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Inquiry Name: Inquiry into End of Life Choices

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SUBMISSION CONTENT:

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Submission to Legislative Council’s Legal and Social Issues Committee in regards to the Inquiry into End of Life Choices

By Robyn, Tara, Ella and Rory Godbold

Dear Committee,

This is a submission from the Godbold family, in conjunction with Raymond (Ray) Godbold’s submission which was made before his recent death. This is written from Ray’s wife Robyn and his three children Tara, Ella and Rory.

Background
In July 2012, Ray was diagnosed with gastro-oesophageal cancer. By the time he was diagnosed the cancer had already spread to his liver and lymph nodes. There was no cure only an undetermined time to live. Ray was nurse with 30 years experience. He had been midwife and manager of Palliative Care services. He knew the system, he knew what his illness would do to him and all the different scenarios of how it might claim his life. He talked about this with us and expressed his desire to have a death that involved choice and control.

About a year after being diagnosed Ray became a passionate supporter of Dying with Dignity Vic. This gave him an intellectual focus and a renewed purpose to his final years.

Rays experience in caring for people at the end of their life demonstrated to him that Palliative Care did not always provide people with comfort at this time. Despite this he was a firm believer in the benefits of good Palliative Care, as demonstrated by his choice to practice in this discipline of nursing over many years both as a clinician and manager. He believed that good Palliative Care is paramount but that choice and autonomy at the end of life is not contradictory to the principles underlying good Palliative Care. He said to Tara in an email one time when they were discussing his advocacy ‘that I have worked in the system that has tried its best but had many failings’. He said that he believed the only way to achieve a peaceful death is by having some choice and control.

Ray commenced his first round of chemotherapy while in Darwin and had two additional rounds of chemo and some radiation therapy in Gippsland. His health deteriorated as the treatment and cancer took hold. His last treatment finished on 27 June 2015, 7 weeks before he died.

Ray’s death
A week before he died, Ray informed us all that he felt like it was time. He wasn’t planning to take the Nembutal that he had previously acquired, he expressed this was not his intention. He was simply going to stop taking his oral medication and have syringe driver with morphine and sedative (midazolam) attached to him. He intended to go to sleep and planned for it to be peaceful. At this time Ray was struggling to swallow his oral medication, he was only eating a few teaspoons of soft food a day (which he would often regurgitate) and even taking a sip of water could cause him pain. He was a 6-foot tall man who weighed between 40-45kgs.

The final days leading up to his death were not peaceful despite his careful planning, his discussions with us and having acquired the Nembutal. Despite our care and access to amazing palliative care services Ray was restless, awake and uncomfortable. Mentally he had periods of delirium and was disorientated about time and place. He would refuse to lie down at times because he thought he needed to shower to get ready for work, even though he had been retired for over two years. He would only sleep for a short periods of time during the day, even with the high levels of morphine he had been prescribed.

We believe he was in existential distress as he talked about and feared. He wasn’t ready to die but this was the only thing he had left to do. He was also complicated patient. Despite his dramatic weight loss and apart from his cancer the rest of his organs were healthy. Ray was being administered increasingly high doses of morphine and eventually the sedative, which despite controlling his pain was not controlling his restlessness, and shortness of breath.

The unfortunate thing for Ray was that even though he had the Nembutal - when he was capable he wasn’t ready but when he was ready he wasn’t capable. On the morning of Wednesday 12 August Ray woke extremely short of breath and distressed. We attempted to get him comfortable with morphine and sedative but it didn’t even seem to touch the sides of his distress and shortness of breath. In attempt to get him comfortable we brought a chair into the bedroom for him so he could sit upright. ‘Finally’ he said when he saw the chair. As we sat him down he pointed to where his Nembutal was ‘get it for me’ he asked. But we couldn’t. Nembutal needs to swallowed and it is very bitter. Even for someone with the ability to swallow and keep down liquids it can be very difficult to get down let alone someone with Ray’s type of cancer. We also couldn’t hand him the Nembutal for fear of what would happen to us. We told him this and he understood but this was left him with a fear that he would asphyxiate to death and this added to his distress as well as ours. It was an incredibly heartbreaking conversation that we will never forget it.

At this stage we had rang the local district nurses who were caring for Ray and a nurse was on her way. As a family we were hoping to care for Ray at home but at this stage his distress was so severe we needed to step away from this and allow others to take over his care.

Ray was admitted to a local hospital on the morning of August 12 2015. He had no subcutaneous tissue, which we feel complicated the absorption of the medication. Once in hospital he required three sites to administer all the medications (he required very large doses of morphine and sedative) he was receiving. This allowed for better absorption of the drugs and led to the relief of his distress and allowed him to achieve some peace and comfort. We could not have managed all this at home.

Thankfully for him the last 15hrs of his life were peaceful but we did have to get him to hospital to achieve this. He passed away in the early hours of the morning on Thursday 13 August. He was surrounded by us. He was in the care of people he had worked with and who were his friends.

Our experience has shown us why Ray’s passion is so important. As hard and distressing as it was and even though we always agreed and supported him we now have the knowledge and experience ourselves to continue fighting the fight for him, for us, for everyone. We thought for many months that Ray had choice and control. In the end he did not. Until changes are made to legislation people will continue not to have control. The death he had was exactly what he had feared. The laws need to be changed so people in Ray’s position can exercise their right when they are ready. Not before their time. With proper help.

Robyn Godbold, Tara Szafraneic, Ella Godbold and Rory Godbold

The Age Articles that chronicle Ray’s journey:

http://www.theage.com.au/victoria/dying-with-dignity-campaigner-ray-godbold-farewelled-by-family-20150819-gj2nvw.html

http://www.theage.com.au/victoria/right-to-die-dr-rodney-syme-hands-patient-ray-godbold-lifeending-medication-20150506-ggv5bl.html

http://www.theage.com.au/comment/righttodiereality

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File2:

File3: