

**Submission**

RE: Inquiry into End of Life Choices

My father recently died a terrible death. His story needs to be told to the committee.

Dad had a long history of skin cancer removal and grafts (over 100), many on his head.

In 2010 a large Squamous Cell Carcinoma tumour was removed from the right parotid artery in his neck. A disfiguring wound requiring 100 stitches ran from the top of his ear to down into his chest.

A May 2014 MRI found malignant Squamous Cell Carcinoma inside his right ear and jaw. Surgery removed his ear, jaw hinge and a large amount of tissue. The right facial nerve was cut to facilitate this. A large unsightly muscle graft with artery was required to fill the hole. The right side of dad's face looked like he'd had a severe stroke. His eye would not close so further surgery was carried out. He was left with no lubrication and had to continually use eye drops. His mouth also would not close and drooped badly on the right side. An operation to insert slings to pull the lower lip up was not successful enough to stop food from falling out of his mouth. He became depressed by his appearance and didn't want to go out in public. In September it was diagnosed that the right nasal passage was permanently blocked so breathing and sleeping were compromised.

In February this year an MRI of his head showed invasive Squamous Cell Carcinoma malignancy on the carotid and parotid arteries, auriculotemporal nerve, infer alveolar nerve, mouth and throat area, (masticator space, right mandibular condyle and pharangeal region), and temporal bone.

No treatment could be offered. His cancer was terminal.

At this time dad let his wishes be known that he had had enough, and did not want to linger. My father had been an active outdoors man all his life – swimming and cycling into his 80s and he did not want a disabling, painful, drawn out death. He joined Dying with Dignity and in his medical directive he stipulated that he did not want to be resuscitated or artificially fed. He knew that others had been medically assisted to die. His hope was that he would be able to nominate a time to be voluntarily euthanised. Unfortunately this help was not forthcoming, for fear of the law by the medical fraternity.

In Victoria under the current legislation there are **no** end of life **choices**. There is only one fate - palliative care which my father had no choice but to commence in late February. He was told that his symptoms would be managed and that he would be kept comfortable.

Nothing could be further from the truth.

## Symptoms

### Throat and mouth

- vocal chord paralysis involving the vagus nerve – great difficulty talking and being understood
- erosion of laryngeal nerve – increasing difficulty swallowing
- violent coughing fits throughout which brought up a phlegm like substance
- valve separating the esophagus and the larynx collapsed – intake of food “went down the wrong way” towards the lungs instead of the stomach, again, violent retching and vomiting
- saliva glands compromised
- oral fungal infection

**Poor sleep** – sleep medication did not stop breakthrough pain and night terrors

**Nausea** – medication did not stop breakthrough nausea

**Pain** – morphine was not effective enough, there was always some pain, at least 4 out of 10 increasing to unbearable pain towards the end

**Severe constipation** as a secondary symptom to morphine – acute treatment brought on acute diarrhoea

### Difficulty urinating

### Headaches and fatigue

### Distress, agitation and depression

### Starvation

By March dad could no longer eat solid food – only soft pureed food. By April, only food the consistency of smooth soup, by May only thin liquid, by June only water. Any intake was in very small amounts. He lost 30 kg in 3 months through not being able to eat.

My father starved to death as a consequence of his cancer under the current law prohibiting voluntary euthanasia. Starvation is a shocking way to die. I would advise the Committee to watch *Sands*, the film about Bobby Sands' hunger strike to his death in Ireland.

If the Committee thinks that starvation is not an acceptable way for Victorians to die they must recommend legalizing voluntary medically assisted death.

Dad wanted to die at home surrounded by family and friends. He wished to farewell us while he was still lucid and not overly suffering. But there was to be no dignity in my father's dying. Towards the end his pain and discomfort got so bad that he had to be hospitalized for intensive medical intervention including enema, catheter, morphine injections as well as the morphine drip. He was agitated and in a state of distress and as the morphine increased he lost lucidity then consciousness. When he died he was unaware that there was a daughter in the room with him. Not the way that he wanted to go.

## Morphine ineffectual for **nerve pain**

Throughout my submission I have underlined the multiple nerves that were affected by my father's cancer. While hospitalized dad let us know that he was in 'agony', a term I cant remember my stoic father having ever used in his life.

I chased up his treating doctor and requested an increase in morphine, and told the doctor that dad didn't care if it killed him, he had wanted to die long before this. Also that we, his family wanted an end to his unendurable suffering.

To my absolute disgust, the doctor said that dad was suffering from nerve pain which morphine would not relieve !!

Morphine is the strongest painkiller used in palliative care. So if you are suffering nerve pain you are condemned to agony. My father's cancer was affecting 4 separate nerves.

The doctor also said, of course, that he was prevented by law from giving dad enough morphine to end his life.

In my father's case the Victorian laws did NOT adequately meet his expectations regarding medical options available at the end of his life. He wished for medical voluntary euthanasia before his suffering became too great, but was left to endure the only fate available - the inhumane and torturous failings of the palliative care system.

We are not in the Dark Ages.

We would not treat a dog this way. In fact, if we did, we would be fined for cruelty.

My father did not want to be treated this way.

The rest of the Victorian population would not want to be treated this way.

The Committee must recommend Voluntary Euthanasia as a medical end of life choice. As well as caring for Victorians in a humane manner, Victoria would be highlighted as an enlightened and progressive state.

I also believe that anyone who no longer wants to live, as they believe that their quality of life has been too compromised, should have the right to be medically assisted to die, rather than being condemned to a miserable existence.

Anne Boyd - [REDACTED]

I wish to appear at a public meeting to tell my father's story.