Pain medication had little effect other than slowing down his breath. In my father's perspective and beliefs, "pain relief" would have meant that his life ended under his own terms.

Contrast to that, I can appreciate that from Tony Abbott's perspective and beliefs that life is a precious gift and should be treasured in all its forms. However, in today's society, one of accepting all religions, skin types and recently, sexual orientation, why does the belief of one person, outweigh the beliefs of another?

March ■■■ 2016. My father's birthday, and now also my father's death day. I stayed with him in the afternoon playing him beautiful Serbian songs by his favourite artists. It started to turn into night and I decided to leave him. I held his hand and said "I love you dad". He squeezed my hand. "Do you want pain medication?" He squeezed my hand. I waited until the nurse gave him what was his final dose of morphine, when I squeezed his hand, said "happy birthday" and left.

As soon as I got home, an hour later, my mother got a phone call. He has passed away. I didn't cry when the person on the phone told me. I went into action and called all family members while my mother was inconsolable. I drove to the hospice and when I walked in, and saw him on the bed, I broke down and fell on the floor. He was still warm. It wasn't

real until that moment, but I'll always remember the rose that the hospice staff left on his chest.

In the moment, you have supportive staff and family members tell you, "he waited for you to leave before he passed away". But then over time, you think more and more about the situation, the regrets and what you would have changed if you had a second chance.

I still have thoughts like:

"He was all alone in his last moments."

"I should have been there by his side."

"Someone should have been there."

"He was lonely."

"He took his last breath by himself."

"I should have spent more time with him."

"I would have worked less if I had known."

But for almost 3 weeks, he could have passed away on any given day. It was so hard to balance work and other commitments whilst trying to spend as much time as I possibly could with my dad. I couldn't help but feel like I was letting other people down week after week of being inconsistent as well as letting dad down by not being around often enough.

If my dad had the choice of picking a day to die, so much pain and anxiety could have been avoided. I could have spent my time solely focused on him, knowing that there is a specific day that he will pass. Not wasting a single moment on anything else. Being with him through to his end, peacefully and together as a family.

After my long recall on the history of my father, I can appreciate that empathising with words on paper may be difficult to envision especially if one has not had similar experiences. So, I welcome the reader to view this video, see the link below.

<http://www.stopthehorror.com/>

Stop the Horror.

This video only portrays 1 month of palliative care. Although most chronic, terminal disease sufferers are tormented for much longer than that, and at home without the aid of doctors, nurses and professional carers.

I cried, every second of this video, as it rings truth and brings up so many memories. The tears, the moans, the thrashing, the frustration, the helpfulness of the staff. It all builds into a moment of sadness which could have been dealt with so much better.

Please watch the video in it's entirety. As it provides a very real representation of things that happen daily.

If upon reading my history and watching the video you can sympathise, but not truly FEEL the sadness and helplessness of being in a situation like this, I ask these questions of you:

Think of the person that you love the most in this entire world. A parent, a sibling, your life partner.

- Can you bear to see them suffer like the man in the video did?
- Could you quit your job (your only source of income) to look after them 24/7?
- Could you handle the financial stress, without working, and still maintain a household? A family?
- Can you lift them off the floor after they've fallen for the 10th time or more?
- Could you do EVERYTHING for them – day in day out – being the ONLY reason why this person is still living? Feed them, shower them change their nappies, clothe them, take them outside, wake them up, put them to bed. Every, single day?
- Could you look at them in the eye every day and say, "it'll be okay – we will just keep pushing" even though you KNOW they are suffering and it will never ever get better.
- Could you do that for 1 year? 5 Years? 10 years? Over 20 years?

The answer to all these questions would be, of course you will try in all your power to help the person you love most in this world. You will try as hard as you can, to provide the best support and love that you can. But no matter what you do, it doesn't change the fact that one day, the pain and suffering will be overwhelming. They WILL degenerate to death. They will have limited quality of life and some people may even want their suffering to end.

That being said, not everyone will want to use a euthanasia service. Some people's final moments, despite suffering with a terminal illness, may have a swift ending with minimal fuss. Others might not be so lucky. So it's so important to give these people a real shot at being able to control at least one thing in their final moments.

Regardless of the situation, every person is entitled to their right to control their own life and make decisions as long as they are found medically fit to do so. As much as it is necessary to protect those who suffer terminal illness who do NOT want to end their life, it is JUST as necessary to provide help and a pathway for those who DO want to end their life.

The remaining portion of this letter is focusing on the practical side of Euthanasia and things to consider whilst preparing future legislature.

My Perspective on Euthanasia

I believe it is absolutely necessary to allow Australians, and more specifically, Canberra's, the right to euthanasia services. Not only can it allow people to have control over the last decisions of their body and to end their suffering, it also provides comfort and support to

the family of the terminally ill patient knowing a date of their choosing as well as dying within the safe and controlled environment surrounded by medically trained staff.

Religion has played a big part in limiting the action of allowing euthanasia services in Australia. It is important to allow people their right to practice their religious beliefs. Yet it is just as important to acknowledge that there are people who do not practice religion, or people who choose to practice only parts of religion who also have their own rights to practice their own beliefs.

Why should a person, who strongly believes that life is precious, and suicide is a sin that should not be committed, has an opinion that outweighs another person's belief (or lack of)?

In a country of equality such as Australia, no one person's right can or should be bigger than another person's. As with other controversial situations such as abortion and gay marriage, euthanasia should be available as a CHOICE to anyone person who chooses to utilise it. Like abortion and gay marriage, euthanasia would not be FORCED upon everyone, but will be available to those who need.

Additionally, why is it okay to euthanise your beloved family pet, who is unable to speak or communicate in any way, to end their pain and suffering, but not a person who is fully capable to communicate their wishes and is deemed medically capable of making decisions? Why is such a luxury unavailable to people who truly wish for their pain to end?

Risks Associated and Management on Delivering Euthanasia to the Community

There are several risks associated with delivering euthanasia services that need to be strongly considered and would require safe guards to ensure that vulnerable, terminally ill patients are choosing to use euthanasia services for the right reasons. Some of these include:

- Patients being influenced by family members to end their life
- Patients wanting to end their life for the reason of "not being a burden to family" who may otherwise be fine with dealing with their terminal illness
- People changing their minds after expressing their interest in assisted dying.

Mitigating these risks would require investigation into currently operational assisted dying facilities around the world and amending their practices to ensure that terminally ill patients are protected.

Risks Associated with NOT Delivering Euthanasia

In a growing population where the average life span is continuously increasing, death from degenerative and terminal diseases are more and more likely to grow. As this number grows, WITHOUT legalising euthanasia, Australia will have more people buried in the public health system. And either, more government money will be forced to go into health to aid the growing population of terminally ill patients, or, the same amount of money will

go into health, lowering care standards as more people will needed to be looked after with the same amount of money.

Conclusions

Legalising euthanasia in the ACT is a matter of not if but WHEN. And why not as soon as possible? Legalising assisted dying services would prevent suffering endured both by the terminally ill and by the surviving family. Having the choice will provide peace of mind for people who are terminally or degenerately ill, knowing that when it's close to their end, they will not have to suffer to struggle through to their finishing line. They will be able to go on, knowing that there is a choice to ease into death without the pain and suffering of those who came before them.

Thank you for taking the time to read my long view into euthanasia. I push so hard for it as I know my father wanted the choice so badly and I want to grow old knowing that if I am ever as unlucky as my father was, that I too will also have the choice that my father never did, to die peacefully around family and friends.