

**Submission
No 82**

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

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Submission to Inquiry on the NSW Voluntary Assisted Dying Bill 2021

Penny Hackett

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Dear Members of the Committee,

I am the President of Dying with Dignity NSW but I am making this submission in my personal capacity to share the reasons why I so strongly support the Voluntary Assisted Dying (VAD) Bill.

In 2013 my best friend Lucy died of breast cancer in her early 40s after a 13 year battle with the disease. Until that time, I had not understood what cancer does to a person's body. Now I do, and I will never forget the last year of her life.

Diagnosed with stage three breast cancer at age 32, as a new mum with a ten month old baby, she went through "the usual" treatment regime – surgery, months of chemo and radiation and long term hormone suppressing medication. It was painful and very unpleasant with nasty side effects but was soon completed. After almost 5 years of regular blood tests and body scans we believed she was in the clear.

But then scans showed a tiny hole in her skull, the size of a grain of rice – metastatic cancer – now in the bones. Suddenly everything changed – she was now terminal. Only a tiny proportion of people survive metastatic cancer and she was given 4-5 years to live.

After 6 months of chemo and a hysterectomy, which put her into sudden menopause, she lived for 8 more years. Seven of these were mostly in reasonable health, but she was in and out of remission from re-emergence of the cancer in bones, liver and lungs. This involved more chemo, more radiation, clinical trials, vicious mouth ulcers, kidney stones, radiation burns, burning nerve pain in her feet, constant blood tests and scans and the ever present anxiety of what lay ahead. Despite this, she lived a full life with her family, ran a business, looked after aging parents and contributed in her community.

However the last year of her life was nothing short of torture, starting with tumours on the spinal cord. It took two months to control the pain with massive doses of painkillers and other drugs – at times she would be grey and sweating with pain. A hole was drilled into her skull to insert a portal through which chemo drugs could be administered through the brain into the spinal column. She had painful lumbar punctures to test the cancer levels in the spinal fluid.

Slowly she lost the control of her legs, first using a stick, then a walker, falling constantly, until her last 4 months as a partial quadriplegic in a hospital bed in her lounge room as the cancer slowly ate away at her spinal cord. Among other indignities, she lost the sight in one eye, almost died from a lung clot, grew a suppurating, oozing tumour on her scalp the size and appearance of a hamburger patty. She took massive doses of steroids which made her face and parts of her body swell up like a balloon.

She had excellent medical care, in and out of the Mater Hospital in Sydney and treated by a leading oncologist. She had 6 months of palliative care – her specialist was a university friend. But her life consisted of handfuls of high strength opioids and other painkillers, chemo drugs, daily injections of blood thinners, anxiety medication, sleeping tablets, laxatives and enemas to deal with constipation from the painkillers, anti-emetics to deal with the nausea from the chemo drugs, antibiotics to deal with chest and urinary tract infections and much more. There were enough drugs in her kitchen drawer to kill her whole family and probably the neighbours too.

Her last few months were spent in her hospital bed at home, barely able to eat, in nappies, vomiting foamy liquid and coughing up green and brown sputum from her congested lungs. She was stripped naked and washed by an endless succession of carers and hoisted out of bed once a day in a sling for "bowel care".

Her actual death, the last few hours at the end of this misery, was peaceful. She was admitted to hospital, unable to breathe. Gallons of liquid were drained from infected lungs but the tumours had progressed to the point that her lungs ceased to function and she lapsed into a coma and died 10 hours later.

She was mentally competent almost to the end.

I tell this story not because my friend wanted to end her life, even though she believed in assisted dying laws - she asked me to suffocate her with a pillow if the cancer ever got to her brain. She was frightened and desperate but she did not want to die - she could not bear to leave her teenage daughters.

Prior to this experience, I did not realise that the process of dying could be so prolonged, painful and dehumanising, and that for some people, death is not the worst thing that can happen to them.

Some people can bear incredible suffering, both physical and mental. But others cannot, and should not be forced to do if they are able to make a voluntary decision to end their suffering quickly and peacefully.

Personally, I could not have borne what my friend endured and I now know that her experience was not unusual or unique. This is the way that many people with cancer and other terminal conditions spend their last months.

Since becoming involved with Dying with Dignity I have personally read over 26,000 emails to MPs from people in NSW who want assisted dying laws passed. Many of them describe witnessing terrible deaths of loved ones from which they carry lasting scars. Others are facing a terrible death themselves. There are many stories from nurses, doctors, paramedics and other healthcare workers who have watched helplessly while their patients die in excruciating circumstances which are beyond their medical help.

The worst describe the suicides of people who make the choice to die alone rather than continue suffering, leaving their families traumatised.

A friend's mother jumped in front of a train at a suburban station in Sydney several years ago. She had a terrible cancer and was unable to bear her condition any longer. She had a loving family who understood her decision but remain distressed by the circumstances of her death. No doubt others who were inevitably involved, such as the train driver, emergency services workers and by-standers will carry the trauma of that event with them too.

It turned out that my friend's mother had been a longstanding member of Dying with Dignity NSW. Had she had access to a safe and legal way to end her suffering, she could have died peacefully with her loved ones at her side.