



## **VALE – VOLUNTARY ASSISTED LIFE ENDING GROUP**

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## **The University of Tasmania’s Independent Review of the End-of-Life Choices (Voluntary Assisted Dying) Bill 2020**

### **SUBMISSION RESPONSE**

#### **INTRODUCTION:**

I confirm and give permission to the University of Tasmania’s Independent Review of the End of Life Choices “Review Panel” to refer to, or quote from, my submission and refer to my name in future publications for the purpose of this review.

I have been an independent advocate for voluntary assisted dying legislation for over 30 years, as was my mother. I have been a vocal and active advocate/lobbyist since 2016 through a social media platform called VALE – Voluntary Assisted Life Ending – in Queensland (my home state), whilst also advocating nationally, and internationally, contributing to numerous parliamentary submissions and providing evidence-based material, and writing to politicians nationally sharing relevant information in support of voluntary assisted dying (including Tasmania).

I have devoted the last 4 years, on a full-time basis, to remaining apprised of legislative progress globally and participated actively in the push for voluntary assisted dying legislation based on my own first-hand experience of nursing family members and friends through harrowing suffering and traumatic deaths,

whilst also being diagnosed with breast cancer twice and now living with Stage IV terminal metastatic breast cancer.

I am an individual who would seek to use voluntary assisted dying legislation when my disease progresses to the point that it is no longer acceptable to me for suffering to continue.

Like other Australians, without other options, in the absence of the legislation, some time ago I put in place arrangements to travel overseas for an assisted death (this has been approved) at such time that my disease has progressed to the point where I no longer wish to receive “time buying” treatments that diminish my quality of life and have no bearing on the inevitable outcome.

Unfortunately, during the extensive parliamentary and political debates in Australia and overseas, when the debate gets to parliament, we do not have the opportunity to hear from those who have experienced the true meaning of the word suffering in rebuttal of many arguments opposed, or presented as “safeguards”. Our understanding of suffering is beyond the imagination of those who have not shared our experience.

If parliamentary debates occurred in an environment where those who have “real life experiences” were permitted to counter political arguments, and proposed amendments, i.e. share the absolute “nitty gritty” of what individuals have to endure as a result of many serious and cruel diseases - we would not need to waste so much time having the same debate, with the same arguments, by the same people, for the same outcome, affecting the same people, state by state.

I am fully informed (unfortunately) about my disease – metastatic breast cancer. It has progressed to my lung and abdomen at this point . It will progress as it has with many of my metastatic breast cancer friends and peers and it will mean a harrowing death in the absence of voluntary assisted dying legislation. I have watched friends die of this disease.

I am a member of a private and closed support group for international women (6000 women so far in this group) living with this disease. The comprehensive information shared, by members of this group, on a daily basis, the extent of their suffering – right from diagnosis to the end – before they eventually die - is heartbreaking. Suffering commences a long time before the last 6 months (if they have 6 months). I would defy any politician, right to life/religious group to spend a day reading the posts by real people experiencing real suffering and tell them they should not have the right to have the voluntary option of this legislation. One of today’s posts was about what others are using to control their pain due to metastases in their bones, organs and other parts of their body. The “chit chat” covers how the medications administered make them feel – how they can’t function with those and have to seek alternate options to try to combat feeling drugged out and not able to function.

I have spent considerable time over the last four years talking to families left traumatised by their loved ones’ deaths who also now advocate for the introduction of voluntary assisted dying legislation. I have spent considerable time talking to those who have been diagnosed with an incurable/terminal illness about their views and support of voluntary assisted dying legislation.

I am respected in the “voluntary assisted dying space” for my advocacy contribution and for sharing the real stories presented by others, through a number of forums, lobbying platforms, media interviews and editorial content by many advocacy groups here and overseas for my contribution and support to parliamentary processes pushing for reform on behalf of those living with a terminal illness and those who have lost family members through horrific circumstances.

I have spent considerable time, over the last 4 years, talking to/interviewing those who work on the front-line as nurses and palliative care nurses who support exceptional palliative care but who support the introduction of voluntary assisted dying legislation. Of concern to me is the fact that many of the voices of those who work on the front line have not felt able to voice their support as a result of workplace agreements and their employer's "hierarchical" position and support for better funding for palliative care, rather than voluntary assisted dying legislation being an additional healthcare option. Many of the stories shared by nurses with me were harrowing in themselves and caused significant distress to those who were willing to share their experiences caring for those at the end of life.

I have the "real life" experience of nursing both parents through horrific cancer journeys and share the horror and trauma of that experience, like many others.

In January of this year I commenced a Change Org Petition appealing to the Qld Premier to introduce voluntary assisted dying legislation. The petition has 75,400 signatures and climbs daily.

## **MY SUBMISSION BASED ON THE PROPOSED VOLUNTARY ASSISTED DYING BILL PRESENTED AND PASSED BY THE UPPER HOUSE, TASMANIAN PARLIAMENT -**

### **PRINCIPLES**

The Review Panel should seek to introduce principles which provide a clear "mission overview" for the purpose of voluntary assisted dying legislation relating to all parties involved.

The Bill should include a statement of the principles to assist in the interpretation of the legislation and to which a person must have regard when exercising a power or performing a function under the legislation (as in the case of Victoria and Western Australia).

The principles of legislation should reflect the "purpose" and "clarity" of the legislation – a "Mission Statement" which provides a clear guide as to the purpose of the legislation and all involved.

The principles, whilst also reflecting all positions relating to the practice of voluntary assisted dying legislation, should seek to remain **patient-focused** and not be allowed to detract from the purpose of the legislation, i.e. legislation for those who are dying. I support the principles outlined in the Voluntary Assisted Dying Act 2019 (WA) and also those outlined in clause 5 of the White & Wilmott draft model Bill (Professors Ben White & Lindy Wilmott, QUT Health & Law Faculty, Queensland) presented to the Qld End of Life Choices Inquiry as part of their submission.

### **ELIGIBILITY CRITERIA FOR ACCESS TO VOLUNTARY ASSISTED DYING**

I believe the eligibility criteria for a person to access voluntary assisted dying should require that the person must be diagnosed with a disease, illness or medical condition that is **incurable, causes intolerable suffering, is progressive and will ultimately cause death.**

As an advocate for voluntary assisted dying legislation over the last 4 years, along with others, I have been incredibly disappointed and distressed to listen to political/religious debates regarding the introduction of voluntary assisted dying legislation where so much has been lost and has not been the focus of those debates.

I have written many articles/posts on what I call “The In Between Stage”. This is the detail and depth of suffering that is rarely discussed or debated but is the reality of what individuals go through leading up to and after a diagnosis of an incurable disease. Much of this detail, if included in the debate, would, I believe, remove much of the argument presented by the opposition. That “detail” could not be imagined unless witnessed by a family member, friend or loved one or by the person living with the terminal/incurable illness.

There are many, many health challenges to deal with whilst living with an incurable/terminal disease along with a great deal of suffering as a result of (a) the disease, (b) the treatments administered and (c) as a result of a compromised immune system – a long time before the last 6 months of life. I speak from my own experience, the experience of witnessing friends suffer, my parents, along with the thousands of stories shared with me by people from across the world – not just in Australia.

I refer to a friend recently diagnosed with vaginal cancer – stage iv – who has had to endure so much pain over the last six months. She is about to undergo extensive radium to that sensitive area for the next two months, in addition to dealing with metastases to her lung – all with no guarantees. Her quality of life is zero. She is in so much pain she can hardly walk, she can’t drive. She can’t do any of the things she has enjoyed doing.

I refer to another friend who was diagnosed at the same time as myself – Stage IV incurable metastatic breast cancer – whose disease progressed through every major organ – 18 months before she passed away. She made the decision to stop chemotherapy 12 months before she died because she was bed-ridden and could not walk. She was depressed and was in pain. 6 months after this decision, at the urgency of her family, she recommenced chemotherapy. This time her disease had progressed to her bones and spine. Her last 8 weeks in one of Brisbane’s best palliative care facilities saw radium being administered to try to alleviate the pain in her spine but the treatment burnt her oesophagus and she could not swallow ... She had indicated her wish for “assistance” 12 months prior and, of course, this was not possible.

Only an individual experiencing all of the above knows when they have had enough and unless politicians/law makers actually take the time to understand all of the nitty gritty of a particular disease, they could not possibly understand why prognostic timeframes and “specific” eligibility criteria relating to prognostic timeframes or “defined” categories, i.e. “advanced, progressive, will cause death, etc” detract from the purpose of voluntary assisted dying legislation.

## PALLIATIVE CARE

Opposition to Voluntary Assisted Dying Legislation continues and always will – much of it on the basis that we need to improve Palliative Care, inject additional funding and resources rather than introduce Voluntary Assisted Dying Legislation.

I appreciate that the VAD Review Panel's purpose is review health, legal and social sciences expertise. I am at pains to throw light on what is rarely acknowledged or discussed nationally when palliative care is discussed.

The link to the article below is an academic research article from Sweden. However, the title caught my attention immediately:

"A GAP BETWEEN THE PHILOSOPHY & THE PRACTICE OF PALLIATIVE CARE". It says it all and it certainly re-confirms the stories shared with me by individuals, families and nurses, not to mention the thousands of posts in advocacy group pages nationally and internationally.

Extract:

*" ... Furthermore, studies show that doctors, social workers and nurses in palliative homecare spend most of their working day conducting patient administration. During their working day, they have minimal contact with patients and their relatives (Karidar et al. 2016; Karidar and Glasdam 2018). Different meetings and medical rounds, driven by a medical logic where diagnoses and treatments are in focus as the agenda for the inter-professional team, structure the professionals' working days. Other studies show that hierarchies in the medical field are constructed on doctor-oriented and institution-oriented rather than patient-oriented practices, which means that psychological and social issues in patients and their relatives have low priorities in the teams' work and collaboration (Glasdam 2007; Klitzman 2007)."*

<https://link.springer.com/article/10.1007/s11019-019-09918-2>

This is in no way designed to detract from the compassion and care that comes from those who deliver exceptional palliative care to those at the end of life. I have spoken to many nurses who have sobbed down the phone as they shared with me the experiences they have endured - how it played out for them - how they felt that "the palliative care system" could have done better but also the reality of why they support voluntary assisted dying legislation.

During the Qld End of Life Choices Inquiry, I listened to the harrowing stories shared by many across our state. I shared my own experiences with others at the Brisbane Public Hearing. I also listened and read the reports of those who oppose on the grounds that we need to inject more funding into palliative care rather than seek to introduce voluntary assisted dying legislation.

There is nothing more frustrating than sharing your experience of watching your loved one suffer - and I mean SUFFER - in ways unimaginable to many unless they have experienced this

personally - to have someone tell you that this could have been avoided with more funding for palliative care when you know that NOTHING could have helped your loved one in their suffering.

There is nothing more frustrating than a Politician saying they do not support the legislation based on the argument that better palliative care is required - when you know that no amount of palliative care could have stopped how your loved one suffered or died.

So how do we get to the bottom of this and put this argument to bed? It's difficult because our Politicians usually revert to those who they believe are knowledgeable - who are deemed to be the "experts" in this field. But what happens when those experts are also saying that palliative care is the answer and yet thousands and thousands of people across the globe are fighting tooth and nail based on real life experience?

I recently brought up the topic of how palliative care cannot alleviate all end of life suffering with two specialists separately. One was a specialist about to perform surgery on a family member. I spoke about "VAD" and his response was that palliative care was great and he had NEVER seen anyone die a bad death ... This is a prominent specialist.

I recently brought it up with another GP who said to me "Oh yes, they give them enough to keep them comfortable so they pass peacefully."

These comments were in stark contrast to several nurse specialists who have worked in palliative care for years. The ones who shared their stories of being the ones to often "plead" with their supervising doctors, on the "rounds" to allow them to administer more medication for their end of life patients - the ones who struggled to understand why some of the doctors in charge wanted to keep conducting invasive procedures - days and hours before a patient died - the ones who had to tell their end of life patient that there was nothing more that could be done for their pain and suffering.

So why is this not coming out in the public arena? Why are we not hearing this incredibly important information and detail about what really happens?

Of course, Palliative Care needs lots of funds to be injected by the government to ensure that it is uniform and individuals do have access to it across the state - just as much as our health system needs to have additional funds injected. It does NOT mean that voluntary assisted dying legislation should not exist on the basis that we need to improve the standards of palliative care first!!

We have seen Politicians do a complete turnaround when suffering knocks on their door! The Tasmania debate has seen several Politicians share their own harrowing stories of suffering recently. So is it the case that as a society, we accept that Politicians know best?

So why is there this GAP? And HOW do we get the real information out there? Isn't it time to ask some questions of those who make decisions which govern our legislation? Isn't it time we ask our Politicians (who oppose) the following:

1. What gives you the impression that Palliative Care can alleviate ALL of the suffering that comes with a terminal or incurable disease?
2. How did you arrive at that decision and who actually told you that?
3. When your constituents share their harrowing stories and experiences with you - and you continue to believe that palliative care is the answer - WHY?
4. How much do you know about the diseases that actually cause the suffering?
5. What do you understand to be meant by the word SUFFERING?
6. What do you understand about the side-effects of some of the treatments or the invasive procedures that are conducted on those who live with a life-limiting disease?
7. How much time have you spent with someone close to you who is dying from an incurable disease and how much time have you spent watching their struggles? The actual nitty gritty.
8. How many frontline nurses have you interviewed - not the HIERARCHY - the workers who don't often have the opportunity to speak up, anonymously and in a protected environment so they can share with you why they support voluntary assisted dying legislation.
9. What do you really understand is meant by "Palliative Care" when a person's suffering is intolerable? What do you believe to be the magic medication that is administered? How do you know if that actually works and who told you that?
10. What do you understand to be the actual real practice of palliative care, the different settings, the delivery of it, what is administered and the actual protocols behind what is given, when it is given and on whose "say-so"?

Earlier this year I interviewed a retired former Palliative Care Nurse Specialist, Beverley Young, with Post Graduate qualifications in palliative care and years of experience. She advocates for exceptional palliative care but is a passionate advocate for "workable" Voluntary Assisted Dying Legislation. She shares several dreadful stories of end of life patients who were told that there was nothing further that the palliative care nursing team could be done to ease their suffering. One such story resulted in the end of life patient jumping off the balcony of the well-known hospice in which she worked, taking her own life, such was her suffering.

## THE VULNERABLE & COERCION

I refer to an extract from the Recommendations of the recent Queensland End of Life Choices Inquiry:

**41 Hearings – 535 Witnesses – 4,729 Submissions**

### **Findings and recommendations (Report No. 34)**

*Health, Communities, Disability Services and Domestic  
and Family Violence Prevention Committee  
Paper No. 5, 56th Parliament, March 2020*

**In regard to arguments raised against introducing VAD in  
Queensland, the committee found:**

- **People opposed to participating in VAD because of religious or other beliefs would have the choice to not access VAD which would be voluntary**
- **Concerns raised about protections for vulnerable individuals can be addressed through safeguards and eligibility requirements, as has been demonstrated in other VAD schemes**
- **The view expressed by some faith groups about the spiritual benefits from suffering at the end-of-life are not universally accepted, even within particular denominations, even within particular denominations**
- **There is no clear evidence that legalisation of assisted dying results in an inevitable move toward the erosion of safeguards and an increase of non-voluntary euthanasia, and**
- **Temporary suicidal ideation is quite distinct from an enduring, considered and rational decision to end one's life in the face of unbearable suffering.**

## PROGNOSTIC TIMEFRAMES

I refer to the original draft Bill presented to Tasmanian Parliament which did not include any Prognostic Timeframe clause. An amendment was made and prognostic timeframes have now been included in the Bill which passed the Upper House.

I must ask the question: “For whom are prognostic timeframes?” Certainly NOT for the person who is dying from an incurable/terminal illness. “What is the purpose of having a specific prognostic timeframe when someone has been given a diagnosis of a ‘life-limiting’ disease?”

As someone living with a terminal illness, I do not agree with prognostic timeframes in terms of eligibility criteria for a person to access voluntary assisted dying. I am now on my third and “last line” of “tablet” chemotherapy medication. Each type of chemotherapy becomes ineffective after a period of time. The medication has never meant to be a “cure” but to “buy more time”. I have personally indicated that I do not want to receive intravenous chemotherapy treatments which, for my disease, will impact significantly on my quality of life (I have witnessed this first hand with many colleagues and friends who have died from the same disease).

Recently, my metastatic breast cancer blood markers have, again, started to increase. In early 2021 I will undergo further scans – unless a bowel obstruction happens which has been predicted as a possibility due to the nature of metastases in my abdomen. This will have its own dreadful consequences. I have tolerated the current forms of chemotherapy tablets up to now (with some distressing health challenges along the way). It is MY preference that as the person experiencing the suffering, I am the only one able to say when enough is enough and when I know acceptable forms of treatment have been exhausted.

My father died of non hodgkins lymphoma. I used to hope that he would not wake up in the morning during his last 12 months of life. Watching the suffering and his body being ravaged by his disease over that last year was unbearable. He spent more time in hospital than he did at home.

My friend’s sister, 52, has aggressive metastatic breast cancer. She commenced chemotherapy 2 months ago and has spent 6 weeks out of the 8 weeks in hospital due to the impact of the treatment on her kidneys and liver. She cannot eat, has had drastic weight loss and is extremely unwell.

As an advocate for voluntary assisted dying legislation over the last 4 years, along with others, I have been incredibly disappointed and distressed to listen to political/religious debates regarding the introduction of voluntary assisted dying legislation where so much has been lost and the end of life patient has not been the focus of those debates.

I have written many articles/posts on what I call “The In Between Stage”. This is the detail and depth of suffering that is rarely discussed or debated but is the reality of what individuals go through leading up to and after a diagnosis of an incurable disease. Much of this detail, if included in the debate, would, I believe, remove much of the argument presented by the opposition. That “detail” could not be imagined unless witnessed by a family member, friend or loved one or by the person living with the terminal/incurable illness.

There are many, many health challenges to deal with whilst living with an incurable/terminal disease along with a great deal of suffering as a result of

- (a) the disease
- (b) the treatments administered, the side-effects (and there are many ...)
- (c) health challenges as a result of a compromised immune system – a long time before the last 6 months of life

I speak from my own experience, the experience of witnessing my family and friends suffer - my parents and the thousands of others who share their stories on so many social media voluntary assisted dying platforms – not just in Australia but globally.

I refer to my mother who, after surviving aggressive cancer in her 50s, was diagnosed with incurable and terminal “primary biliary cirrhosis” – a rare auto-immune disease of the liver. For 3 years she was bed-ridden, her stomach subject to ascites and having to be drained every few weeks, her mental capacity impacted during the times of “toxicity” and a range of complications associated with her disease. During her last 18 months she slept all day in the 24 hour specialised care facility – rarely eating or drinking. It was not how she wanted to die. A prognostic timeframe would have meant that by the time the last 6 months did come she wouldn’t have had capacity to make the decision.

I refer to a friend recently diagnosed with vaginal cancer – stage iv – who has had to endure so over the last few months and will now undergo extensive radium to that sensitive area for the next two months, in addition to dealing with metastases to her lung – all with no guarantees. Her quality of life is zero. I could write half a page on her symptoms and conditions and you would struggle to read the information.

I refer to my friend who was diagnosed at the same time as myself – Stage IV incurable metastatic breast cancer – whose disease progressed through every major organ – 18 months before she passed away. She made the decision to stop chemotherapy 12 months before she died because she was bed-ridden and could not walk. She was depressed and was in pain. 6 months after this decision, at the urgence of her family, she recommenced chemotherapy. This time her disease had progressed to her bones and spine. Her last 8 weeks in one of Brisbane’s best palliative care facilities saw radium being administered to try to alleviate the pain in her spine but the treatment burnt her oesophagus and she could not swallow ... She had indicated her wish for “assistance” 12 months prior and, of course, this was not possible.

Only an individual experiencing all of the above knows when they have had enough suffering and unless politicians/law makers actually take the time to understand all of the nitty gritty of a particular disease, they could not possibly understand why prognostic timeframes and “specific” eligibility criteria relating to prognostic timeframes or “defined” categories, i.e. “advanced, progressive, will cause death, etc” detract from the purpose of voluntary assisted dying legislation.

I refer to a comment by UK Dr Miriam Day, an advocate for Voluntary Assisted Dying Legislation:

*“The more people I speak to about the Oregon model the more I realise how many people it fails. By being so restrictive it means that many, many people who are terminally ill and suffering cannot access assisted dying at a time of their choosing so are forced to continue to suffer. It frustrates me that people say that six months prognosis is a safeguard. What it really is, is creating a law that isn't accessible to many who have a terminal illness and are suffering. Is that a safeguard or just an inhumane way of forcing people to suffer for longer?”*

I refer to a comment posted this week from the husband of one of the members (who died this week) of a private and closed group of Stage IV incurable metastatic breast cancer females of which I am a member:

*“This is X, X’s husband. She wanted me to let you all know when she could no longer communicate. 2 weeks ago I had to take her to Emergency because she had a serious change of mental status. After lots of testing it was found that she had cancer on her meningitis. She started radiation and has had 8 treatments. There has been no change. I talked with her Dr and discovered that the radiation was not effective. Not really sure where we go from here. As a Nurse I am seeing signs of her passing. We were told 3 months but that was optimistic. It looks like a few weeks is all she has left.”*

And another comment from a member of the community to my social media advocacy page:

*“All of the states that have legalised assisted death but only if you have 6 months left to live really need to evaluate that. My mother had just a few weeks left when her one specialist told her “it’s not time to talk about that yet” when she tried to talk about assisted death. Her other specialist had his own religious reasons to object to her request. What good is “Voluntary Assisted Dying” if a doctor’s personal religious objection and inaccurate projected life expectancy get in the way? So frustrating.”*

The Tasmanian VAD Bill should provide that for a person to be eligible for access to voluntary assisted dying legislation, the person must be acting voluntarily and without coercion. I support this fully. Arguments regarding the possibility of coercion are often presented by opposing groups, right to life groups and religious institutions – known as “the slippery slope”. There are many articles which support the fact there is no evidence of “coercion” in countries where voluntary assisted dying legislation is legal. I refer to two research articles which debunk this concept.

US National Library of Medicine: National Institute of Health (July 2016) "Attitudes and Practices of Euthanasia and Physician Assisted Suicide in the US, Canada and Europe - conclusion: "Euthanasia and Physician Assisted Suicide are increasingly being legalised, remain relatively rare and primarily involve patients with cancer. Existing data do not indicate widespread abuse of these practices."

2007 [Journal of Medical Ethics](#) report about the Oregon Voluntary Assisted Dying law:

**Results:** Rates of assisted dying in Oregon and in the Netherlands showed no evidence of heightened risk for the elderly, women, the uninsured (inapplicable in the Netherlands, where all are insured), people with low educational status, the poor, the physically disabled or chronically ill, minors, people with psychiatric illnesses including depression, or racial or ethnic minorities, compared with background populations. The only group with a heightened risk was people with AIDS. While extralegal cases were not the focus of this study, none have been uncovered in Oregon; among extralegal cases in the Netherlands, there was no evidence of higher rates in vulnerable groups.

**Conclusions:** Where assisted dying is already legal, there is no current evidence for the claim that legalised PAS or euthanasia will have disproportionate impact on patients in vulnerable groups. Those who received physician-assisted dying in the jurisdictions studied appeared to enjoy comparative social, economic, educational, professional and other privileges.

Whilst examining the issue of “coercion”, it is ironic that what is often not examined by opposers, is the issue of “coercion” by family members of loved ones who insist and want their loved ones to receive treatments that an individual does not want to pursue ... Coercion can also be interpreted as exactly that when families make the decision to admit their terminally ill loved ones into palliative care/care facilities – when they would rather remain in their own home and receive care there.

## DECISION MAKING CAPACITY

Whilst the Tasmanian VAD Bill should provide that for a person to be eligible for access to voluntary assisted dying, the person must have decision-making capacity in relation to voluntary assisted dying, a great deal of supporters of the legislation, including myself, believe that a person, with full mental capacity, should be able to state their wishes to access voluntary assisted dying legislation through an Advance Health Directive.

I refer to the Canadian legislation, in particular the case of Audrey Parker (now deceased), from Halifax, who did have access to the Canadian MAiD legislation but the requirement that she have mental capacity to administer MAiD meant, that when her metastatic breast cancer progressed to her brain, she had to request MAiD earlier than she wanted to, to ensure that she did not lose capacity. She accessed MAiD on 1 November 2018 and had wanted to spend her last Christmas with her family. This is incredibly distressing.

I agree with “decision-making capacity” as defined in the Voluntary Assisted Dying legislation in Western Australia. Making this statement I appreciate the legal and medical aspects of “decision-making capacity” and draw on my “real life experience” of what it means to have “decision-making capacity” in terms of living with an incurable/terminal illness and suffering greatly.

What does come to mind is a video distributed by Dignity in Dying UK of the daughter of a lady who had died a dreadful death. Her daughter said in her mother’s last months she looked at her daughter, pointed two fingers to the side of her head, implying “shoot me”... Again, how ill an

individual feels, the extent of their suffering might impact on their decision-making capacity in terms of reading a contract of sale or complex legal contract of some nature might be questionable, an individual, suffering extensively, having gone through treatments, surgeries, knows when they want to be able to say “enough is enough”. As long as that individual fully understands the voluntary assisted dying process, understands that their request and access to the practice will end their suffering, that should be deemed acceptable for the purpose of “decision-making capacity”. The Western Australian legislation covers this simplistically.

Whilst the Tasmanian VAD Bill should provide that for a person to be eligible for access to voluntary assisted dying, the person must have decision-making capacity in relation to voluntary assisted dying, a great deal of supporters of the legislation, including myself, believe that a person, with full mental capacity, should be able to state their wishes to access voluntary assisted dying legislation through an Advance Health Directive.

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## **INITIATING A DISCUSSION ABOUT VOLUNTARY ASSISTED DYING**

The Tasmanian VAD Bill should NOT provide that a health practitioner is prohibited from initiating a discussion about voluntary assisted dying as an end of life option. Whilst the Victorian legislation included a clause prohibiting a health practitioner from discussing voluntary assisted dying as an end of life option, Western Australian legislation improved on this and included it in their legislation (as it is included in the draft Tasmanian EOLC (VAD) Bill.

My concern also stems from the fact that now that Victoria and WA have passed legislation, with Tasmania to follow soon, hopefully, the option of VAD will become much more common in the community and therefore is it wise to have members of the community discussing this amongst themselves, putting this forward as an option, family members “suggesting” this (coercion?) with their loved ones, or is it better for the treating healthcare professional to be able to discuss this as part of the patient’s end of life options. I believe it is essential that healthcare professionals are able to discuss ALL treatment options.

How the discussion progresses could be “tailored”. I spoke with my own oncologist about this some time ago. He agrees with “VAD” but did not believe he should initiate the discussion and saw it playing out as a conversation as “We can try chemotherapy, radiation or voluntary assisted dying which means we end your life.” I thought that example to be totally unbalanced. There are patients who, when diagnosed, choose to not receive chemical/radiotherapy treatments – they simply do not want to. They want to live their life as well as they can for as long as they can. What about patients in the situation of those I have referred to earlier in this

submission, who reach the point where their treatments are causing them untold suffering and impacting significantly on any quality of life at all.

Voluntary Assisted Dying Legislation is, as was recently described in an article, “A prescription for peace of mind”. Knowing that the option is there allows the individual to maximise their remaining days with peace of mind knowing that when suffering does become too much, that is a peaceful option.

I refer to a procedure I had to have recently – a nerve root sheet injection to my neck in the C6/C7 area. The nurse looking after me for the day came to discuss with me all of the potential risks/side-effects. One of those included “death”. These discussions happen routinely every day as part of surgeries/medical procedures. Voluntary Assisted Dying should be no different and it should be an option initiated by a health practitioner if the patient is stating they are suffering, they don’t want any further treatments, they just want to have the best quality of life possible.

There should be no exceptions to any discussions but how they are initiated or delivered could be reviewed with healthcare practitioners who, I am 100% confident, are able to “read” their patients because patients do talk to their doctors and oncologists and, just as with the assessment of whether their patients have mental competency, so would a healthcare professional understand when a patient does not want to receive chemical therapies, stop chemical therapies, or when the health professional is having to advise patients that their treatment options are exhausted or the patient is incredibly ill.

## **THE VOLUNTARY ASSISTED DYING PROCESS**

Requesting access to voluntary assisted dying – the Tasmanian VAD Bill should provide that the person who makes a written declaration must sign the written declaration in the presence of a coordinating practitioner and one other witness.

The Tasmanian VAD Bill should provide that a person is not eligible to witness a written declaration if they are (a) or (b) in Question 18, i.e. have an interest financially or materially from the death of the person making the declaration. I find it totally acceptable that any health care professional involved in the patient’s healthcare should be able to witness any request by the person, along with one other witness and that that other witness could be a family member.

## **WAITING PERIODS**

As an important “safeguard” there should be a short “waiting period” within the Tasmanian VAD Bill from a person’s first request to the final request for access to voluntary assisted dying but that “waiting period” should be limited, i.e. 7 days. I believe, as is the case with the Tasmanian Bill, that there should be included in the Tasmanian VAD Bill, that there should be a clause that allows for this period to be waived if it is likely that the person is likely to die very shortly after the initial request or if that person is likely to lose decision-making capacity for voluntary assisted dying within that period. During the Second Reading by Michael Gaffney MLC (Draft Tasmanian EOL (VAD) Bill he referred to a discussion whilst in Canada with the family member of

an individual where this is exactly what happened – the person had requested voluntary assisted dying but had lost capacity just prior to being able to self-administer the medication.

## **ELIGIBILITY ASSESSMENTS**

Legislation needs to ensure that two medical practitioners are involved in the initial eligibility assessment process and that they are independent of each other. Consideration must be given to the actual process, particularly with reference to regional/remote areas, in the eligibility assessment process.

In the Tasmanian Bill the initial eligibility assessment must be undertaken in person with the first medical practitioner but I understand the second assessment can be undertaken by video conferencing.

It is crucial that this part of the legislative process does not become so onerous that it creates access barriers for the patient user.

Assuming that the coordinating practitioner/consulting practitioner are medical professionals it would seem questionable that they are not able to determine if a person has decision-making capacity in relation to voluntary assisted dying – particularly in light of the fact that the “practitioners” would most likely be part of the patient’s health-care team and for a period leading up to the request for voluntary assisted dying. That being said, if either practitioner could not determine decision-making capacity then, as is the case with Victoria and Western Australia, either practitioner should refer the person to a practitioner with appropriate skills and training to make the determination.

If either practitioner is not able to determine if the person has a disease, illness or medical condition that meets the eligibility criteria then the practitioner should refer the person to a health practitioner with appropriate skills and training as in Western Australia.

## **UNDERSTANDING THE REAL MEDICAL PROCESS AFTER A DIAGNOSIS**

It is important to understand the “medical process” after a diagnosis, healthcare professionals who are involved and the role of the patient’s general practitioner. This explains why a “specialist medical practitioner” should not be mandatory. I speak from experience.

Patients diagnosed/living with a disease, illness or medical condition that is incurable/terminal see their treating specialist (in the field of that disease) for that specific purpose (i.e. the specific disease and treatment and follow-up appointments). The patient’s own medical practitioner, i.e. general practitioner, takes care of everything else.

Copies of all my blood tests, scans and oncology reports are sent to my general practitioner by my oncologist. My general practitioner has access to the Qld X-Ray portal where she can see my scans and read my reports.

When health challenges arise as a result of the impact of treatments/a compromised immune system – it is my general practitioner who I have to visit. It needs to be understood that oncologists are extremely busy people and you do not get to see them – even in the “private system” when you have health issues. Over the last 4 years I have seen my general practitioner many, many times. She is able to communicate more quickly with my oncologist, if necessary, than I am. She is fully conversant with my disease, its progress and what is happening with me at any given point in time.

During the Western Australian voluntary assisted dying legislative process, general practitioners publicly stated their objection to not being qualified to determine whether or not a patient meets the criteria for voluntary assisted dying. The Victorian legislation, which requires that a patient must be referred to a “specialist in the field of the disease” has caused challenges for the patient wishing to access the Victorian legislation due to the limited number of “specialists” available to work in the voluntary assisted dying process.

A health practitioner with appropriate skills and training is suitably qualified to be able to provide an eligibility assessment based on whether or not a patient has an incurable/terminal disease based on all of the information at hand to that health practitioner.

If either practitioner is not able to determine if the person is acting voluntarily and without coercion they must refer the person to another person who has appropriate skills and training to make a determination as is the case in Western Australia.

### **Administration of the voluntary assisted dying substance**

The individual using the voluntary assisted dying process should be able to decide, in consultation with and on the advice of the coordinating practitioner, whether the “VAD” substance should be self-administered or practitioner administered. This decision should NOT be taken away from the individual using the substance. The individual should be allowed to self-administer and should also have the option to seek assistance from the practitioner if the individual requires assistance.

It is important **to focus on the individual**. It is important for the individual to be able to use the substance when the individual feels it is the right time, rather than a “diary appointment” to use the substance. There are several scenarios to consider in terms of “administration of the voluntary assisted dying substance” and this should be focused on the individual’s choice with “input” from the medical practitioner as to any concerns the person may have.

The Tasmanian Bill should NOT provide that any practitioner must be present when the person self-administers the voluntary assisted dying process. This should not become a “diary appointment” for several reasons. The individual may choose to be alone, or with family; the time and date of the proposed ingestion should not be to suit a medical practitioner’s diary commitments. The option should be there for a practitioner to be with the individual should the individual wish that to be the case.

Having applied (and been given the 'green light') for an assisted death overseas, at the time of my choosing, it would be very important to me, if the legislation was available in Qld, to have the option of having a practitioner when taking the substance, but also being able to do so at a time of my choosing. The timing of this must be at the individual's discretion. The individual should not feel obliged to commit to a date.

## **PROCEDURAL MATTERS**

With regard to any other issues relating to other procedural matters, I again re-emphasise that the focus needs to be on the individual and making the process peaceful, compassionate and on the individual's terms re timing and the actual process. This is imperative. This really is so important. The individual's "situation" needs to be taken into consideration. No-one would wish to be in this position and "the event" is the "final step" after significant suffering from an incurable/terminal illness. I speak from experience when I say that this decision is a decision you wish you did not have to make but all decisions are removed by virtue of your terminal/incurable disease.

### **Qualifications and Training of Health Practitioners**

The Tasmanian VAD Bill should set out minimum qualifications and experience requirements for a medical practitioner to act as a coordinating practitioner or a consulting practitioner.

I do not believe it is necessary that the "medical practitioner" be a "medical specialist" with relevant expertise and experience in the disease, illness or medical condition expected to cause the death of the person being assessed as is the case in Victoria. Please let me explain why.

1. Based on my own experience, since my terminal diagnosis in 2016, and based on the experience of friends also diagnosed as "terminal", the specialist (oncologist) plays a significant role in the initial diagnosis – usually after the referral from the individual's medical practitioner to the "specialist" (oncologist). Tests, scans and treatment options are then organised by the "specialist" (oncologist) and the individual then commences the "treatment journey". The individual's referring medical practitioner receives copies of those tests, scans, reports from the specialist by way of "update" on the individual's health status. The medical practitioner has on-line access, through the online medical portal of the service providers, to those scans, scan reports, blood tests and other pathology reports.
2. The individual may only see the "specialist" (as in my case) every 8 weeks, or, in the public health system, every couple of weeks as chemotherapy is administered.
3. When health challenges arise (as in my case over the last 4 years) I have always been advised to return to my usual general practitioner. I have had to do this on many, many occasions. Specialists are very busy people – the patient is not able to go to a specialist when the need arises. I am in the private system but I have had to call my specialist a few times re concerns that have arisen and days can go by before any response is received.

This has resulted in me returning to my general practitioner who then intervenes. My general practitioner is as fully apprised of my health situation as the specialist.

4. During the Western Australian parliamentary debate re voluntary assisted dying, I wrote to all WA Politicians. One Politician asked to have a phone call with me. We spoke about the issue of whether or not one of the coordinating/consulting practitioners should be a specialist in the field of the illness. The politician replied that he did not have “that relationship” with his general practitioner and only saw him once per year for a flu injection. I had to advise the Politician that should he be diagnosed with an incurable/life-limiting disease the frequency of his visits to his general practitioner would change from his usual “once per year” to very regular visits” ...
5. I could recount several stories of friends who are living with life-limiting illnesses who have to wait weeks to see their “specialist” due to busy schedules.
6. The reports coming from the Victorian legislation have also demonstrated that including a “specialist” in the field of the illness has caused problems and delays – particularly in regional and remote areas where accessibility to a “specialist” is extremely limited.
7. Should the legislation provide for at least one “specialist” then the confirmation of the individual’s health should allow confirmation of the individual’s health position to be confirmed by written reports and not require the individual to have to “attend” a physical appointment.

The VAD Tasmanian Bill should provide that the voluntary assisted dying substance can be administered by:

- The coordinating practitioner (as in Victoria and Western Australia); or
- A medical practitioner who is eligible to act as a coordinating practitioner for the person (as in Western Australia); or;
- A suitably qualified nurse practitioner (as in Western Australia); or
- A Registered Nurse, who meets the training and other requirements (re the Voluntary Assisted Dying process) and which is included in the draft Tasmanian End of Life Choices (Voluntary Assisted Dying) Bill.

I refer to the recent robust parliamentary debate in the Tasmanian Upper House regarding the inclusion of Registered Nurses to be able to administer the voluntary assisted dying substance (with which I whole-heartedly agree).

I refer to Recommendation 15 of the Queensland End of Life Choices Inquiry:

Recommendation 15:

*15. Assessment of applicants where doctors are not available. The committee recommends that the Minister should consider including flexibility in any voluntary assisted dying scheme in Queensland for applicants in rural and remote areas of Queensland where a doctor or second doctor are not available, to permit a registered nurse who meets the training and other requirements to participate in the scheme to assess an applicant for voluntary assisted dying and to administer the voluntary assisted dying medication.*

To elaborate further: When talking about “Registered Nurses”, there are a range of different levels, different levels of experience and expertise.

Registered Nurses operate within a “scope of practice”, which is subjective, but there are guidelines. Registered Nurses work within their “scope of practice”. In the event a Registered Nurse had limited experience, that would then call for that particular Registered Nurse to work under the guidance/instruction of a medical practitioner (if we’re talking about administering medications).

When it comes to determining mental capacity – Registered Nurses make that call regularly – the process is called “mini-mentals”. It happens Australia wide and 90% of the time these “mini-mentals” are undertaken by Registered Nurses. It is a standard test used widely, particularly with the elderly and these are undertaken by the Registered Nurse before they see a general practitioner.

Registered Nurses are also involved in the delivery of health care within the home, e.g. Blue Care Nurses, who are attending end of life patients regularly and who get to know the individual and their families.

I refer to the limited number of Nurse Practitioners – particularly in rural and remote regions which would cause problems for the individual.

I refer to the expanding role of Registered Nurses in the United Kingdom over the last 10 years where, due to the size of the population and increased waiting lists to see a local general practitioner, the role of Registered Nurse has expanded.

I refer to confirmation of this from a doctor in the United Kingdom who is also an advocate for Voluntary Assisted Dying. This was her response to Registered Nurse involvement in the Voluntary Assisted Dying process:

*“A nurse is a very broad title now in the UK. Obviously, they all have the same basic training but then can develop their roles and really have quite amazing roles as nurse practitioners, physician assistant types roles and something called surgical care practitioners.*

*They really can carve out amazing roles which can include:*

- 1. Seeing patients independently (in primary care for example as your friend had mentioned)*
- 2. Prescribing drugs - obviously as part of their role both in primary care but also in the hospital setting.*
- 3. Trained to do surgical procedures - perhaps relatively simple things such as carpal tunnel decompression, veins, endoscopy*
- 4. Consenting patients for their surgical procedures*

5. *Macmillan Nurses. Most people in the UK will know this term. They are palliative care nursing staff and really are the backbone of care for lots of people who have incurable cancer. They provide care, will give medication and will be able to prescribe (in a very clear protocol). They are usually based in hospice but will work independently in the community.*

6. *Mental Health Services: Patients will be assessed by a specialist mental health nurse this will involve assessing capacity and some senior nurses will be part of the sectioning under mental health act.*

*Other AHCP (allied healthcare professionals) are also trained to prescribe drugs (pharmacists can prescribe) and treat and give certain drugs autonomously (paramedics) so it really isn't just doctors that feel they have to do everything in the UK.*

*Nurses with appropriate skills and training assess capacity on a daily basis, discuss consent for surgical procedures and other treatment and will be the healthcare professional that signs the form with patients confirming they have consented for the treatment/procedure.*

*So, yes, nurses in the UK can do courses and increased training and really gain a lot of professional skills and autonomy. They most definitely can assess capacity and many do so on a regular, daily basis.*

*Nursing staff and other healthcare professionals have to be an integral part of any provision of VAD. Personally, I am offended that patients are given choice but then the final say is still going to be left with a doctor?"*

Finally, the role that nurses play at this current time, is often overlooked. From speaking to/interviewing nurses during my 4 years of advocacy for voluntary assisted dying, many share their own traumatic experiences of nursing end of life patients and their challenges trying to get their superiors to actually understand what they know to be what the end of life patients need. Some of the stories are truly alarming and an indication that contrary to the belief that doctors take on the lead role with palliative care patients – it is the nurses themselves who understand the needs of those who are suffering at the end of life. I refer to the document I tabled at the Qld End of Life Choices Inquiry, on 23 August 2020, Brisbane Public Hearing, called “Nurses Corner”.

The Tasmanian VAD Bill should require any health practitioner participating in the voluntary assisted dying process to receive mandatory training in terms of assessing a person’s eligibility for access to voluntary assisted dying.

## **CONSCIENTIOUS OBJECTION**

A registered health practitioner, who has a conscientious objection to voluntary assisted dying, should have the right to refuse participating in the VAD process.

The registered medical practitioner, who has a conscientious objection to voluntary assisted dying, should be required, under the Tasmanian VAD Bill, to refer a person elsewhere or to transfer their

care. This is patient autonomy and a human-rights issue relating to the patient. The referral to others **must be mandatory**.

### **Refusal of “entities” to participate in the VAD process:**

Regarding the issue of whether an “entity” (other than a natural person) should have the right to refuse access to voluntary assisted dying within its facility, my views, as someone living with a terminal illness, are very, very strong on this matter.

The purpose of the Tasmanian VAD Bill is to provide the voluntary option of a peaceful death to an individual who has been diagnosed with an incurable, life-limiting, terminal illness, which will cause death, and to avoid further prolonged suffering from that incurable, life-limiting, terminal illness.

Speaking from experience, as a daughter who nursed both parents for a very long time with both parents’ incurable diseases, speaking from experience of living with a terminal disease (metastatic breast cancer with current progression to the lung and abdomen) and from 4 years of robust advocacy/lobbying for the introduction of “VAD” legislation and speaking and interviewing many individuals, including nurses and families who have experienced the harrowing suffering of their loved ones, when it comes to whether or not “entities” should be allowed to refuse access to voluntary assisted dying within a facility, the following should be borne in mind:

1. When an individual is diagnosed with an incurable/life-limiting/terminal disease, they become part of the health care system and also a particular health care facility/entity.
2. Specialists/oncologists and the individual’s health care team is wherever the specialist/oncologist/health care team happen to specialise in a particular field of disease. The individual usually attends wherever that specialty care is delivered.
3. Some specialists/oncologists only work from specific health care facilities/entities.
4. The individual comes to know the facility/entity well and all of the health care professionals who work within that facility.
5. The individual will most often have been an in-patient of that health care facility/entity on several occasions during that individuals’ “incurable/life-limiting/terminal illness journey”.
6. Health care facilities/entities are supposed to offer the full suite of health care options not be selective.

To even contemplate that the individual would, by the time they seek to access voluntary assisted dying legislation, have to start to find a new specialist, a new health care team, is appalling and there is no doubt that this would cause immense distress on the individual who, by this point, would most likely be very unwell.

I refer to the Qld End of Life Choices Inquiry, in particular the Public Hearing in Brisbane held on 23 August 2018 where I, along with others, presented our submissions. I refer to the submissions presented by the Catholic/Anglican Church representatives at the start of the day where they referred to just how many health care facilities they operated and how those

services might be impacted as a result of voluntary assisted dying legislation. This prompted a question from the Chair of the Committee (Aaron Harper MP) as to how they fared in Victoria. They were not able to provide an immediate response to that question.

I refer to the following from Catholic Health Australia's VAD Bill Discussion Paper re the Victorian legislation, in 2017):



I refer to the recent public statement from the Mater Health Group (The Australian – 14 October 2020) which stated:

*“Queensland’s biggest private hospital operator will deny access to elective euthanasia and won’t refer-on patients seeking to end their lives if the right to die is legislated by the next state parliament.*

*Mater Group chairman Francis Sullivan says it is ‘not in the mission’ of the 10-strong hospital chain to facilitate voluntary assisted dying and it would opt out if Queensland became the third state to embrace it.*

*‘We are determined to provide comprehensive healthcare from cradle to the grave,’ he says. ‘We respect the process of life including the dying process but it is not in our mission to accelerate death and certainly not in our mission to directly intervene to cause death.’*

And I must ask the question: What about the individual? What about their views? Where does that leave an individual living in Queensland, who is dying, who wants to die peacefully, but with so many health facilities/entities threatening to refuse to allow voluntary assisted dying on the basis of their “entities’ mission statements?

These “entities” are government funded ...

As with all of the other states that now seek to introduce voluntary assisted dying legislation, opposition comes from religious/right to life based groups. It is incredibly dangerous to have a health-care process that is so influenced by “religious mission-based values” that it is hypocrisy

to be fine with administering medication to “sustain” life when an individual is dying, at all costs, yet has an issue with medication which seeks to reduce suffering.

It is unacceptable for such control to be exercised which is detrimental to those who would seek to access voluntary assisted dying legislation but cannot do so.

#### **Views:**

1. “Entities” should not be able to refuse voluntary assisted dying practices which ultimately form part of a “palliative care” suite of services. They are not “mutually exclusive”.
2. Should “entities” be allowed to do so then it the QLRC may consider new facilities/entities being set up to allow this service to those who seek to access voluntary assisted dying.
3. “Entities” that do not allow these practices should have to facilitate the transfer to such new facilities/entities.

#### **OVERSIGHT, REPORTING & COMPLIANCE**

The Tasmanian VAD Bill should provide for an independent oversight body – a VAD Commissioner, not necessarily a VAD Commission, as has been amended in the current VAD Bill - with responsibility for monitoring compliance with the legislation but should also seek to collect data which is currently not reported on (Victorian legislation).

I refer to the article in The Conversation – 21 February, 2020:

<https://theconversation.com/without-more-detail-its-premature-to-say-voluntary-assisted-dying-laws-in-victoria-are-working-well-132096>

*The Voluntary Assisted Dying Review Board has this week published a report detailing the first six months of the legislation in action in Victoria.*

*The report reveals 52 people legally ended their lives from the time voluntary assisted dying became legal on June 19 last year to the end of December.*

*While the Victorian government is hailing the report as an indicator the law is operating successfully, some questions remain.*

*Notably, the report only documents people who have accessed the legislation. It doesn't tell us about those who may have wanted to be assessed for voluntary assisted dying, but not been able to.*

*What the report tells us*

*The Voluntary Assisted Dying Review Board will report on the operation of voluntary assisted dying in Victoria every six months for the first two years, and then annually.*

*The review board's first report was tabled in parliament on August 27 2019. As this initial report only covered the law in effect from June 19 to June 30, this second report, tabled in parliament on Wednesday, is the first to provide any real detail about voluntary assisted dying in practice.*

*The report gives us a snapshot of the number of patients progressing through various stages of the assessment and approval process. In brief:*

- *136 patients had completed a “first assessment”*
- *102 patients had completed a “consulting assessment” (this is a second assessment to confirm a person’s eligibility, performed by a different doctor)*
- *81 voluntary assisted dying permits had been approved*
- *52 deaths had been confirmed. Some 43 people self-administered the lethal substance, while nine required a practitioner to administer it for them.*

*The review board concludes these figures demonstrate “the Act has struck a balance between being strict with compliance, while still accessible to those who want this choice”.*

*The Victorian government estimated about a dozen patients would access voluntary assisted dying in the first year, so the number of reported deaths already well exceeds this.*

*The Chair of the review board, Justice Betty King QC, said the number of patients accessing voluntary assisted dying shows this is something Victorians wanted, and now it’s available, they’re using it.*

*Victorian Minister for Health Jenny Mikakos said the report indicates the legislation “is working well and as intended”.*

*What the report doesn’t tell us*

*Importantly, the report doesn’t provide any information about patients requesting access to voluntary assisted dying prior to the formal first assessment.*

*This means we don’t have any data at this stage about patients who may have wanted to access voluntary assisted dying but were not able to, or the reasons why this may have been the case.*

*For example, we’ve seen anecdotal reports of people unable to find a doctor willing or qualified to assess them for voluntary assisted dying.*

*Patients in regional or rural Victoria have also reportedly had difficulties accessing voluntary assisted dying due to a federal law prohibiting doctors from discussing it with patients over the phone or online.*

*These issues are in addition to the “gag clause” feature of the Victorian legislation, which prohibits all health practitioners from initiating a discussion about voluntary assisted dying with their patients.*

*The review board said it has recently started collecting data on terminally ill people who were unable to access the laws. But it’s an oversight that systematic processes to collect this information weren’t in place from the beginning.*

*In regards to those assessed for voluntary assisted dying, the report doesn't explain the differences in reported numbers at each stage of the assessment and approval process. While some of the discrepancies are likely explained by the time it takes people to move through the steps, it's unclear whether some patients decided not to proceed, or died during the process.*

*The report also doesn't detail how long it takes patients to progress from a first assessment through to the permit application stage, though the review board noted the process can take several weeks.*

*Further, the report doesn't provide any demographic detail about the patients who have accessed voluntary assisted dying, such as their age, sex, level of education or income. While the review board receives information on demographics, and acknowledges this is important, it didn't report this data.*

*The limited information reported by the review board should be interpreted with caution, particularly in terms of understanding community access (and potential inaccess) to voluntary assisted dying in Victoria.*

*Without further detail, it's premature to conclude the voluntary assisted dying legislation is "working well".*

*What's next?*

*Other jurisdictions considering or implementing voluntary assisted dying have an opportunity to learn from the initial period of operation as well as data collection and reporting in Victoria.*

The oversight body should have all of the functions and powers conferred on the Voluntary Assisted Dying Board under the Voluntary Assisted Dying Act 2017 (Vic) and Voluntary Assisted Dying Act 2019 (WA).

Yes, the Tasmanian VAD Bill should include specific criminal offences related to non compliance with the legislation similar to those in Victoria and Western Australia.

## **OTHER MATTERS**

The death of a person who has accessed Voluntary Assisted Dying, for the purposes of the Births, Deaths and Marriages Registration Act 2003 and the Coroners Act 2003, should reflect the nature of the incurable/terminal disease from which the person has suffered.

## **OTHER KEY ISSUES/CONSIDERATIONS:**

There is a plethora of information that rarely sees the light of day in the parliamentary debate process.

1. The focus of the legislation needs to be highlighted and the target of the legislation is those who are dying. This is so lost in the parliamentary debate process. Over the last 4 years, during my intense advocacy and lobbying I have felt that every man and his dog has the right to an opinion based on "their views" when the legislation, the passing of the

legislation and the implementation – with robust safeguards – needs to keep in mind always the position of the individual seeking to access the legislation, the reasons why and all that that individual has gone through before coming to this decision.

I thank The VAD Review Panel for taking the time to read my submission.

Sincerely

**Tanya Battel**

**VALE – Voluntary Assisted Life Ending Group  
Brisbane, Queensland**