Submission No 59

INQUIRY INTO PROVISIONS OF THE VOLUNTARY ASSISTED DYING BILL 2021

Organisation: VALE (Voluntary Assisted Life Ending) Group

Date Received: 22 November 2021

VALE – VOLUNTARY ASSISTED LIFE ENDING GROUP

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21 November 2021

NSW Parliamentary Inquiry into Voluntary Assisted Dying

Dear NSW Parliamentary Inquiry Committee

Re: Voluntary Assisted Dying

On behalf of many Australians, the VALE (Voluntary Assisted Life Ending) Group, has sought to represent the voices of those living with a terminal illness (myself included), those who are no longer with us, families left traumatised forever by their loved ones' suffering and death, over the last 5 years. VALE has been an independent, self-funded advocacy group in support of Voluntary Assisted Dying Legislation nationally for the last five years.

In 2020, a Change Org Petition was started by myself advocating for the introduction of VAD legislation in Queensland. This petition was tabled at the start of the Queensland VAD debate in September 2021, had reached 115,000 signatures in support of the legislation, with signatures from across Australia spanning 3,840 pages in support of VAD legislation.

On behalf of the VALE – Voluntary Assisted Life Ending group, our submission to you is on behalf of many, many advocates, individuals living with a terminal illness, front-line workers and nurses/palliative care nurses who have shared on many social media platforms why they support end of life choices for those living with a terminal illness.

I also speak personally as someone living with terminal metastatic breast cancer, having endured a 25 year battle with breast cancer (now terminal metastatic breast cancer), receiving ongoing continuous chemotherapy (to buy more time) and my hands-on experience nursing both parents through horrendous suffering, over several years, before their cruel and painful deaths.

Principles

We concur with the principles that underpin the NSW VAD Bill. We would also like to make mention that "coercion" can also incorporate families/friends of loved ones who would like them to accept anything and everything in order to sustain breath and a pulse because they cannot bear to lose them. This, too is a form of "coercion". Individuals living with a terminal/incurable disease often do not want to move outside of their home but have to spend their last years/months/weeks in a place they don't want to be because the care they require cannot be received within the home or family/friends are not able to provide that care, thus rendering the end of life patient "coerced" into being where they do not want to be.

Health care worker not to initiate discussion about voluntary assisted dying

As someone living with a terminal illness, as a member of a 7,000 member-base support group of international women living with terminal metastatic breast cancer, VAD legislation is about having peace of mind to be able to determine when **we** have had enough. Evidence-based research demonstrates that in the countries where VAD legislation exists, many do not take up the option.

It is crucial that people faced with a terminal illness **do** have all options discussed with them. How those options are actually delivered should be addressed and one should be entitled to expect that medical professionals who do support end of life options would deliver that information based on a "worse-case" scenario, providing peace of mind to the individual who (from my own experience) has already experienced a great deal of suffering and exhausted many treatment regimes.

Some individuals choose not to pursue any treatment regime because the side-effects of that treatment regime will cause intolerable suffering in itself. That should be their choice. Many advocates of VAD legislation and close friends, have experienced horrific side-effects from their treatment regime resulting in them being bed-ridden most of the week before they start their next round of treatments. Some have said they would not be able to sustain their treatment regime for much longer and some have said they would never do it again.

Reality vs Myth

On 23 October 2021 we lost a dear friend and advocate, **Lyn Bailey**, to terminal vaginal cancer. Her last two years was, as she often described, a journey to hell and back and back again. In spite of receiving the best of palliative care, nothing could ease the excruciating pain of 48 sessions of radiation to her vagina – the internal ulceration and third-degree burns. She could not walk, she could not sit. Her daily phrase to us was, "I can't keep doing this. I cannot do this one more day." To understand Lyn's suffering would require any decision-maker on VAD legislation to understand all of the detail of Lyn's disease and understand, also, the unfavourable consequences of her treatment regime.

By the time Lyn was diagnosed she had a tumour the size of an orange in/out of her vagina. She had been initially told it was a cyst and not to be concerned. This malignant tumour eventually "exploded" in the middle of the night leaving her in a dreadful situation. The subsequent treatment regime was 48 sessions of radiation internally. Unfortunately, the extent of the internal ulceration/burns, together with the fistula (a common side-effect from radiation to the vagina, i.e. hard lumpy scar tissue causing excruciating pain pain) is well known to those who work in palliative care and those who are prepared to be truthful (including specialists like Dr David Grube, Oregon) and they attest to the fact that palliative care just cannot alleviate the pain associated with this dreadful disease. Lyn suffered cruelly until she died of a cardiac arrest on 23 October 2021. Lyn contacted Palliative Care regularly to tell them that everything they were giving her just was not doing anything to ease her excruciating pain. She could not sleep for more than a couple of hours and even going to the toilet or trying to bathe was hell. If the government had invested $1 million into Lyn's palliative care privately and personally – it still would not have made any difference to what she had to experience.

Another advocate, a retired Palliative Care Level 3 Nurse Supervisor, with post graduate qualifications in Advanced Palliative Care, and experience working at the Calvary Hospice in NSW, has shared the story of a patient at the end of life whose pain could not be controlled by the Palliative Care Team, such was her condition. That person waited until late in the evening and jumped off the balcony of the Hospice … What more can you say to outcomes like this?

VALE has received many experiences shared by those left behind who will forever be traumatised by their loved ones' deaths.

I have terminal metastatic breast cancer. I have endured two mastectomies, radiation treatment and many years of chemotherapy. It is currently in my lung and the omentum (the muscle/tissue in the abdominal wall that covers the bowel and the bladder). I have been advised to "watch for abdominal pain" as this could signal a bowel obstruction and the consequences following are not appealing, I can assure you. My chemotherapy and the cocktail of other medications keep buying more time but they all lose their efficacy and one by one they stop working. My time is limited. As a member of 7,000 international women in a private support group for women living with terminal metastatic breast cancer, I have, unfortunately, observed the sharing by many of the progression of this disease until it completely ravages their bodies. I don't know anyone who wants to have to see this out to the bitter end. It's 2021. There are kinder ways to die.

Discussions with Healthcare Professionals

All options need to be discussed with the end of life patient and not totally restricted. It is naïve to believe that patients have not said to their healthcare team, along the path to death, "I've had enough. I can't do this anymore. I don't want to continue on with this treatment that is making me so ill I have no quality of life. I do not want to spend my days non compas mentis because of medications and pain medications which have their own side-effects.

So, one might assume the conversation is going to be with the end of life patient's GP or Specialist who will, you would hope, have taken the time to consider how a patient is coping. Sadly, the reality is that GPs and Specialists do NOT always enquire as to how the patient is coping with the treatment and its side-effects. That's not a criticism, it is a reality.

Eligibility

Myself and many others question why there should be any "prognostic timeframe" after a diagnosis of an incurable/terminal illness. We ask again, "Who are these timeframes actually for?" They are not for the patient. Both my parents endured many years of suffering due to their incurable diseases which would not necessarily constitute "terminal" until the very horrific last 6 months. My mother was diagnosed with primary biliary cirrhosis, a rare auto-immune disease for which there is no cure. She had to be admitted to specialist nursing care 24/7 and stayed there for 4 years, in pain, waiting to die. That being said, if there does need to be in place a "prognostic timeframe" to appease opposers of the legislation, then 12 months should be the very least.

The issue around Politicians wanting to determine "prognostic timeframes" is that many do not understand the "nitty gritty" and all that is involved in living with an incurable/terminal illness. Because of that, if they have not been exposed to a loved one having to live in such an horrific way, they cannot possibly understand why there should be no prognostic timeframes after a diagnosis.

Conscientious objection by entities

As someone living with a terminal illness, having nursed both parents through terminal illnesses and having friends going through hell right at this time, to even contemplate they would need to move to another facility or have the focus removed from their plight based on an "entity's faith-based objection" whilst receiving funding (government and private sector) is hard to digest. Many, many supporters of VAD feel that this is totally unacceptable.

It is with scepticism that we acknowledge that faith-based groups will seek to have their way. In that event, just as appropriate safeguards are demanded by decision-makers, appropriate safeguards should also be put in place to ensure that any facility that does not offer Voluntary Assisted Dying services/information does nothing to hinder or obstruct an individual seeking to access information or access to the VAD service by those who are in charge of operating the facility.

Safeguards

We all acknowledge the need for safeguards but the Victorian legislation and the Review Board reports also demonstrate that some of the safeguards cause obstacles for those seeking to access the legislation. The legislation needs to work. The end of life patient, by the time they make the decision to access VAD, has had enough and is very unwell. The legislation needs to protect the vulnerable but the terminally ill ARE the vulnerable. The scaremongering by opponents that if introduced, VAD will lead to dangerous ground is unfounded. Taking the time to read evidence-based research and information from Oregon (US), Switzerland, Canada, demonstrates the success of this legislation over many, many years.

Religious opposition to Voluntary Assisted Dying

Along with 80% of our national population who support Voluntary Assisted Dying Legislation, to seek to block the wishes of someone enduring a terminal illness journey and their personal end of life wishes, in favour of religious views that are not shared by that person is cruel and inconceivable. It certainly has not helped all those who have shared their experiences with our group. It certainly infuriates me that the religious views of others dictate how my own ending is going to be. It is not acceptable, nor should it ever be acceptable, to deny compassionate legislation to those who seek to not quickly end their life but, rather, to quickly end their suffering and death in a peaceful and compassionate manner. Only the individual knows when they have had enough. Contrary to the belief of some religious institutions and entities, no one wants to die. I don't want to die, either. But being diagnosed with a terminal illness takes that choice away. The least we can hope for is to call it on our terms.

Conclusion

During 5 years of advocacy, the biggest frustration has been listening to Palliative Care Hierarchy and Religious Institutions claim that with more funding Palliative Care is the panacea that it is not. What is missing in this political debate is the detail – every bit of it – of what is meant by "suffering". "Suffering" is a word that can cover a range of areas. It is crucial that the conversation about what happens to an individual living with a terminal/incurable disease is explored fully to understand why Voluntary Assisted Dying is such a personal and human right.

Sincerely

Tanya Battel
VALE – Voluntary Assisted Life Ending