

**Submission
No 3**

INQUIRY INTO PROVISIONS OF THE VOLUNTARY ASSISTED DYING BILL 2021

Name: Mr Arian Levanael

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THE LAST DANCE – My plea for Voluntary Assisted Dying in NSW

by [Ari Levanael](#)

Where do I begin such a morbid tale? The slow torturous agony of cancer treatment? The suffering? The disrespect? The poisonous drugs? The brain tumour? The surgery? The delirium? Being put into a permanent state of unconsciousness leading to death? I could go on.

I could also talk about the beauty in the mystery of it all, the connection I feel to life in his death, the strength, the honour, a whisper of awareness that is spreading through the people. That butterfly effect. Change is coming.

Let me take you back on a journey, as my dad was suffering...

The doctors and nurses kept saying when my dad was in hospital that they would “make him comfortable” and almost two months later when they walked in to check his 24-hour slow drip morphine and cocktail of other drugs that I could barely even pronounce they said, “he looks comfortable”. Does he? I ask. Really? He looked bloody awful if you ask me or any one of his many visitors that walk in to wish him well on his next voyage. He was drugged out of his mind and had been for about seven weeks. He had had enough and so had I. But this tale is not really all about me.



Can you imagine experiencing someone you've loved and known for 47 years slowly lose their dignity? Watch them cry out in pain at the hands of people that say they know what they're doing? I shared this pain, cried with him and I experienced the worst days of my life over those many weeks; and I know my dad did too. What he felt has sent shock waves through me, that I will never forget. They woke me from the ignorance of what is happening to the dying in this country and it is shocking. Our family listened to the ‘experts’. That said they will “try this and that”, and that “it might cause this or that” (and it did), then that “they didn't think this would happen” (and it did).

I listened to the unintentionally condescending tones in the voices of some of the doctors who really didn't hear anything I said. They just nodded politely, then provided me with some text-book response that, at times, a robot could have explained with more feeling. I know, I sound harsh: the nurses and doctors aren't to blame, are they? Some of them are lovely people and I admire them greatly for the job they do. In fact, I'm not blaming anyone.

But government legislations and the medical profession (and all the bureaucracy entailed) has a lot to answer for. I'm angry at the damage done to my dad.

We don't want him to suffer, we said. He would never have wanted this...

He said before he went in for surgery, that if he couldn't walk the dog anymore and do the things he wanted to be able to do when he came out of hospital it was to be a 'DNR' (do not resuscitate) on the operating table. But he made it off the table after the full-on brain surgery, and it's what happened next which is where the trauma happens.

I was sitting next to my dad, in palliative care, listening to his rasped breaths, and hoping that soon they would become irregular and stop all together, so his suffering and that of all of us close to him could also stop. So that we could begin to find a way to get on with life without him. I see his sunken face, drawn and pale, and still find the beauty in this man. This father who laboured so bravely to raise me, and the cheeky humour that brought joy to so many. I was sharing his breath in that small room only 15 minutes away from the home he worked so hard for.



It's terrible you know. My dad got up at 4am every morning for a lower-than-average wage to pay off the house of his dreams, raise a family with a woman he's loved for 60 years, paid loads of taxes, didn't complain about any of it because that is 'what he wanted to do' and now the result is this! He was forthright and dignified, positive and filled with that bright sense of humour even through all of his pain and confusion. He bought a smile to the nurses and doctors faces even as he went through the torture. Hopefully the chemicals and delirium blanked it all from his awareness.

I know he waited patiently for it to be over, to be able to go back home, to walk the dog, to get in the garden and paint the house again. I wished that for him of course, we all did, but now I just wished him a good death. But that's not what happened. He held on. This is not a way to live and die with self-respect.

As a devoted animal lover my dad was the first to take any of our furry animal family to the vet when they were suffering, to stop that suffering and hold them 'til the end. It broke his heart every time, but he did it because it was the right thing to do. It's obvious if you see. Could you imagine contemplating suffocating your dad to death so you could put an end to his suffering? This coming from me, a person who is awed by all life and would never hurt anything intentionally. I had been tortured by this thought for weeks, on a roller coaster of emotion that bought me to express this. I had all the possible thoughts, the... is he getting better?... will he eat and walk again... can he go home?... thoughts that go round and around. But, as my mother says, now we just "let nature take its course". But what has pumping my dad full of drugs (but not enough to kill) got to do with nature?

Keeping dad sedated (often called 'continuous palliative sedation'), but apparently able to hear all the conversations going on around him? Conversations that whispered of his death, his treatment, his cremation... I was sitting right next to him. I hope he didn't understand. I'm determined to give respect to his body, his life, now that his breath stopped and everything that made him Barry flew off into the mystery.

When I looked at him I saw my face, my son's face, and all our relations and ancestors past, present and future. I contemplate a better way to live with dying than this. But, according to the current law in New South Wales, Australia, it is illegal to voluntary assist the terminally ill a clean death (other than in Victoria (since June 2019) and Western Australia (in mid 2021)). This means it is a crime for me, or any person – medically qualified or not – to aid or abet another human being to commit or attempt to commit 'suicide'. Is it suicide though? Is it murder? No.



As of March 2021, active human euthanasia (medically assisted suicide) is lawful in the Netherlands, Belgium, Colombia, Canada, Luxembourg, Spain and here, in Western Australia, Victoria and Tasmania. Even though, currently in this country, it is legal to both suicide and attempt suicide, to refuse unwanted, painful and futile medical treatment leading to death from an illness (I wish we knew this sooner). It's also legal to refuse food and drink, leading to death from starvation and dehydration, whether you are able to eat or think for yourself or otherwise. This has been a tricky one for me to watch. Nurses that did not persist in feeding my dad because he said no. Even though he was in delirium and hasn't

understood what he wants or what they are doing. The brain is an organ of vast complexity but, once it's been hacked into, often some of the synapses, memory and storage – that which represents humanity as we understand it – won't work properly so... It's also legal to be administered large doses of pain-relieving drugs, even though this may hasten a person's death, and are, otherwise against the law.

The bureaucracy surrounding this has to change. To listen. There is an art to dying that we need to understand and put into practice. We need to contemplate and talk about this.

We must declare a legislation that enables competent adults, experiencing non-relievable suffering from a terminal or incurable illness, to receive medical assistance to end life peacefully at a time of theirs, or their families', choosing.

I emailed my local member of parliament about my frustration and to my surprise I got a response. Soon, he said, the issue of voluntary assisted dying laws will be put before the parliament, again. And my story and my dad's experience will be at the forefront of his mind. It's a start. But it's too late for Barry. Tricky. Where was I?

So, what happened?

One morning at the end of January this year 2021, my dad woke up and was talking to my mum and couldn't finish his sentence properly. Then it happened again when he visited our neighbour. He was beyond distressed at not be able to get the words out. My mum took him to the local doctor and they booked him for all the tests. Scans, bloods, and eventually an MRI. By the time they had waited for the next appointments they had eventually diagnosed that a brain tumour was affecting his speech. The next appointment was with a neurosurgeon, many weeks later. First frustrations were already making the hairs on my arms prick up.

On the first of March 2021 he entered the public hospital system. He could have chosen to go private but insisted that this was the 'best hospital' in Australia, and he would be looked after. The surgery went fairly well, they cut out all the tumour (instead of taking a biopsy) as they said it was "aggressive". He was up and about, eating the disgusting hospital food (that is supposed to be nutritious) and I was chatting to him the next morning, with that huge scar on his head. He seemed a bit confused with sentences, but we could understand each other. A few days went by; he was joking around with all the nurses and didn't seem to be alarmed. They said he could be home soon. Great, he could get back to the dog and the garden. Or so he and we thought. Always so positive, even in the face of such a violation as this. The doctors decided to do another scan because they had found large quantities of an anomaly in the tumour which could mean something else. I don't know why they hadn't done this scan before, but anyway, they found out he had lymphoma of the central nervous system and he would need to start chemotherapy straight away. That was their next mistake.

My dad was 77 years old, and he had just had a massively invasive surgery on his brain. They were giving him steroids and other medications and his behaviour was getting a bit strange. He never liked sitting still, and he was confused and angry because he was getting up early, showering, then waiting all day before someone would tell him what was going on.

Eventually, after much frustration (nutrition included), we figured out what needed to be done before they started chemotherapy. I was there when they gave him the first and only doses. If you have never seen it, chemo chemicals are covered in a black plastic bag and the concoction is bright yellow. It looks like it comes straight from an episode of The Simpsons at that nuclear power plant. I remember telling him that he might get some side effects from the chemotherapy and to stay strong. His response was “it’s not going to bother me”. He was wrong.



I've heard a saying that "death waits for no-one". Well, death sure took its sweet time with my dad. And all this could have been avoided if we lived in Victoria or Western Australia, or a different country. So many things could have been avoided. I spoke to one of his main palliative care doctors and they told me that sometimes people can last weeks without food or water, at it just depends on the situation. Seriously? The prospect of my dear dad going through weeks of starvation is brutal. Is that the best death he can get?

He's made it through the next morning and the next day without barely opening his blue glassy eyes. He only did when they moved his stiff, aching body, within the bed that he had been in for weeks and weeks. I stared into them with such deep love and affection that only a son of the mysteries could do. I know he heard me, felt me as we breathed each other in that room. For a man that was active and outdoors most of his life this was a bitter end to a vitality he loved. That's one of the reasons I sat there, with him on this vigil. To give him back the individuality and person-ness that had been taken from him, to provide the respect that I wish I had given when I was a rebel teenager. It worked both ways. But that's another story.

So where to next? His breathing had the raspy sound that some call the death-rattle or cheyne-strokes breathing. It doesn't sound too good. Kind of like Darth Vader on a good day. Every time I walked in the room it was like I was being punched right in the heart, and my instinct was to touch him and whisper to him in soothing sounds, just like he did with horses. What else could I do? I kept saying to him I wish I could help; I wish I could do something. But I couldn't, it's against the law. I couldn't end his suffering. I would be thrown in jail and then what about my son and my job and my life? But, this was animal

abuse, and no-one likes do they? How could anyone deny his right to die with a speck of dignity.

So, I waited and listened for his breathing to get worse, for the slits of his milky glazed eyes to close and the warmth to drain from his body that had loved his life with its every inch. I researched the washing and wrapping of a dead body because that was my next duty.

I played his favourite songs on a playlist I made for him, I had done it for the whole journey of this, so that hopefully, somewhere in him, it brought comfort. Because this suffering is plain wrong. I just wanted to take him somewhere beautiful. I did my best to return the dignity that was taken from him through this whole, useless, drawn-out, pointless and dehumanising ordeal.

I wished, in this grief, that he'd had a good death.

Hopefully, somewhere and most importantly somehow, he felt my presence – this love – and that could bring him grace.