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8<sup>th</sup> June 2021.

The Queensland Parliamentary Health & Environment Committee  
A Legal Framework for Voluntary Assisted Dying in Queensland.

Re: A submission in Support of VAD for the terminally ill.

#### Formal Qualifications & Experience

I completed my Nursing Registration in 1988, later attaining a Bachelor's Degree in Health Science (Nursing), from Armidale University N.S.W. Employed at [REDACTED] Base Hospital for three years, then relocating to Sydney in 1992, and commencing employment at [REDACTED], a dedicated Palliative Care Hospice. This facility now comprises a range of other health services.

During my twelve years at [REDACTED] Hospital, I completed Post Graduate Studies in Advanced Palliative Care at the University of Technology Sydney, also gaining accreditation as a Clinical Nurse Specialist in Palliative Care. In 1998, I was seconded for a period of four months, to [REDACTED] Hospital as CNS, working alongside Dr [REDACTED], attending Palliative Care Specialist from [REDACTED] Hospital. Additionally, I was a consultant on [REDACTED] Community Palliative Care Team for a period of two years. My final four years at [REDACTED] I served in the capacity of Level 3 Supervisor. Relocating to Queensland in 2004, I was employed a further seven years delivering Aged Care, until retirement in 2013.

#### Overview

Voluntary Assisted Dying (VAD), is both complex and controversial. For those opposed on moral or religious grounds, I doubt any amount of information provided, either anecdotal or as hard evidence, would be persuasive enough to change their minds. Likewise, Doctors as conscientious objectors, who decline to assist terminally ill patients, in their quest for VAD.

With due respect to these groups, I completely support their right to take whatever position they might choose. However, I totally reject the idea, that they should have the right to impact upon choices affecting my life, OR my death.

Much has been said by supposedly 'informed' people, that improved Palliative Care, can achieve 100% symptom control. This is...just...not...true!

No-one could be more passionate than I about effective Palliative Care. I have been a staunch advocate, knowing what great benefits Palliative Care can deliver in supporting those with a life limiting illness – not only with cancer, but many other terminal health states.

Palliative care has never been about giving up hope, nor does it centre on dying. It more readily focus's, on living the best life possible, while managing the prevailing health condition. Under most circumstances Palliative Care provides excellent pain and symptom control – BUT NOT FOR ALL CONDITIONS. For a small percentage of terminally ill people, their disease creates some horrendous side effects that the best Palliative Care is unable to alleviate, or control. It is for this group of people, that the most compassionate, and compelling alternative, is the proposal for VAD.

All I ask, is that you bear with me, and read the following with an open mind.

### **A Personal Journey**

Tiredness had been my companion for a-while. Everyone's busy, and the stress of working, raising kids, keeping house, and paying off the mortgage not uncommon.

A few friends started complimenting me on my weight loss, jealously asking how? I assured them I wasn't keeping any diet secrets. My weight loss likely linked to my decreased appetite of late. Time constraints often had me grabbing anything at hand to eat, quickly wolfing it down. Probably accounting for increasing bouts of indigestion, and gas. I really needed to slow down. Sometimes I was just too damn tired to eat.

Occasionally my stomach felt quite bloated, with an odd pain every now and then in the abdomen...a bit early for menopause I reckoned. I had a fleeting thought, maybe I might be developing a stomach ulcer? Mental note, mention it to the doctor at my next check-up. I hadn't been to the doctors since my last pap smear, a couple of years ago.

The pain under my right rib cage was hardly worth mentioning at first, until it started to extend through to my back. I began to wonder if maybe it might be gall stones instead of a possible ulcer? The pain was intermittent, so I never really gave it much thought, except when it was present, and I did plan to follow up on it. It seemed to be worse at night somehow, at times extending deep into my abdomen.

Awoken suddenly in the middle of the night, the pain in my upper right abdomen significant, I was a lather of sweat. I hoped I wasn't coming down with a stomach bug? Suddenly nauseous, I realised I was going to throw up. I made it to the toilet, the taste of acrid bile remaining in my mouth. I turned on the light to wash my hands and rinse my mouth. I got a shock to see the face looking back at me in the mirror was jaundiced. Bugger! Gallstones. Hubby would have to get himself off to work today without my prompting, as would the kids to Uni, I was off to the doctor.

How long had all this been going on I was asked? Hard to think back to when it all began. I hadn't really connected all the vague things happening until the jaundice started, maybe two or three months?

A thousand questions followed, what were my bowels doing, what did my motion look like, my appetite, any nausea, tiredness bla, bla, bla. Lastly an abdominal examination, Doc took some time, and despite the gentle nature of the examination, a few times he hit a sore spot. His frown had me a bit concerned. I asked a few questions, but he wasn't keen to engage in conversation, a busy day ahead no doubt? He went out to the desk for a brief while. Sitting in the surgery waiting for his return I looked at my hands. The jaundice was increasing, and my skin was beginning to get itchy. The vague stomach pains were becoming more frequent and more intense, and I was increasingly nauseous, especially when I thought of food. I wasn't eating much anyway, trying not to overload my bloated stomach. The Doc returned with a bunch of referrals. Pathology forms for multiple blood tests, a urine test, stool sample, and a CAT scan. All this arranged by the Doctor while I waited, and all ASAP. I had never had so much attention! Another appointment made for follow up results the week following the CT scan. Some prescribed medications to help settle my symptoms, and I was out the door. I had an uneasy feeling, but dismissed it, putting it down to being overtired, having missed half a night's sleep.

I sat waiting in treatment room number two. The Doc came through the door with a stack of papers, my results no doubt. He'd been our family doctor for ten years, and more like a friend for much of that. I went to flash him a big smile as he entered, but it froze on my face. I didn't even need to hear the words, his expression said it all. His eyes not quite able to reach mine, he read from his notes, his voice devoid of all emotion. Advanced Cancer of the Pancreas, with extensive metastatic spread. His voice continued, but I had stopped listening. I was going to die. Maybe there was a mistake? I'm 43, fit, active, I don't drink or smoke? This can't be happening.

It's not even the thought of dying that completely shatters me, it's thinking about all the milestones I am likely to miss. Seeing the kids graduate, make a career, get married, have my grandchildren...Grow old with my partner!

"How long?" I heard the words, saw the Doc's head come up to look me in the eye. Did I really ask that? Obviously! It must have been me, there was no-one else in the room. He took a long time before answering. I felt dizzy, I realised I was holding my breath.

"No-one can be sure...maybe a year?"

Barely above a whisper I asked, "Does anybody ever beat pancreatic cancer?"

I could hear the pain in his voice as he spoke. "A small percentage if they are diagnosed early."

(Later I learn maybe only 2% if very lucky, and the prognosis for advanced pancreatic cancer is somewhere between 3 and 8 months. I am already Palliative, a word not mentioned yet).

The terrible reality that very soon I'll be leaving everyone, and everything, I love behind is starting to sink in. It is only just the beginning of this terrifying journey.

I learn that it's too late for surgical intervention, I will most likely face radiation therapy, and certainly chemotherapy. I am assured the Oncologist is very good, such reassurance! Chemotherapy...I've had friends go down the same path. They say it changes everything about who you are. How you look, how your food tastes, the overwhelming fatigue, and the never-ending nausea...and the constant fear.

It's too soon for me to have a clearly defined idea of what death might be like. I get up to leave, dazed, in shock, hearing all the reassurances about managing symptoms, how well medication can control any nausea, and anything else that might come up. I want to scream I have to get out of there. I hear that strange voice again, monotone, emotionless,

"Thank you, doctor." Ever polite. Ironic, saying thank you for a death sentence. I think I'm going crazy.

I begin chemotherapy, this vile toxin that's buying me a little time. My deterioration has been rapid. Massive weight loss, my previously poor appetite, completely gone. Everything tastes metallic. Sleep is constantly interrupted with pain. It starts as a gnawing ache deep in my hips and pelvis. My right leg, heavy at first and with pins and needles, is now starting to drag. Shooting pains pervade my lower back, sending lightning bolts down both legs. Bone scans show I have extensive bone metastases in my pelvis, long bones and lower spine. Radiation has been deferred because of my condition, unless there is some paralysis. Pain relief is sporadic, despite trying multiple combinations of medications, opioids such as Morphine and Oxycontin, Fentanyl, even Ketamine. Dexamethasone, Octreotide and Ondansetron to 'quieten' down my bowel. Even breathing is an effort.

Week four of chemotherapy. My hair has gone, and I'm about to lose a couple of fingernails as well. I barely recognise the face staring back at me in the mirror anymore, sunken cheek bones, black circles around dull eyes, a skeletal frame. My loving husband gently rubs my back to comfort me, at the same time holding a bowl as I throw up for the tenth time, wondering how long I can keep doing this – do I even want to keep doing this. Even though everyone appears to act 'normally' around me, I see how my journey is affecting others. I see the sadness, pity, helplessness...and especially the fear on everyone's faces, and sometimes...even relief for some, perhaps thinking, 'thank God it's not me'.

Two months have passed. My abdomen is grossly distended, my arms and legs swollen, my breathing increasingly difficult. I've stopped eating solids all together, just managing to take a small liquid diet. In spite of my tissue engorged with fluids, they tell me I am dehydrated. I have a catheter which is uncomfortable, the output is less and less each day and now bright orange.

For the first time I contemplate ending my life while I still have the capacity to do so. That would be if I had the means, and I don't. Then I think about my loved one's finding me, and realise I couldn't do that to them. I start to weep. Funny how I haven't been able to cry until now, and it's not even about me, it's for others, and what they are dealing with.



Almost three months have passed. The coping mechanisms at home are breaking down. Everyone is exhausted. The kids are struggling emotionally, I can tell when they have been weeping. My husband put work aside to become my full-time carer. He shouldn't have to be doing all this alone. They have all done their very best to keep me with them, but I have to set them free. There have been many times over the last three weeks, I have just prayed to God to let me go, to just let me close my eyes and not wake up.

It's time to embrace Palliative Care full time. My journey may have been easier had I been linked in with them sooner? I thought Palliative Care meant 'the end of the road', but now I find many people have been in their care for extended periods, even years, only having a short stint in hospital to sort out their symptom control. The nurses are so kind, nothing is too much trouble. They pop in with a smile and light banter, and make the long hours through the night bearable. In the few days I have been an inpatient, my family know I am receiving care twenty-four hours a day. The fear and sadness are still there, but there is also relief. I am turned every two hours, mouth care attended, extra pain relief given if requested.

One more week gone. I have lost track of time, it doesn't have any significance anymore, just one more day closer to peace. I'm no longer taking anything by mouth, which has become ulcerated and very dry, despite regular mouth swabs, my lips are cracking as well. The pain is severe now, with less time pain free. They tell me it is nerve pain, and difficult to control. My abdomen feels as if it will burst. I haven't passed a motion for five days now.

They offer me sedation. I decline. I choose to be conscious, not convinced I won't be able to still feel the pain, just be unable to respond. I sense my time is close. Many come to visit, but stay briefly. It's difficult to lift my head now. Everything is getting quieter around me. Only my man stays. The kids are struggling, no longer trying to hide their tears.

Suddenly a violent spasm starts somewhere deep inside my abdomen, a cramp like sensation forcing its way up through my stomach, to my throat. Bile and faeces gush out of my mouth, spraying the bed. I gag as more putrid liquid is expelled. God help me, let me die.

The pain is unrelenting. I don't even complain anymore, nothing is working. I continue to vomit bile and faecal matter at regular intervals. A nasogastric tube is pointless they say, it will block after the first episode of vomiting. They rinse my mouth out each time. There is a perfume diffuser in the room, but nothing disguises the fetid stench. My husband has to go outside to hide his gagging.

I wish I'd taken my life back when I had the chance. I should have found a way. There is a big difference between living, and just existing. Anything rather than leaving this earth, with the last few weeks imprinted on the minds and hearts of those I love so dearly. The sound of my laughter a distant memory, now only an echo of happier times.

Ironically, as I close my eyes, I realise with absolute clarity, there are a lot worse things than dying.

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Footnote: This was not MY journey, but one day soon it may be. I have had acute bowel obstruction once already. But I HAVE nursed ‘THIS’ person more times than I care to think about. I have stood at the bedside of someone with Motor Neurone Disease (MND), trying to comfort them as they asphyxiated, have sat on the floor holding a man’s hand, his carotid tumour having ruptured, his body slowly bleeding out. Constantly sponged a lady with cervical cancer, fistulas causing faeces to leak continuously from her vagina. **These people and countless others, all expressed their wish to die long before they deteriorated to this point.**

### Conclusion

Some may say this submission is ‘too personal’, but I ask, how can you adjudicate on the necessity for VAD, if you have no idea what it’s like to walk in the shoes of someone with a terminal illness?

Palliative Care and VAD are inextricably linked. Even with increased Palliative Care services, and improved care delivery, It does not negate the very compelling need to introduce VAD on compassionate grounds – when it’s serving the needs of the patient, desperate to end their suffering, and requesting this measure.

The Law Reform Commission has produced a comprehensive and thorough draft ‘Voluntary Assisted Dying Bill 2021’. All the salient requirements and safeguards have been addressed, as well as an excellent guided pathway highlighting, step by step, how the process might proceed successfully.

Facing the potential of suffering horrendous side effects of some terminal illnesses is a daunting prospect. Thankfully, this is not the case for the majority of affected people, but IT IS the case for some. In 2020 almost 50,000 people died due to cancer alone. This data does not include mortality related to other terminal states with significant side effects impossible to manage effectively. For example, MND, Multiple Sclerosis, Parkinsons Disease and many more.

If only 1% of those 50,000 experience intolerable side effects of their terminal illness, that is still 500 people. In my belief, ONE IS TOO MANY! There needs to be a compassionate, merciful alternative. That is, Voluntary Assisted Dying.

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APPENDIX:Recommendations: Questions requiring answers.

Q 1. WHY - do Doctors fail to identify someone as palliative sooner? and suggest/request linking them in to a Palliative Care (PC) service for ongoing support, for the duration of their illness, regardless of the prognosis? The treating Dr can then arrange regular liaison with the Palliative Care Team (on a regular basis) for updates on the patient's condition, and the need for any preferential treatment changes.

Q 2. WHY – Isn't there a greater promotion/uptake towards the P.E.P.A program? (Program of Experience in Palliative Care) a PC education and training program is available for all health professionals, with clinical placements, and interactive workshops throughout Queensland. Co-ordinated by Metro North Hospital Health Services (MNHHS). Funded by the Australian Government Department of Health for FREE. Accessible for all health care personnel, doctors, nurses, aboriginal health, allied health, in all fields (hospitals, community, residential aged care facilities, and general practice). PH: 07 36466216 Email: [pepaqld@health.qld.gov.au](mailto:pepaqld@health.qld.gov.au)

Q 3. WHY – Isn't there greater promotion and education towards the role of Palliative Care and Hospice? That it is not there ONLY for 'end of life care'. There is so much misinformation or simply lack of accurate information, on the true role of PC. Their focus is NOT about dying, but in providing the best symptom control available, to live the best life possible.

Q 4. WHY – Do General Practitioners, Oncologists, ANYONE – continue to pursue invasive procedures, radiotherapy, chemotherapy, scans, blood tests etcetera, etcetera, when it is clearly evident, that despite ALL interventions, NOTHING is alleviating, or slowing the progress of the disease?

- What that often does, is rob the patient of viable time when they might remain well enough to go and achieve some unfulfilled 'wish', a trip, a family reunion interstate? ANYTHING that might actually benefit their mental well-being, possibly the only thing that might achieve some positive outcome!
- GIVE THE PATIENT AN INFORMED CHOICE.

Q 5. WHY – Is so little known about home care services delivering PC, such as Karuna Home Hospice? [SEE PROBLEM ONE]. Most, if not all people would choose to reside in their own home given the choice. Here they have far greater control over their illness management [SEE QUESTION FOUR].

Q 6. Why- Isn't there standardised, uniform PC treatment across facilities 'designated' as such? You can't just dictate so many beds in a General Hospital or Oncology Ward, or Aged Care facility, call them 'Palliative Care Beds', and believe they deliver PC, unless you have doctors and nurses trained to do so. Doctors TRAIN to be surgeons, psychiatrists, Oncologists. To deliver effective PC to meet such complex care needs unique to each person, requires no less expertise [SEE QUESTION TWO].

Q 7. WHY – Not develop a team of Palliative Care doctors and nurses able to visit facilities on invitation, or liaise online, with health practitioners caring for terminally ill people? An on-call phone service to answer doctor's enquiries, or seeking advice, would be of great benefit, especially for remote communities having little or no access to Palliative Care.

- Annual evaluation to gauge service utilisation, and identify any measures that might improve benefits, or create greater access [SEE QUESTION TWO].

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