Submission into the Voluntary Assisted Dying Bill 2021

Submission No.:	446
Submitted by:	[redacted]
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Position:	I/We support the Voluntary Assisted Dying Bill
Comments in relation to:	Eligibility criteria* ,The request and assessment process,Administration of the substance,Safeguards,Conscientious objection by either individuals or entities,Oversight and review
Attachments:	See attachment
Submitter Comments:	

Dear Queensland Decision Makers

Thank you for considering my submission regarding the draft bill for Voluntary Assisted Dying Queensland 2021.

I dedicate my comments to Duncan Pegg (deceased) and honour his service and memory as a fine human being, an exemplary Member of Parliament and a compassionate man who gave his adult life to serving the State of Queensland. Vale Duncan.

IT IS WITH GREAT HUMILITY THAT I SUPPORT THE DRAFT BILL AS IS

I thank the past committee, the secretariat staff and the Queensland Law Reform Commission for your integrity and dedication to the enormous task of delivering a draft Voluntary Assisted Dying (VAD) bill for Queensland.

I commend this draft bill to the 2021 Health and Environment Committee and invite other interested parliamentarians, their electorate and Ministerial staff and members of the public to have mercy on this dying woman and read my submission.

WHY I CAMPAIGN FOR VAD

My first experience of witnessing a devastating death was in 1981, when my partner died during chemotherapy, aged 45. It was ‘guinea pig’ treatment for adult leukaemia and in those days, we were in an isolation ward wearing full personal protective equipment (PPE) and restricted to one visitor per day. After almost four months of no success with chemo, my partner came back by ambulance from a large city hospital to our hometown for her last three days of life. There was no hospice nor specialist oncology ward, but the care given in our local hospital was very kind-hearted, patient-focused and professional.

During the ambulance trip ‘home’, my partner’s bowel and contents prolapsed severely, causing dread and fear for all of us. It was a horrible experience, both for her and for me. We had been warned that she might not survive the road trip and the ambulance drivers were volunteers as it was a ‘compassionate run’. The driver took a detour to an ambulance station off the freeway about half-way from home. The best the paramedics could do at the stop-over was a very thorough clean-up, administer morphine and then manually push the prolapsed parts back into her body as far as possible. They then packed and bandaged before putting large incontinence pants on my partner. Such as her trauma and distress, the journey to our hometown continued without any communication from my partner.

Soon after arrival at the hospital, the emergency department doctor advised my partner was in a coma and she was admitted to a private room in a women’s surgical ward. The oncologist described her condition as organ failure and sheer exhaustion of spirit. However, the specialist was also quick to say my partner was most likely conscious of us being with her. This state continued for about 48 hours, but I read to her and talked quietly about our good life and passed on the prayers and loving messages from family and friends. In the early hours of the third and last day, my partner opened her eyes and I told her I loved her and that her trip to heaven was here. She nodded, said ‘thank you’ and took her last breath.

You might ask, what was bad about that? My partner was hospitalised a long way from home for the last four months of conscious living. She did not see her elderly and very frail mother as her mum could not travel. By the time my partner arrived home to our local hospital, approximately one hour from her mother’s home, she was unable to communicate and her mother said she was too distressed to come and sit with her near-dead daughter. My partner’s mother preferred looking at the photo book we had made of their life together, including a few shots from hospital in the early days when her daughter could sit up and smile for photos.

During the emergency in the ambulance on the road trip home, my partner’s eyes showed two things – panic and shame. She was a modest and proud woman and the awful smell and loss of ability to control her bowels was the final indignity that I believe made her stop speaking. She always said, ‘don’t let them keep me alive when I can’t get out of bed to go to the toilet’. We were well past that point in the isolation ward for several months, but there was no option to die with dignity, in the loving companionship with family and friends; or arrest the toxins of chemo that killed her immune system.

Had the law allowed, my partner would have opted to die with medical assistance at least three weeks before her final humiliation in an ambulance on the way home. She could have experienced a dignified and quick death, without suffering, and in the company of her loved ones. Surely everyone deserves that small mercy at the end of their lives. After her death, I sat with my partner for 20 minutes before telling the nurses she had gone. They looked after her gently and modestly and after an hour, the funeral director came to the hospital. I found it hard to let them take her to a lonely place and then to call a cab knowing I was going to our home alone and she would never be with me again. My emotional suffering and torment would have been much alleviated had my partner been permitted to die quickly, painlessly and at a time of her choice.

I was 24 years old and had lived with my partner for six years – my whole adult life. After being home alone for four hours, I called our best friends who set out on a two-hour car journey to come and stay with me. I also rang my mum and dad who arrived within an hour with fresh bread and milk, but no words. We cried and had a cuppa then I went to bed, not to sleep, but to weep quietly for the loss of a dear woman who deserved better in life and in death.

MORE REASONS TO CAMPAIGN

Bad deaths occurred again in my life and the lack of a compassionate, medically-assisted death, haunted me.

My brother died at aged 48 of lung cancer during chemo and soon after vascular surgery. If my brother had been told there really was no hope of any improvement, he would not have put himself through what turned out to be useless chemo, pointless vascular surgery and then a torturous, painful death. My brother would not allow his children to visit in the last week of his life and did not allow us to tell mum that he was dying until his third last day. He believed his frailties and largely uncontrolled pain, were too severe for his 60-year old mother and children, aged 11 and 13, to witness. In his last 48 hours, my brother was at home in a drug-induced coma and thankfully, mostly unaware of his incontinence and other very unpleasant side effects of a body battered by chemo. What saddened us most was that he took his last breath without knowing he was going, so there was no opportunity for him to say goodbye.

Mum and dad had similarly unpleasant dying journeys. Mum lingered, bed-ridden and incontinent for 13 months. Her care was described as palliative and 'kept comfortable', but as mum was almost non-communicative in the last two weeks, it was impossible to know if she in fact was 'comfortable' and hard to glean any quality of life. When she did speak in the year before her death, mum said 'this is not life, it is an existence. Pray that it ends soon'. And pray we did, but 13 months of personal humiliation and pain did not seem like a very prompt answer to a purposeful, prayerful request.

Dad died of complex conditions including chronic obstructive pulmonary disease (COPD), prostate cancer and septicaemia. He was hospitalised in ICU for nine weeks before opting to discontinue all treatment. He knew the sepsis was going to take him out. On that day, he saw three of his children to say goodbye and we called our brother who lived interstate. Dad was transferred to the ward at 2.00pm and died at 6.30pm. At least dad had the option he needed, a guaranteed option to die with dignity and say goodbye to his children. However, had the law allowed dad to go earlier, he would have gone a month before and his son from Tasmania would have been with him. Dad would have chosen to be at home in his hostel room with his dog Tammy and his four children.

My mission for others, choice and dignity in death, became an active campaign when I met Tanya from VALE and Fiona from Nurses Supporting VAD at Queensland Parliament House in 2018. At that time, I had no idea that in the near future, I would need VAD myself.

WHEN CANCER GOT THE CAMPAIGNER – MY OWN STORY 2021

In early December 2020, I was referred to a gastroenterologist to address months of vomiting, abdominal and lower bowel pain. I have a high tolerance to pain and have always been inclined to vomit, so I wasn't worried about investigative surgery and an overnight stay in hospital. The results came back as oesophagitis, irritable bowel syndrome and the removal of benign polyps. I was relieved.

A concerned friend suggested I have a routine breast screen, which I did prior to Christmas and received very kind and professional service at Wynnum-manly Community Health Centre, Gundu Pa. The team advised that due to the Christmas holiday season, the results might not be available until mid-January 2021. I was happy with that as I wanted to enjoy some family time without worrying about medical issues.

On 4 January 2021, I received a call advising me to attend QE2 Hospital Breast Screen Clinic as a matter of urgency. After almost six hours with the very best care, I was invited back in three days to be advised that I had cancer in both breasts. On 18 January 2021, I saw a profoundly good breast cancer surgeon at [redacted], and underwent a double mastectomy on

25 January 2021. It was quick though parts of it were very nasty and painful. For example, nuclear medicine is used to try and find the cancer invasion into lymph nodes so the surgeon has a target to biopsy or remove nodes entirely for pathology testing post-surgery. I understood that procedure involved injecting a dye into my nipples but until it was happening, I did not know that procedure was torture. No local anaesthetic or any form of numbing agent was applied, and a horse-sized needle was injected six times in each nipple. As mentioned earlier, I have a very high tolerance to pain, not needing pain support after injuries or during dental work; but this pain was excruciating. I had a panic attack on the fourth injection and begged the young female technician to stop until I calmed myself. She stepped out of the room for approximately five minutes and then returned to say 'it really is better if we get this over with fast'. Terrified and praying for courage, I was relieved when the procedure ended. The technician pushed my trolley into a waiting bay where I spent 10 minutes alone thinking 'no-one told me how bad that procedure would be, do I really understand how bad removing my breasts will be? And, do I really want to have breast surgery in 20 minutes?' I wondered why the medical team didn't give me my pre-med before injecting the nuclear dye when my operation was scheduled to take place within half an hour. I seriously considered not going ahead with surgery fearing death far less than the loss of quality of life.

Medical systems have evolved as places to 'get things done', and there are gaps in co-ordination. Some professionals have little time for kindness. Those who do, seem unaware of the pain and suffering imposed by others. I truly believe we can do better, and research reveals that injecting dye into nipples is done with mild anaesthesia in other facilities.

Bewildered, afraid and isolated, I was transferred to pre-op where I prayed for forgiveness for any wrongs I had done throughout my life and for blessings for my partner, family and friends. My surgery was long, but it went well. I was very sick and frightened in the recovery ward as I was vomiting, and the recovery team were focussed on getting me to the ward in the 'usual' turnaround time of two hours post-surgery. I am not one to ask for help, but I did ask them not to transport me on a trolley along open corridors and in public lifts while the vomiting and nausea persisted. I was kept another 30 minutes and then transported without incident.

The ward team were wonderful, but I was so drugged I hardly understood anything, except I recall saying 'keep the bag there as I am going to vomit'. My wife was allowed in to see me late in the evening and the shattered expression on her face told me that I must look poorly. I asked her to take a photo as I sensed there was more to this journey than accepting the loss of my breasts. The only other words I said were 'this is terrible but don't stay.' My pain was under control, but my bewilderment was not. I did not want my wife to be traumatised by my fear so I asked her to go home and promised I would contact her if I needed support. Fortunately, a kind family member had driven her to the hospital and waited with my wife while I was in the recovery ward. I will never forget the relief I felt knowing that my wife was safe, and I was through the worst of it. Or so I thought!

In the ward, six hours post-surgery, I asked the team to stop the 'hard' drugs for pain. It was difficult for the nurses as the drugs were charted for 72 hours, but I knew those drugs were causing my nausea. Fortunately, I also knew I could manage the pain better than the vomiting. A call to the surgeon resulted in charting a temporary lapse in the pain medication and, fortunately for me, they were never reintroduced.

I asked to go home early on the morning of day two post-surgery, and even though my surgeon was surprised, she graciously trusted me. I was discharged with a box of Panadol tablets having refused a script for stronger medication. My pain was manageable and despite the drains from a chest wound stretching the expanse of under both arms across my chest in one big line, I felt confident that we could manage at home. And manage we did!

I was able to shower myself on the first morning after surgery and continued to do so at home. It was a slow and steady process, but the warm water felt good. I experienced the humbling lesson that, at age 63 and for the first time in my life, I needed to be looked after. Applying surgical stockings and emptying and measuring drain discharge fell to my wife, as well as every other household and acreage duty that I had managed as a recent retiree while she worked 12 to 14 hour days as a senior public servant looking after vulnerable clients. Fortunately, my wife's 32-year service resulted in years of accrued sick leave, so she became my 'carer'.

The transition for me was gentle because I felt loved and safe. The experience for my wife was not so easy. Seeing my frailty and the huge chest scar for the first time was shocking. We both cried, not for the physical change, but the scope of the injury to my body and the length of time that would be needed to recover.

On my first post-surgery consultation, I was advised by the surgeon that the cancer had spread to lymph nodes and the chest wall. Surprisingly, each breast revealed a different cancer, so I had two types of cancer and it was present in four places. 'Metastatic' was a word I hoped not to hear. Rather, I wanted to be told 'we got it all and your follow-up will be regular breast screens'. I attended all my appointments alone, choosing to hear the news by myself and have the freedom to ask hard questions and receive answers without traumatising my wife.

All along, without knowing my prognosis, I thought 'if I am cactus with cancer, I am not having chemo to treat it'. I had seen the devastating effects of chemo on my loved ones. To me, chemo was the systematic destruction of the body in the hope of gaining some length in life. Without quality, longevity was of no interest to me as I had lived a wonderful and much blessed life. But how things change when your tribe tell you how much you are loved and needed. And your wife says, 'I will do anything to support you'. Furthermore, I have friends still on the breast cancer fight back after 15 years and several recurrences, and their courage inspired me to give the chemo treatment plan a go. My brothers too had undergone radical and recent treatment for prostate cancer, so in the face of all that bravery, I felt like a wimp for wanting to surrender my life without a fight.

Nevertheless, upon meeting my wonderful chemo oncologist, I attended alone to ask the questions 'how long and what kind of death if we don't treat it?' The answers were not unexpected; after all, I had been living with the cancer (exhibited as severe fatigue, pain and intermittent vomiting) for at least seven months before going near a doctor. The pathology revealed the cancer was advanced and had spread to nearby areas, so I was closer to ‘cactus with cancer’ than I ever dreamed I’d be! Faced with a best guess of six good months of life left and the final weeks suffering a painful death if we didn’t treat the cancer, I chose chemo for six months followed by radiation every week day for five weeks.

That choice has severe consequences and I am less than half-way through the treatment. As at June 2021, and having been on chemo for less than three months, I have been hospitalised three times due to severe side effects, spent 70% of my time bedridden and dependent on my ‘carer’, and reduced to hiring and using an outdoor portable ensuite. The toxicity from chemo is so high as to potentially destroy our $30,000 environmental waste system (no thanks to Brisbane City Council for refusing town sewerage to a very small acreage suburb only 14 kilometres from the CBD). The expense of hiring the portable ensuite and the very cold and rainy nights have not made the chemo journey easy.

In addition, our home is a Queenslander and I can’t manage stairs anymore. I’m reduced to living in a detached granny flat near the house and being visited regularly throughout the day by my wife and pets. It is very comfortable but not desirable at this time in my life when my own bed and the joys of our real home upstairs would be much nicer. I thought the final straw was having to buy a mobility walker so I can safely attend appointments, but that was trumped by finding out my chemo treatment has already caused liver damage. No wonder I was in so much pain and desperately fatigued most of my time. Still clinging to the Panadol to reduce pain and ‘toughing out’ the fatigue, I was very disappointed to discover the liver damage required a step down in my chemo treatment. While the change of drugs might be as effective, it extends the chemo treatment by several months, thus delaying the radiation and hormone blockers still to come.

Oh joy, oh bliss, having survived menopause without any drugs, I will eventually be on hormone blockers that will bring on all the symptoms of menopause – permanently. Living with that for the rest of my life is just as frightening as the cancer! Cancer and chemo are tormentors that distract me from my good life. Stingy pee and burning, itchy skin, mouth ulcers, headaches, sore eyes, nose bleeds , constant pain and numbness in fingertips and toes, are all normal on chemo, but when I am very tired, they make me cranky. Cranky is not good for harmonious home life!

YOUR VOTE

I wrote my story so anyone who votes on law reform for VAD might pause to consider the needs of others. It is not about how you feel or your religious or ethical framework. ‘A conscience vote’ does not mean you can ignore the truth of your constituents.

Your vote is about supporting the will of the people you serve and more than 80% of Queensland constituents support choice at the end of life.

Churches will tell you granting our choice to leave this earth a little early is immoral or against God’s will. They will tell you that this legislation will erode society and cause a slippery slope towards discarding life too soon.

We will not tell you any predictions. We will only speak for ourselves. We will stick to the facts. We will discuss our lived experience. This is true evidence.

My dying friends and I simply want to die with dignity. We did not cause our own terminal illnesses. We want to live as long as we can function as independent, loving human beings. We only want to say goodbye to our partners, families and friends when our bodies have already failed us and know that a pain free easy death awaits us.

Granting our dying wish won't hurt you in anyway. Nor will it impinge on the needs or rights of others. Death is coming for us; we just want to look it in the eye, without fear, and as we thank the world and our significant people for our good lives, all we ask of you is:

LIVE AND LET DIE

ADDRESSING THE 'DOOM SAYERS'

I address the 'doom sayers' who offer false argument that introducing law reform to allow safe-guarded VAD is a creating a 'slippery slope'.

I do this submission in support of the draft VAD legislation so the thoughts of the dying become a matter of public record. In addition, because many powerful, institutional Christians in Queensland will not listen to the voices of the dying.

Introducing VAD legislation to Queensland will not undermine the fabric of society or establish a group of murderers destined to kill their relatives. Similarly, those of us who are already dying, will not suddenly become proponents of suicide.

Churches have a very 'good run' in Australian society and have greater wealth than dying people. Catholic institutions in particular have less worshippers but escalating demand for education, aged and health care. They are not philanthropic and do not distribute their wealth and sadly, they are dominated by ageing men in all the powerful positions. Those same men have lived an adult life of privilege, rarely experiencing poverty and homelessness and never wondering how they will meet pharmaceutical expenses.

That being said, I think the contribution of staff and volunteers and many priests in Catholic institutions is of the highest order; and in most cases, these direct service providers live a life of vocational commitment without ever receiving wages commensurate to the hours of dedication they give to their 'clients'.

So I declare myself to be a devoted Christian – not aligned to any church, but practising my Christian values every day of my life. But does my faith mean I assign any greater power or wisdom to the Christian institutions that seek to rule society? No way! Some would argue that in Australia we have a clear separation of church and State, but constitutionally, we do not. Therefore, it is up to society, through our democratic processes, to guide social justice and seek and support law reform. As our people evolve and the world we live in tries to enable a level playing field, or egalitarian platform for citizens, wealthy churches will not share their power, nor pay their way.

Politicians have a greater right to determine the law and guide the experience of citizens than any church should ever have. That is democracy, and for all its flaws, it is fundamentally the Australian way. While churches have free reign to dictate and coerce without meeting basic standards of accountability—for example, paying taxes, embracing other cultures, including women, respecting other faith communities, paying genuine reparations to victims of abuse, authentically recognising and respecting First Nations People—the opportunity for vulnerable Queenslanders to thrive is diminished.

Therefore, churches pose a far greater threat to equality and free will by desperately and irresponsibly opposing choice, than any VAD campaign or VAD law reform will ever pose to our State.

My message to churches in Queensland (in the context of VAD) is simple:

> Do not deny me the destiny our creator has already chosen for me. Do not speak for God when God speaks directly to the suffering and offers hope to the dying. Be humble in your faith practice, not judgemental, overbearing, all-wielding of power. Be gentle with those whose faith or lifestyle differ from yours.

Finally, instead of blaming government, institutional failure or funding limitations for example, in palliative care or low wages in your own facilities, pay taxes. Your withheld taxes would easily fund the improvements in palliative care that our superb Queensland practitioners want to make.

The government does not have a bottomless pit of money, but seemingly churches do. You choose to withhold taxes and then you receive enormous amounts of funding, both capital and recurrent, but there is no evidence that you distribute your wealth to the poor.

In closing, your desire to limit my life and death experience, based on some notion that you are superior to me in God's eyes, is unconscionable.

In summary, I do not accept your moral vision, nor do I respect your spokespeople who oppress others. Your aversion to human diversity is wrong. Your belief that suffering at the end of life is worthy, is cruel and a perversion of our creator's love.

[redacted]
Address and phone number supplied to Secretariat