

**Submission  
No 22**

**INQUIRY INTO PROVISIONS OF THE VOLUNTARY  
ASSISTED DYING BILL 2021**

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## The Appalling Death of Our Brother Tom Barry

Our brother Tom Barry set up and ran a successful IT company after a strong public sector career. He owned his own home and had numerous interests. He was loved and valued by his family.

At aged 69 in July 2019 Tom was diagnosed with terminal metastatic facial carcinoma. Tom's cancer was so advanced, that his specialists said it was untreatable and he was given 6 months to live. Tom passed away in NSW 6 months and 2 weeks later on 21 February 2020.

Twice after he was diagnosed, Tom asked his siblings if we could assist him to end his life – the first time after he asked the Oncologist how he might die. The Oncologist told Tom his dying may include, choking, pneumonia, erupting skin lesions, stroke and bleeding. The second time was 2 weeks before he died when very strong medications and other palliative care started to gradually lose their effectiveness.

We told Tom that because he lived in NSW, neither we, nor the medical staff, could help him to pass away to prevent or end his suffering.

After his diagnosis, Tom was given excellent care by his GP and also nurses at his independent living unit. Tom was referred to a Palliative Care Specialist at the nearby base hospital who over the next six months titrated up a combined range of medications (including morphine) for attempted relief from the increased facial swelling, pain and pressure, and severe anxiety.

Tom assiduously followed an extreme pureed diet because of his increasing difficulty swallowing. His jaw became more deformed leading to frequent drooling and mouth ulcers. The gaping (hole) and seeping cancerous lesion on the left side of his face slowly diminished left eye sight and hearing in his left ear. Tom was found semi-conscious on several occasions and lost control of his bowels before being moved to respite care.

During January and early February 2020 - 2 months before he died, Tom told us that he was the happiest he had been in his life - he felt very well cared for. However, he also said he felt increasingly weak and knew he was dying. He emphasised his wish to be free of his pain and to be unconscious to avoid severe suffering towards the end of his life. Much was done by his doctors and nurses to attempt to relieve his physical and emotional suffering but towards the last weeks of his life their care gradually became less effective.

Despite all the excellent care, in his last 2 months Tom became increasingly frightened and unable to do things that gave him pleasure including watching his beloved Parramatta Eels, listening to the Rolling Stones, reading Choice Magazine, discussing politics, using his mobile phone and managing his personal affairs on his computer. His quality of life was devastatingly diminished.

During the week of 06 February, 2 weeks before his death, Tom assured us that he was thinking clearly and was not despondent. However, he told us and a nurse that he was ready to die as he felt unbearably sick and in pain all over his body. On Thursday 13 February Tom also told his GP of his wish to die. Tom's pain medication was increased and a medication pump was ordered.

Tom was moved from respite care into a high care room on 14 Friday February. The pump administered medication for pain and anxiety in a continual, controlled way. Despite the pump Tom kept complaining of pain and pressure in his body. He became increasingly unable to carry out basic tasks. On Sunday he became extremely agitated with the pumped medications having little effect. His nurses were so distressed that the facility manager was called in. The Palliative Care Specialist and a GP were also called and Tom was transferred to the local regional hospital.

That night the hospital staff asked Tom's brother to stay and assist as Tom was so distressed. We were told that Tom was then up most of the night, yelling and trying to escape and sometimes running around naked and urinating on the floor. Orderlies were called to restrain him.

Throughout the week he was prescribed changed medication regimes as each new one did not work. There were periods (between 20 and 60 minutes at a time) when Tom would fall asleep but for the most part his terrible pain and distress continued. The family sat with Tom during the week. Tom clenched his fists, crushed our hands and arms, kicked, moaned, groaned and tried to get out of bed.

One dedicated night nurse told us his siblings that Tom's pain could not be controlled during the night. During Tom's final week one of the senior nurses said that none of the nurses were happy about Tom's suffering.

Tom's ability to speak was limited to two very occasional, barely audible words, 'inhumane' and 'help'. Tom was given a 'stress ball' by the hospital to bite down on to help his extreme pain and agitation - he ripped apart the ball with his teeth. Tom kept trying to lift his legs up to escape from the bed. He often tried pulling his incontinence nappy off and pulling out the catheter.

Tom also experienced terrible discomfort with a swollen stomach and blood in his urine.

We felt horrified and sick realising that Tom's pain and distress were not under control and wondered how much suffering he would have to endure each day and night. We also felt overwhelmingly sad. We saw agony, desperation and anger in his eyes. There were many times when we wept and begged medical staff to relieve Tom's suffering.

It took over two weeks of unbelievable, relentless pain and distress and anxiety before Tom passed away at 6.15 pm on Friday 21 February 2020 in Ballina Hospital with his sister Angela by his side.

Tom wanted to be offered voluntary assisted dying. It would have given him great comfort in the 6 months after his diagnosis to know that he could access this option if his pain, pressure and anxiety became unbearable – which it did - but it was not available to him because he lived in NSW.

Had Tom resided in Victoria he would have met all the criteria to have passed in a painless and dignified way as he wished. Not having the option of VAD for people like Tom NSW is discriminatory and cruel.

The palliative care in the last weeks of his life did not work for Tom and he died after a horrific and prolonged period of agony and indignity. Please ensure that the option of Voluntary Assisted dying is available to NSW residents so that they do not have to endure the terrible suffering that Tom endured.

Cathy Barry, Angela White and Tony Barry (Tom's siblings)