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Inquiry Name: Inquiry into End of Life Choices

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SUBMISSION CONTENT:

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On the 17th February 2012 we started the year by celebrating my mothers 70th birthday, my parents who had been divorced for many years were there together, with extended family, second marriages, step children etc from all around the country came and had a most memorable time.

On August 12th, family gathered again not only from all around the country, but from all around the world to celebrate my fathers 72nd birthday. Some very memorable times were made on that late winter day in the park, rugged up against the cold.

On September 26th 2012 my father was diagnosed with angio-sarcoma a rare blood,soft-tissue and bone cancer that progresses so fast little research is available on it.

On October 1st, the associate professor in charge of my fathers case gave us an indication that we could 'try' chemo/radiation but that the cancer had already metastasised in two other areas and that we had 'Months, not years' with him. My father was a man full of life and loved by many as he devoted a lot of time to volunteer organisations like the Men's Shed, Stephanie Alexander Kitchen Garden Programme, Ardoch, amongst others.

On October 11th, my son's 6th birthday, he had one dose of chemo and never did it again. It made him so sick and didn't help at all. He went to the hospital in Heidelberg from his home in Murrumbidgee, 3-4 times a week for blood infusions. Being a rare blood type (AB+) this was often a long and involved process. 2-3 hours for infusions meant the days were gone.

On Nov 1st my father was told that there was nothing more the doctors could do for him and we had "weeks, not months". We talked about palliative care and what his wishes were, He stated at the time he didn't want to be a burden, and he didn't want to die at home.

On Nov 10th we celebrated again, but it was a much more sombre affair, My step-mothers birthday. She was running around trying to make my father comfortable and much of the family were there, but not all as we knew the end was near it was a waiting game. One that we couldn't plan for.

On Nov 11th, my younger brother was told to get his family to come down and see him, because next weekend would be 'too late'. His eldest daughter was about to start her VCE exams but they decided to come down anyway.

Late afternoon on the 11th the Palliative care nurse came and installed a pump.

He fell asleep, and woke only once to say the word "Destiny" to his then wife of 14 years.

On Nov 12th the Palliative care nurse came in the afternoon, he woke of the second time and said, "Its time to take me now".

We waited the 36 hours out at the hospital, the same hospital my younger brother was born in, my father died in the early hours of the morning of the 14th of Nov.

His wish was to not make anyone suffer.

We all did though waiting for his life to end like that, not knowing when.

My younger brother couldn't be there as he couldn't take the time off to drive the 3 hours

My older brother and I sat vigil, the nurses begged us to go home for some rest and would call us if there was any change.

They did, but we were too late. Nine minutes. From the time the phone rang to the time I walked into the room, and my father died alone.

His choice was not respected.

We should not have had to wait 36 minutes, let alone 36 hours.

He didn't need to have his dignity stripped away, while his children watched his body become lifeless over 36 hours. He'd said to the nurse,

"It's time to take me now"

Please understand he was of a sound mind at this point still and knew fully the impact of his words.

We are fortunate that it was ONLY 36 hours, but even that was long enough for us to have the memory of his dignity stripped.