

'A Buddhist Prayer for Peace'

May all beings everywhere plagued with sufferings of body and mind quickly be freed from their illnesses.

May those frightened cease to be afraid, and may those bound be free.

May the powerless find power and may people think of befriending one another.

May those who find themselves in trackless, fearful wildernesses—the children, the aged, the unprotected—be guarded by beneficent celestials, and may they swiftly attain Buddhahood.

I don't want to live like this!

I recently saw a moving tribute to famous US games show host, Alex Trebek who died in November 2020. He was eighty-years old and, in his own words, had lived a charmed and wonderful life. Mr Trebek had one dying wish - he wanted his final day to be sitting on his garden swing next to his wife, Jean, watching the horizon, surrounded by family and friends.

It seems his wish was granted and I guess that makes him even more fortunate – He had a good death. Gently, lovingly and peacefully transitioning to the other side. He died with dignity and love, in a setting of his choosing - he was lucky!

Contrary to that, my sister, Tricia who had passed three weeks earlier on 19th October 2020, went exactly as she feared - in pain and begging for me to kill her! She was sixty-six and had been, in her words - "imprisoned", in aged care from age sixty-two.

'I suffer in miserable, breathless silence and just wish I could die'

With a complex cocktail of medical conditions, including Chronic Obstructive Pulmonary Disease (COPD), Fibromyalgia, Lupus and many other ailments, Tricia suffered terrible pain for the last twenty years. But mostly it was her breathing that, at times crippled her both physically and mentally. Over the last ten years, she lived on opioids that seldom rendered relief and did little for her anxiety. As Tricia would so often say, "I suffer in miserable, breathless silence and just wish I could die".

Tricia had lived on her own for many years and as her illness deteriorated, she spent more time in hospital than out. In October 2016 she entered the aged care system and shortly afterwards was diagnosed with approximately 20% lung function and in the final stages of her COPD illness. In short, she was dying but no-one could say – when!

In March 2020 when COVID-19 hit and the restrictions preventing visitors came into effect, depression set in – Tricia's condition spiralled downwards. In May, she applied for access to Voluntary Assisted Dying (VAD). However, was determined 'not a candidate'. Later that month, she did receive a glimmer of hope when we found an excellent doctor who introduced medicinal cannabis to Tricia's treatment regime. It made a significant difference initially; however, it was too little, too late. With the introduction of cannabis, and as a trade-off, her doctor, reduced her opioids dosage. Over the ensuing months, her condition deteriorated with numerous episodes that required hospitalisation. Adding to Tricia's anguish was the constant bickering and bartering with her doctor and the nurses administering her medication. Often Tricia would call me distressed and pleading for help as she was not only in pain, but she could also not breath. It was like torture for Tricia and she felt so helpless.

The system is failing.

Occasionally I had to turn my phone off when I went to bed. On Tricia's rough days, it was not unusual for her to call me six or seven times. Saturday 17 October was one such day, so I was not aware she was admitted to the hospital for what was to be her last time. Tricia had an [Advanced Care Directive](#) (ACD) in place that called for no life-saving procedures. I presumed her ACD would go with her in the ambulance. For some reason her carers, who were responsible for Tricia's wellbeing, did not send it. As a result, the ER doctors did precisely what she did not want - they saved Tricia's life! This was the beginning of her most feared nightmare.

At 5:00am, the following morning, one of my sisters called to let me know a doctor from the hospital had been trying to contact me to advise me of Tricia's situation. Immediately, I called the hospital and spent almost ten agonising minutes on the phone as the nurse refused to provide information claiming she did not have my sister's file to confirm my name was on the list of emergency contacts. I was distraught, angry and very frustrated with what seemed the lack of empathy and failure in the hospital's procedure. I advised the nurse it was unacceptable! Finally, she advised me I needed to ring back in another thirty minutes as the Administration Department was closed. Due to the COVID-19 restrictions they were required to approve my visit to my sister. I understand now, many people did not get the same opportunity to be with their loved one like we did. Nonetheless, that held little currency at that time, and we are extremely grateful for that.

I would have said yes to anything.

What could I do? I made my way to the hospital, a twenty-minute drive, and fortunately by the time I arrived, the nurse called me to advise they would allow my visit – with a caveat: I may have to leave if the administration declared it was contrary to their policy! I did not want to hear this but accepted anyway. I was desperate to get to my sister's side. I wanted to make sure someone was with her to hold her hand. I had promised Tricia I would not let her die on her own - I would have said yes to anything!

It must have been around 7:00am when I was finally at Tricia's side and surprised as she did not seem as bad as I had been anticipating. Over the years, she had had many close calls - Tricia was a fighter! She'd had a tough life and knew how to fight. Although I knew from our many conversations over the last four years, she was tired of fighting, tired of everything. The system and failing health broke her. Quite simply, Tricia wanted to join George, her partner and the love of her life. The one man who blessed her life with the only real love she ever knew. When he died fifteen years earlier, a large part of Tricia died too. She longed to be pain-free and back in the arms of her beloved George!

Despite Tricia's grave condition and the pain, she could still talk. She was disoriented, extremely breathless and could not remember what had gone on. The nurse was tending to her and advised me they were doing what they could for the pain. She said the doctor would visit and give me an update.

At 10:00am, I finally spoke to the doctor who treated Tricia when she was admitted. At this stage her condition had deteriorated, and she was begging for relief. He advised me they would have lost Tricia through the night had they not taken the necessary procedures to save her. I was trying to reconcile what was happening. I could not understand why the doctors had gone against her ACD. My mind was racing with questions whilst I was coming to terms with the reality of Tricia's plight. The doctor inquired with Tricia as to what her wishes were. She told him, in no uncertain terms, she did not want to live! He acknowledged this, and then looking at me advised they would keep her comfortable.

When the doctor left and the reality started to sink in, I became confused. The doctor had not said that death was pending or Tricia was now in palliative care. Despite having thought I had prepared myself for this moment – In fact, I now realised how unprepared I actually was!

God bless the nurse.

The nurse who had been patiently caring for Tricia looked at me with great compassion. I told her I was confused. I was not sure exactly what I was supposed to report to our family. God bless the nurse; she told me the truth - "She is dying!" I needed to hear this! I was sad, yet also relieved my sister's suffering was coming to an end.

A familiar dilemma returned – Tricia's pain! Along with her eldest daughter, Renee, we attempted on many occasions to mediate with her various doctors in the management of my sister's pain. Sadly, chronic pain was Tricia's constant companion, particularly her last five years, and it seemed her doctors were more concerned with her potential addiction to prescribed medication than relieving her pain and suffering. It was a constant battle we fought and constant distress to all concerned - none more so than my long-suffering sister!

Not long after the doctor left, Renee arrived, and I was able to bring her up to date. By 11:00am Tricia's condition began to deteriorate.

I could see she did the best she could.

As the hours progressed, Tricia continued to deteriorate and as the pain increased, she cried continuously for more relief and still struggled for breath. I called the doctor to address both the ACD and pain management. The first doctor had left, and the new doctor seemed uncomfortable in this setting, however, we could see she felt she was doing her best. I asked how and why the doctors had administered the life-saving measures contrary to my sister's ACD. The doctor advised they did not receive an Advanced Care Directive when Tricia was admitted and were currently still waiting on it to arrive from her Aged Care Provider.

We were shocked but too overwhelmed to contemplate – how this had happened? Both Renee and I had discussed this many times with Tricia and we fully supported her – it was important to us all. I asked the doctor what would happen as Tricia's condition deteriorated. She advised they would keep her comfortable. On reflection, I now understand the term 'comfortable' seems a convenient term to placate families grieving and supporting their loved ones and has limits that often fall short of the perceived meaning. In many ways, it seems they, the doctors and nurses, and the whole system, unconsciously conspire for the sake of expediency and I suppose self-preservation. In hindsight, I get that, yet still, it does little for the patient or the loved one's battling to hold everything together in our most vulnerable of moments. We are left in a somewhat delusional state of false hope.

I was not in the mood for apologies.

An hour later, around 6:00pm, I asked the nurse if they had received the ACD - they had not. We were not happy! Tricia seemed to have stabilised, so I decided to go to the Aged Care Facility to get the ACD. I knew of the existence of Tricia's ACD and what her wishes were. We had discussed it many times over the last couple of years, but I had never seen or read it. On arrival, a nurse from the aged care facility handed me the ACD. She apologised that it had not gone with Tricia in the ambulance. Really - I was not in the mood for apologies! I advised the nurse that whilst she was sorry, my sister was denied her rights and is now suffering intolerable pain. Not to mention the stress and pain it had placed upon us, her family. She lowered her head. Silently, she retreated.

I looked to the evening sky. Even the clouds looked cold and unfriendly! I felt so alone in this world. I screamed out loud. The whole world seemed out of kilter. 'How could this be happening? What had my sister done in life that was so bad? Why should she have to suffer such terrible pain? Why are we forced to watch her die like this - why? why? why?'

All too clearly, I remembered Tricia crying on the phone and pleading with me – 'I don't want to live like this'! I was devastated with the thought that something so simple, a procedure to ensure such an important

document, could be overlooked. I was angry that a multi-million-dollar corporation with millions of dollars in government funding, did not do their job. Despite this, I felt guilty. As if I could have prevented this. Of course, I realise this is futile, yet that was how I felt in that moment and the fact that had the ACD gone with my sister I most likely would not be in this position - How selfish of me!

The System is Broken - Yet We Feel Guilty!

Which is the lesser of the two evils? Would it have been better for Tricia to die in the Emergency Department? Or now with her family by her side, suffering agonising pain and desperately fighting to breathe? We did not want to see her like this. I did not want to witness my niece bear the weight of her mother's nightmare, with no idea when it would end. Damn the aged care centre and damn those doctors for saving Tricia's life. Here we are left with all this pain and anguish lumped back in our laps, and we had no alternative - forced to endure whatever was to come our way! How is it that the system is broken - yet we feel guilty?

I arrived home totally exhausted and finally sat down to read the ACD around 10.00 pm Sunday. Immediately, I realised this did not fully articulate Tricia's wishes. I knew this because we had discussed them many times. In an instant, I learned the importance of having a document that fully reflects your end-of-life instructions. What I was reading was a generic document that I could now see is flawed! Once again, I was angry and distressed. I did not know what to do. I was so tired of fighting the bureaucracy and the system that always seems to abandon the voiceless victims of a broken system! Again, it seems no one is connecting the dots. Why had I not been more vigilant? Why did I not realise there are so many potholes to navigate?

The document I was studying bears the letterhead of the Aged Care Facility which had the responsibility to provide Tricia's care and wellbeing for the last four years. In her darkest, most fearful moment, they had abandoned my sister! The reality is they had failed her long before this fateful day. There were so many other incidents I have not touched on here, so if I sound bitter, I make no apologies. In failing her, they fail us, her loved ones, and they fail our whole community. We are all vulnerable whilst these inequities exist. Equally, I understand, we all, must take responsibility and educate ourselves and prepare for our eventual destiny. We must change our attitude to death. After all, it is only natural!

If only our laws and culture were open and willing to recognise these fundamental flaws.

Only with hindsight, when I look at this poorly written document supplied, do I realise, along with so many other gaps and failings in the system – many things need to change! If only our laws and culture were open and willing to recognise these fundamental flaws that cause so much distress and unnecessary anguish. Suppose it was common knowledge to us all and there is a set of prescribed and statutory ACD guidelines, that along with the Voluntary Assisted Dying (VAD) laws in place and they were more widely recognised and acknowledged in our communities, we will all be much better for it. It is essential we are aware and are educated in these matters. I determined at that very moment to make sure I did not let this go by the wayside. After all, it could be you or me, or someone you love, and you find yourself in our shoes! Little did I know it would take a full twelve months to reconcile all I had, and was about to experience!

**I am not sure he fully understands the true measure and generosity of spirit
- the immeasurable relief he brings to those who seek his advice.**

Early Monday morning, I decided to take some advice and seek counsel to ensure I was interpreting things correctly? In May 2020, desperate for guidance, I became a member of Dying With Dignity Victoria (DWD). I had connected with Dr Rodney Syme over the phone. At that time, I was unaware Rodney, a living legend in the battle for VAD. Dr Syme had been instrumental in introducing VAD legislation and has championed the cause for many years. He graciously and patiently listened whilst I unloaded my frustrations in my attempts to assist my sister to access the VAD legislation. Rodney ever so patiently, and tenderly listened, and counselled me. He guided me in understanding the process and the appropriate manner of navigating the road ahead. I was and am forever grateful for the kind and thoughtful way this total stranger had afforded me so generously of his time and guidance. I am not sure he fully understands the true measure and generosity of spirit - the immeasurable relief he brings to those who seek his advice!

Once again, I found myself calling Rodney - I needed his help! He was equally as generous in time and counsel. However, Tricia's death was imminent this time. He was most alarmed when I had informed him of the events, mainly the matter of the ACD and the failure at this most critical moment. He once again patiently and in a very kind manner reminded me of Tricia's rights, and he advised me how to approach the doctors and nurses in a respectful but determined way.

Whilst Tricia's life was slowly ebbing. I was determined to make sure I was there, along with my niece, to ensure my sister's rights were recognised. Thank goodness for DWD and Dr Rodney Syme.

Renee called around midday. She was beside herself and could not cope. She requested that I go to the hospital as my sister was pleading with anyone who came to her, for help. Tricia's pain was intolerable. She was gasping desperately for breath and Renee was beside herself. Tricia was also calling for one of our older sisters. She wanted her to come to her bedside.

My sister was entitled to maximum 'relief', even if that meant she might die due to administering such relief.

Upon arrival, I could see a marked deterioration in Tricia's condition. Earlier, Renee had been advised it was decided to move Tricia to the palliative ward at Sunshine Hospital. However, when the palliative team arrived, they immediately assessed her as too far gone – So this is what 'comfortable' looks like! Despite this we were still uncertain how long this would go on for and Tricia was struggling for breath. Still desperate for answers, we called the nurse to find out what was going on. We were in a constant state of flux. We knew the nurses were doing their best, nonetheless we still felt it was not enough. We requested they increase her medication and reminded her my sister was entitled to 'maximum relief', even if that meant she might die due to administering such relief. The nurse left and came back and administered more morphine - it seemed to have little effect! Tricia was still begging for an end to her life, as we looked on feeling lost and ever so helpless. It was like being on a speeding train and knowing it was going to crash, but not when!

She said - "Kill Me – Please"

It was getting towards mid-afternoon. At one point, I was sitting at my sister's bedside, holding her hand. We were on our own. Tricia looked at me and again cried for my help! I asked her what she wanted me to do? She looked directly at me, her eyes, so pitiful and pleading, she said - "Kill Me - Please!" My heart sank; my breath escaped me - I felt so powerless and pathetic I could not take her pain away. I was numb. My mind was blank, yet I was somehow able to contemplate my options. I stared at the pillow sitting behind her and turned to see if anyone could see me! My mind was racing out of control! I could not believe I was contemplating taking my sister's life. To my inner core, I felt empty as I pondered the consequences! I was angry at my sister for asking this of me! Angry at the system for putting us in this situation. Angry at the doctors and angry at every damn thing that brought us to this moment in time. Most of all, I was angry; I did not possess the courage to end her suffering!

Tricia's greatest fear was to die struggling for breath. Often she reminded me of her fear of dying like our mother. Mum died of an asthma induced heart attack back in 1991, and all these years later the impact of this weighed heavy on her mind! On so many occasions Tricia would cry fretting over this, and I rarely knew what to say to ease her burden. Mostly, I just wanted to run away and not have to deal with this, but I couldn't! I do not want to imply I was the only one around to support Tricia. Fortunately, there was Renee, ever so loyal, and Tricia had a couple of wonderful friends who shared the burden – they were incredibly loyal to her, and she knew she was lucky in that department.

Instead, we wept and held hands as I consoled her.

In reality, only minutes had passed, but it seemed like hours - a lifetime of memories flashed through my mind. We were two of ten children. Tricia was just shy of three years older than I. I could see and hear, as if a movie was playing in my head, those familiar memories. I was transported back in time.

We were kids at our kitchen table. Christmas, Easter, the traditional Sunday roasts came hurtling back to me. I could hear the familiar voices and see us all. The chitter-chatter that would occupy us 'till dinner was served. I remembered all the games we played and old neighbours. Huddling under blankets in the midst of winter, watching Disneyland, came to mind. Lined up like ducks, four at a time in the bath and mum, or our older sisters making sure we washed behind our ears. And of our teenage years and the gradual courting and moving on to begin our lives. The marriages and births and everything else - it all came back in a flash of memory. Suddenly, sixty years have gone by, and here I am holding my sister's hand - she was dying, and it was not supposed to be like this.

Around 4:00pm, Tricia's pain worsened. We called the nurse and advised her we wanted Tricia's medication increased to relieve the pain. The nurse was doing the best she could and announced she could only prescribe what was ordered by the doctor. She said she could not administer anything that would kill Tricia! I let the nurse know we were only concerned about relieving her pain, and if it were possible, or lawful, I would administer the fatal injection if it meant the end to her suffering. Even though we were all uncomfortable and there was much tension building, we were determined to do what we felt was best for Tricia. I reminded her again, Tricia was entitled to maximum relief, and we felt it was not being delivered! Suffocate her I could not, but administer a lawful and painless injection, or tablet – I could live with that! I felt terrible for the nurses and it seems so unfair on them, left to manage an impossible situation. If only the VAD laws were broader and readily accessible to those who freely chose this option, we would not be suffering like this. How is it that we are subject to some outdated law, or some strangers' religious belief? I will never understand.

I walked away totally gutted and disgusted.

Around 5:00 pm, we decided to lodge our concerns with the Patient Representative. We were so distressed and felt like we were placing an unfair burden on the nurses. However, the complaints department could only be contacted by email – I needed to speak to someone and there was no one to hear me! I walked away totally gutted and disgusted!

I know this seems harsh and unfair to think of the doctors as uncaring, but this is how you feel at these most vulnerable and painful moments. Abandoned and so few of us are prepared for these moments. On the other hand, it is precisely that. It is unfair and harsh to allow such suffering to exist! Why does it have to be this way? Who is this serving? Why does this disconnect occur when you are vulnerable, confused and hurting?

Everything is spinning out of control, and all you want to do is run and hide!

There are so many thoughts and emotions swirling through your head. You feel like you're trapped, trapped in a cold, empty vacuum of pain and anxiety. You are free-falling into a long dark vortex. Everything is

spinning out of control, and all you want to do is run and hide! But you know you can't. You must be there; you have no say in it - that is how it is!

Around 5.00 pm, my two elder sisters arrived. I could not help but notice how aged they looked. Now in their seventies, I felt sad as I remembered how graceful they seemed as the beautiful young women in my mind. They were cherished memories locked deep inside me. As my mind drifted back to the present, I focused, as the two old ladies holding hands, supporting each other as they shuffled toward me. My heart, once again, filled with love and so grateful they were here for Tricia - Damn getting old!

I could not help but admire how good it must be to have such a loyal friend as Karen.

Karen, my sister's lifelong friend and Renee's aunt (it's a long story), came down from saying her goodbye, and my sisters made their way up to Tricia's room. Karen had been at my sister's bedside week in week out, often taking Tricia on outings for lunch and a little shopping, for the last four years. I could tell the heavy burden this was taking. At the same time, I could not help but admire how good it must be to have such a loyal friend, and I will be forever grateful for Karen's love and dedication to my sister.

Tricia was lucky when it came to friends. She had several outstanding, kind and supportive people in her life. Her good friend Rhonda was like a rock, and despite always having disagreements over something or another. They were like to jealous teenagers and Tricia would always make me laugh recounting her version of their latest spat. Regardless, Rhonda lovingly supported Tricia through much of her illness.

Maggie, who was like a sister to her, was in New Zealand, but they always talked and loved each other immeasurably! A couple of years earlier poor Maggie made a last minute dash from New Zealand to be at Tricia's bedside when we thought we were going to lose her. On arrival, she found Tricia and my nephew Paul arguing with the poor nurse over her medication. Tricia was far from dead and was letting the nurse know who the boss was. Maggie was shocked. Relieved, but shocked, and it was a wonderful opportunity for two old friends to spend some time together. They spoke often on the phone and were a great comfort to each other.

Our Aunt Grace, Tricia's favourite Aunt, had been there for Tricia's whole life. Aunt Grace seemed to understand Tricia's complex character and never judged, only ever supported and loved her - In many ways, she was the mother Tricia always yearned for all her life. They spoke weekly - it was one of the few highlights of Tricia's week.

Sometime later, when my sisters came downstairs, we huddled together and talked. Strangely, it still did not seem real. No one ever really knows what to say at these times, so we talked about some mundane things; I cannot remember what? Occasionally we talked about Tricia, though.

'It's ok, mum; you can go now - I love you'

When we arrived back in her room, I could sense a strange stillness in the air. Tricia lay on her right side as she had become accustomed to during the last couple of years. She was heaving deep short breaths. Her body rose with each breath and seemed to collapse as she sighed heavily with each expulsion. I looked into her eyes, and they appeared blank. I reached for her hand - it was cold. I looked to my niece, who had taken a position on the other side of the bed, and we knew it would not be long now. I beckoned Renee to swap sides so she could be closer to her mother.

I watched my niece hold her mother's hand, lean over her heaving body, bury her head and cry, "It's ok, mum, you can go now - I love you!".

I remembered when Renee was born. When my sister took her daughter in her arms and held her tiny hands, "It's ok little one. I'll look after you!" she said and told her how much she loved her. It struck me how the

roles reversed and how each of us reacts so differently in these situations. Some people are not made for this and run as far as possible, yet others, like Renee, stay to the very end, duty-bound, love bound, no matter how hard it is! I was so proud of her - I felt a rush of pure love for both my sister and my niece.

Deeper and deeper she began to slip away, surrendering to her fate. Each breath seemed more profound, and each sigh seemed shallower. Breath by breath, we watched as her life was slipping away. She moaned, and fortunately, we no longer had to plea for more relief. The nurse began to administer the relief Tricia had so desperately wanted. I watched as the needle plunged, full of morphine, into the canister. As it slowly made its way down the thin clear tube into my sister's arm. I felt an overwhelming sense of relief. The weight was lifting from my shoulders as Tricia gently began her transition.

How horrible, I remember thinking.

In many ways, I felt detached from myself. It felt like I was observing this from up above, and I remember feeling conscious of this, strangely aware, I was both here, but not here. Months beforehand, I read the Tibetan Book of Living and Dying, and I recognised this moment as my sister transitioned to what the Buddhist call 'the Bardot'. Her journey to her next life, or wherever one believes, we either go or do not go. Whatever it was, it had begun. Relief was finally here!

We heard a deep rattle in Tricia's breathing. It was more robust with each breath, and each moan became a rattle. How horrible, I remember thinking! We knew death would soon take her from us, and she would be free from pain, yet still, we were overwhelmed with grief. Still, in my racing mind, I asked myself, had I done enough? Then the what if's, started coming. It is such a crazy thing to think, and I had to force myself to focus on my sister. I wanted her to know we were there with her to the very end!

We had shared so much of what life had thrown at her, and it seems like I have spent my adult life rescuing her, and here we are together again, only this time I was helpless. There was nothing I could do other than be there for her, as I had long promised. To let her know, I too, never judged her. I understood all Tricia had been through, and I loved her – no matter what!

When finally, she took her last breath, I felt both relief and guilt. I felt hollow inside. I felt numb - empty! Out of nowhere, I heaved, and a powerful gush I had no control of came from deep inside; I cried a long, deep, howl and buried my head in my sister's still and lifeless body. She was gone - the pain had gone, and finally – there was peace! I turned to Renee, who was at my side and holding me. We cuddled. We cried some more, and when we looked each other in the eye, we nodded, relieved she was no longer suffering!

When a loved one is trapped in their body.

It has taken me months and many attempts to find the words to describe how it is when a loved one is trapped in their body and seemingly put aside in an aged care facility where their rights and dignity are slowly eroded and stripped away from them. Day by day, they live a hell no one deserves. Often, voiceless, with no one to represent them. Tricia was very lucky to have people around her to support her, yet still she suffered, and sadly, unnecessarily - if only we had better laws and a system that catered more humanely for the aged and infirm.

In the meantime, many politicians, combined with a medical system that continues to deny us the right to make a humane exit from a miserable existence. We all deserve the right to make our own choice and not be burdened for years as my sister was.

I have recorded conversations of calls from Tricia in the middle of the day and the night. She would be crying and begging to die, begging me to help her. Begging to make the pain go away! I asked her if I could record them and tell her story. Tricia wanted me to do anything I could so others would not suffer the same fate she did.

I do not say this with malice, simply a matter of fact! A doctor who decided she was not likely to die within the next twelve months determined her most feared fate. Within five months, she was dead, and that doctor was not there to make sure she did not suffer. Her GP, who promised to support her, abandoned her weeks before and did not answer my calls. That is the way the system is - even though we do have VAD laws in place, they do not go far enough or wide enough to consider anyone like my sister, who was forced to endure more than four years of what she described as: -

‘Hell, and misery!’

Today marks twelve months since Tricia's passing. Whilst I still think of her almost every day and miss her much more than I ever thought possible, it is only now I feel strong enough to speak up. Tricia wanted me to use her experience to make other peoples' experience better!

When you witness your sister's suffering and she begs you to kill her, it has a profound effect on you. When I hear all the arguments against VAD, it makes me wonder, often in disbelief at what seems to me, selfish reasoning.

In a recent opinion article arguing against VAD, former prominent Premier shared an experience of his mother's passing. He recounted:

Why I hope NSW does not embrace voluntary assisted dying

"In the last 12 months of Mum's life, my eldest daughter was going through a marriage breakdown. It was heart-wrenching for everyone. In the middle of this, my daughter went to visit my mum. She greeted my daughter with tears and eyes that shared the pain. When my daughter came home, she said, "I have never felt so loved." It was as if my mum's eyes had given her the hug she needed, the tears, the comfort.

Life to life. Soul to soul.

It was a reminder of the beauty and power of life. Surprising, connecting and caring when no one thought this was possible."

Particularly after my experience, and with the utmost respect to his mother and her family, I find this reasoning somewhat shallow. How can we compare the comfort of his daughter suffering a marriage breakdown, seeking solace from her dying grandmother? To compare that with a dying person who has been denied access to VAD and is now suffering all measures of pain and suffering and begging to die is not the same, by a long shot, and seems incomprehensible for me to consider as a valid argument to reject VAD. Tricia's story, like so many others, is a stark reminder of just how ugly and unfair, life can be!

What does this say to those poor souls trapped for years by a system that sees them suffer, absent of all dignity? Aged care facilities, driven by profit with thinly disguised practices that serve their bottom line - not our loved ones. That said, there are many unsung heroes in the aged care system. They do their best and are like angels from heaven. But there is only so much they can do – it's the system that needs to change! The corporate and profit driven business models. That is a fundamental problem in and of itself. What about the loved ones? Those forced to witness, like us, horrific moments of anguish? Those who receive the phone calls in the middle of the night from a loved one trapped in aged care, begging for help! What can he say to offer solace and comfort and love and compassion to those of us who do not share his views? Simply satisfying or impressing one's religious, moral, or any other belief upon any person who would rather die at a time and with the full dignity we all deserve, seems selfish and brutal to me!

By contrast, how would it be if we all had a choice? Whether it be sitting on a garden swing, like Mr Trebek. Or watching a sunset surrounded by family and friends, at a time and place of your choosing, and in a manner respecting and maintaining your dignity, absent of mental anguish, pain or suffering?

Indeed, we all have this right – Don't we? It must change. Unless we speak up and fight for the VAD laws, nothing will change. We need to support the outstanding work of the many proponents of VAD and encourage awareness and education. If you do one thing only, please take the time to prepare an [Advance Care Directive](#) and discuss it with your family. You will be doing them and yourself a great favour. It is so easy to go back to our busy lives and say, 'Gee, I hope I don't go like that!' Well, guess what? It could well be you begging -

"Kill Me! Please!"

To the memory of my sister - **Tricia Smith**

A troubled, mischievous soul with a heart of gold and a wicked sense of humour!

Thank you for your support and much reverence to Dr Rodney Syme, the [DWDV](#) team. To Andrew Denton and his team at [Go Gentle Australia](#) and all who work tirelessly to be the voice we need!

Why do we need Voluntary Assisted Dying laws?

Voluntary Assisted Dying laws give a choice about end-of-life to competent adults suffering from a terminal or advanced incurable illness that creates intolerable, unrelievable suffering. Although palliative care provides a great deal of support and pain relief, often, it is simply not enough.

DWDV believes that voluntary assisted dying is a dignified and reasonable choice for people to make when their medical conditions result in untreatable and incurable suffering and pain. We also believe that simply having the option of assisted dying can be of great psychological benefit.

Having a choice means having control. Many people dealing with traumatic illness and suffering feel they are losing control of their situation and themselves. End-of-life choices, including voluntary assisted dying, can restore a sense of agency over their own lives.

Is there anything I can do to assist in the successful implementation of VAD?

1. You should ask your doctor if you would receive the support required if you needed it. If so, ask if that doctor has done the VAD training or intends to do it.
2. Speak to your local member of parliament if you think there are defects in the legislation.
3. Join DWDV. Our influence grows the more members we have. <https://www.dwdv.org.au/join-us/>

ACT NOW - become a member of [Dying With Dignity Victoria](#) and help us support and guide those suffering at the end of their lives.

Our purpose is to relieve distress, helplessness and suffering for Victorians with untreatable, painful or terminal illnesses.

Click the relevant link below to become a member today to help those who are suffering at the end of their life learn about their rights and choices under the laws passed in the Victorian Parliament in the last few years. Or support us by donating.

Please call our office on **0491 718 632** for any further membership queries you may have.

Alternatively, you can send an email to office@dwdv.org.au

Other Resources

<https://www.vadsa.org.au/>

<https://www.dwdwa.org.au/>

<https://www.dwdq.org.au/>

<https://www.gogentleaustralia.org.au/>