Inquiry into End of Life Choices – Legal and Social Issues Committee

By Vickie Janson

[redacted] / [redacted] / [redacted]

My primary concern in making this submission is to address the social issues regarding end of life choices and to ensure the State of Victoria continues to foster a culture that values life and offers hope. The elderly and infirm should receive the best palliative care available and Victorian laws should send the message that life itself is valuable. Legislation that enables the lawful taking of another person's life undermines the need to invest in the best palliative care and may remove hope in a time of crisis. Our laws shape our culture and hope is something that should be fostered. Life itself should be valued because where there is life there is hope. I don't believe the answer to relieving the suffering of others should be to relieve them of life itself. This is an incredibly dangerous idea.

In order to illustrate the importance of cultivating a culture of life and hope I would like to share my own short story as the mother of child who suffered severely following diagnosis and treatment for childhood leukaemia. My child's case was ultimately diagnosed as terminal. I faced my experience with end of life choices in Melbourne's Royal Children's Hospital in 1999. Had euthanasia been legalised at this time it would be unlikely my son would have received the palliative care needed for him to feel cared for and valued in his hour of need and the outcome for him may have been radically different. The question is 'do we want to cultivate a resilient culture that fights for life or one that gives up on it?'

My son Nathan Williams was diagnosed with childhood leukaemia when he was 6 ½. After 2 years of chemotherapy and only 3 months off treatment he relapsed, requiring a bone marrow transplant. As an only child there were no siblings who could provide the marrow and therefore Nathan received higher doses of chemotherapy to put him back into remission and keep him there until a suitable unrelated donor could be located. He was 9 years old in 1999 when he was admitted to the Royal Children's Hospital 'Bat Cave' for a high risk transplant from an unrelated UK donor.

It seemed that everything that could go wrong did go wrong. He suffered one of the worst cases of 'Graft versus Host disease' (GVHD) the hospital had ever seen and not only did hair, nails and skin fall off – even his stomach lining was stripped and excreted as the graft attacked every cell in his body. He had more complications than I can now remember. He was 'nil by mouth' for months, muscle wasted and on such high doses of steroids that his skin was paper thin and would tear on contact. He had no platelets so his blood wouldn't clot; he was covered in bruises, he had a collapsed lung and he began fitting. There were many other complications with issues around blood pressure, his own phobias about needles and taking medicines and collapsed veins meaning it was difficult at times to find enough access points to give him the treatment and IV nutrition he required. In total that year he spent 7 months in isolation and had a couple of trips to the Intensive Care Unit (ICU) bordering on death row the whole time. We were told no one had yet survived such an aggressive case of GVHD and we were warned he was on the permanent 'Code Blue' alert list and was expected to die at any time.

It was after the second visit to ICU that he was put in a room with a nurse we were told was 'dedicated to him until he died'. It was recommended by the hospital we allow the children's *Death Councillor* in to speak with him. As supporters of life and still with hope, we refused. We wanted life councillors. Our doctor also advised that the only thing keeping Nathan alive was the bags of blood that had to be continually hung to replace the blood loss from his bowel. At this point Nathan's entire gut was lacerated from top to bottom and he was effectively bleeding to death with the replacement bags of blood just holding him here. It seemed completely hopeless from a medical perspective and some thought it 'cruel to keep him alive'. But where there is life there is always hope and we too often underestimate the power of this. At the height of this vulnerability, perhaps others may have 'let him go'.

We refused the Death Councillor and we refused to remove the life giving bags of blood and we hoped and believed for a miracle. And that's what we got.

Three weeks after being told it was completely 'hopeless' Nathan's gut stopped bleeding and he grew a new stomach lining that today is as fit as most people's. We were told he would be in a wheel chair for quite a while and when he returned to school he wouldn't be able to manage a full day. But he left the wheelchair as soon as he left hospital, and when he returned to school he walked both ways and he never had time off classes as anticipated by the doctors. We were told he would have to stay home for the winter because he didn't have any neutrophils to fight infections common in school during winter; but he didn't stay home and he didn't get sick. We were told he would have to receive hormone replacement treatment to get through puberty – but he didn't.

Today Nathan is a healthy 26 year old who won a 2014 Banyule City Council Volunteer Award for his work with disadvantaged youth. Despite life's challenges and his suffering, Nathan was raised in a culture of life and hope and he therefore is able to impart these to others.

Young people today need to know that life is valued and worth fighting for and that even in the worst case scenario, it is better to die with hope than to die hopeless. We should always err on the side of protecting, nurturing and promoting life. Where there is life, there is hope.

The laws our parliaments make will send the message about how much life is actually valued and this will in turn shape the values society holds. If in 1999 assisted suicide was the norm, would my son be alive today? In my emotional weakness, would well meaning doctors have convinced us to ‘let him go’. Would the state have refused to give him blood because he was deemed hopeless? Should hospitals promote a culture of life or death?

If children like Nathan who struggle with treatment, and others who struggle as teens even in normal circumstances, receive the message that opting out is the best way to deal with depression or negative circumstances, they may be robbed of the life that is often born through suffering; a life able to influence and transform so many others by offering hope. For some that suffering is depression related to broken relationships. But whether it’s a broken body or a broken heart, surely our laws and culture should always promote life.

I implore this committee to contribute to building a culture that values life and offers hope. As my story shows, not every terminal diagnosis is actually terminal. Changes to our laws in normalising euthanasia and assisted suicide will impact attitudes in society; those of children, teens, adults and the elderly. To die with dignity is surely to die with hope knowing your life itself is precious and valued by others. Life is not to be wasted and considered worthless or something to be discarded when it’s broken. There’s a bigger message to consider and exceptional palliative care is the most humane answer to the pressing issues around end of life challenges.

Let’s invest more in palliative care to ensure people are genuinely treated well, comforted, valued and therefore can really die with dignity at their appointed time, and not a moment before, because life is far too precious to legislate cutting it short. Please don’t offer assisted suicide as an option as that grey cloud over a life may not be permanent and may blow away. And if not, that precious life is too precious to be cut short. If legalised, cutting life short may just become a utilitarian and dehumanising option particularly for our aging population. I am appreciative that the State of Victoria supported me and allowed me to hang on and give hope to my son; something he now offers many others. Please continue to do so for all Victorians.

NB: The following page is an extract from the *2014 Banyule Volunteer Awards* featuring Nathan Williams.

Young Volunteer Award Nominations

Nathan Williams, 24

Heidelberg West

Almost a year ago, Nathan teamed up with friend Sonni Ford (page 19) to create a community basketball club called Hoop Dreams for young people in Heidelberg West. Both Nathan and Sonni found sanctuary in basketball when they were younger which they attribute to getting them through tough times. Having basketball in his life motivated Nathan to overcome health issues and move forward with his life. Hoop Dreams has become an outlet for youth in the area and has helped create a sense of neighbourhood pride and belonging. Through his positive influence on and off the court, Nathan is scoring points for the community at large.

"Many of the boys involved look up to them as mentors and role models, which is a role they do not disappoint in, frequently helping out younger participants in different areas of their lives."

Amelia Willis, 22

Eaglemont

Amelia has been supporting Banyule Council's Arts and Culture team since February 2012. Volunteering a day a week as the Art Curator's Assistant she has been pivotal to many of the successful events and programs run by Council. Her work includes managing the volunteer gallery-sitters at Hatch Contemporary Arts Space, producing high-quality educational resource kits to accompany exhibitions for school visits to Hatch, as well as a range of administrative tasks and coordinating mini-exhibitions. She has also volunteered for the Australian Youth Climate Coalition and the Oaktree Foundation, working on a variety of campaigns raising funds and awareness.

"Amelia is an incredibly committed individual. Her contribution to the arts in Banyule on an ongoing basis is inspiring."