Submission to End of Life Decisions Parliamentary Committee.

Firstly we would like to thank the committee for the opportunity to put forward a submission on this extremely important issue.

For many years we have had a jointly held opinion in relation to end of life decisions/dying with dignity, which is that patients who have done everything in their power to beat a disease or overcome a medical condition must be allowed to die at a time of their own choosing.

However, in the last few months that opinion had its most rigorous test with the passing of our eighteen year old daughter, Cassandra (Cassie), from metastatic melanoma cancer.

In March of this year we were devastated when Cassandra was diagnosed with a Stage 4 metastatic melanoma on her pelvis/hip. There was no indication that the melanoma was skin related and the first time the cancer revealed itself was as a sore hip in late December, for which Cassie received physio treatment as we all thought it was muscle injury.

It was only after a blood test was taken in early March that it became apparent that there was an issue and then an x-ray revealed a tumour on her hip/pelvis area.

We live in Morwell and her disease was not able to be treated in Gippsland. We were referred to the Peter McCallum Cancer Centre in Melbourne and therefore we made the decision for Cassie and us to relocate and live with Cassandra's grandmother at Rosanna.

Whilst awaiting an appointment to Peter McCallum, Cassie's pain spiralled out of control and so we attended Austin Hospital Emergency where Cassie was admitted firstly to the Olivia Newton John Cancer and Wellness Centre, from where she was transferred to the Orthopaedic Oncology ward at St Vincent’s Hospital where the melanoma diagnosis was made. We were then returned to the Olivia Newton John.

When Cassandra was readmitted to the Olivia Newton John Centre treatment options were laid out. After discussion with Cassandra and us, it was decided that Cassie would take part in a trial of two trial drugs which had had good results with skin related melanoma cancers. This treatment is known as immuno therapy.

Cassandra had three cycles of immuno therapy during the three months that she was at the Olivia Newton John Centre and although doctors thought there may have been only very minor improvements in her condition, there was still an optimistic view that the treatment was assisting.

She also received two cycles of radiotherapy treatments in the hope of “shrinking” two tumours, the one on her hip and one on her L4 spine, which caused the eventual collapse of that vertebra.

In late May, Cassie was discharged and we left the ward and moved into a relative’s residence in Northcote. This was done at a time when doctors still held out some hope the immuno therapy treatment would work and she would receive treatment as an outpatient at the Olivia Newton John Centre for what was hoped would be an extended period of time.

After approximately nine days at the Northcote residence Cassandra developed a lung condition described as pneumonitis, a side effect of the immuno therapy she was receiving.
We attended at the Austin Hospital Emergency Department and she was then readmitted to the same ward we had been on at the Olivia Newton John Centre.

After further tests, including a bone marrow biopsy which showed that the melanoma had moved into her bone marrow, doctors decided that they would not continue with the immuno therapy with which they were treating Cassandra.

A discussion took place with doctors explaining that the only option left for Cassie was “traditional” chemotherapy. Cassandra and her doctors, with us present, discussed the fact that she would not feel any sicker however and doctors said there was a “one in a hundred or less” chance it would work and assist her into remission as she was "desperately sick".

The doctors explained there was nothing else they could do but they were prepared to let her try traditional chemo because she was so young and they wanted to give her every chance. The doctors said they had thrown the kitchen sink at Cassie but offering her the chemo was clutching at straws and they were not optimistic. It was explained her life expectancy was very short both with and without treatment.

We now realise saying the chances of traditional chemo working being one in 100 was actually being very kind and overly optimistic.

Cassandra then discussed the option of having traditional chemo with us and she bravely made the decision to refuse any further treatment. She knew she was going to die.

After informing the doctors of her choice to not continue with treatment Cassandra asked if they could give her one week to say her goodbyes. She was told they could they could give her a maximum of four days as she was desperately ill. The doctors told her they could now only “make you comfortable.”

During the next day, Saturday, when Cassandra was saying her goodbyes to her family she became increasingly dependent on oxygen to breathe and her need for pain relief became more. She eventually became drowsier as the pain medication increased and she became outwardly unresponsive but could, we were told, still feel pain. She would regain consciousness long enough to acknowledge that she was being given pain killers to “make her comfortable” and occasionally speak to my wife and me.

She very quickly became too sick and was unable to say her goodbyes to her extended family and friends.

During this time Cassandra asked the nurses delivering the pain killers for "the biggest dose they could give." At one stage early on the Sunday morning she begged the nurse “Please tell me this is going to kill me.”

She was in excruciating pain and was in distress.

The distress to not just us as her parents, her brother and two sisters who were present throughout her final days, but to the medical staff who had cared for her for three months was evident.
In the end Cassandra lingered for all of Saturday, Sunday and Monday eventually succumbing late on the Monday night. Only, four days after making the decision not to continue treatment.

The last forty-eight hours of Cassandra's life consisted of her family sitting around her whilst she struggled to breathe, even with assistance from oxygen, and in obvious excruciating pain. Crudely put we sat around her waiting for her to die.

As an aside to this we mention the fact that the doctors had asked Cassandra if she wanted to be resuscitated if she passed. She verbally said no and this was accepted as her wishes not to be resuscitated.

Obviously, the question of how she wanted to finish her all too short life was never broached with her by the medical staff, as they have no authority to ask. It would be illegal to help her to die with dignity so the question would have been mute.

However, even though we also did not discuss this with Cassie, after watching her die, after hearing her asking the nurse for the biggest painkilling dose they could give her, and listening to her beg “Please tell me this is going to kill me,” we have no doubt Cassandra wanted the right to make an end of life decision, to choose to die with dignity at the time of her choosing.

We ask the committee to consider the fact that here was a highly intelligent eighteen year old girl (she had just been awarded a $20,000 scholarship to study Criminology at university) who had been told by the most highly qualified melanoma specialist in not just Victoria but Australia, who had consulted world-wide in Cassandra's case, that there was nothing else that could be done and she would die from the disease within four days.

Cassandra had said her goodbyes to her family and yet could not ask to be treated with respect and allowed to die at the time of her choosing.

We would like to say that Cassandra had 'ticked' all the boxes throughout the course of her treatment in that:

1. She was highly intelligent and understood the nature of her illness;

2. She did absolutely everything the doctors advised (with the exception of taking one particular laxative which she described as disgusting and which caused her great distress to take) in her efforts to beat her insidious disease.

3. She agreed to participate in medical trials of drugs that were not yet approved for human consumption, Pembrolizumab (Keytruda), in a desperate search for a cure.

4. She submitted to radiation, CT scans, blood transfusions and excruciatingly painful biopsies; and

5. Finally, throughout she maintained full control of her mental faculties and was capable of making a fully informed decision that her time had come to die.
Cassandra was eighteen years old. She was legally allowed to drive. She was legally allowed to drink. She was legally allowed to vote for parliamentarians such as you who make up this committee. But she could not be allowed to decide the time of her death.

We put it to the committee that if we had allowed a pet or animal to linger the way Cassandra did after ceasing treatment then we would be prosecuted for cruelty. And yet we seem to think that we should allow humans to linger for as long as it takes for them to succumb to their disease.

We guess the "silver lining" to our cloud was that it was not a long period of time that Cassandra was made to suffer.

As we said we have always had the opinion, and expressed it to our family, that if we ended up in a vegetative state or were being assisted to breath and “live” then we would not want to continue.

After having now been through the trauma of Cassandra’s passing we are even more adamant that we, as individuals, must have the right to make the most important decision of our life. And that is when to medically end our own lives.

We understand that medical authorities would need to have a hand in this process and that all the boxes must be ticked before a patient would be allowed to die at the time of their choosing.

We also firmly believe that most medical staff, as in Cassandra's case, would assist if it was the patient’s wish.

Thank you for considering our submission.

Brett and Dianne Godden, parents of Cassandra Godden who passed away on 8 June 2015.