Submission No 11

INQUIRY INTO PROVISIONS OF THE VOLUNTARY ASSISTED DYING BILL 2021

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Submission to the Law and Justice Committee, NSW Legislative Council – *Voluntary Assisted Dying Bill 2021*

1. I am the Director of the Liverpool Hospital Cancer Therapy Centre. I am a senior staff specialist in Medical Oncology at Liverpool Hospital. I hold a conjoint appointment as a Senior Lecturer in Medicine with Western Sydney University Medical School. My main areas of expertise are in clinical oncology, more recently sub-specialising in breast and lung cancer. I have been engaged in health service development in Southwestern Sydney since 1988, and have contributed to many national and international clinical cancer trials. I graduated from Sydney University with a Bachelor of Medicine and Bachelor of Surgery in 1980. I have been a Fellow of the Australasian College of Physicians and a practicing Medical Oncologist since 1986.[1]

2. "Doctor, I don't want to go on like this" is a statement that I have heard on more than one occasion during my 40 years as a doctor and 35 years as a Medical Oncologist. "Please, make this end" or "can't you kill me?" are other phrases that I have had put to me that reflect severe distress in someone with advanced cancer. Thankfully, these events are infrequent, and most often occur at a time when symptom control and suffering are at a peak, triggering despair and desperation. They are seldom voiced or repeated when the triggering symptoms are well controlled, and the emotional toll that they have caused has been addressed.

3. The major concerns I have regarding the *Voluntary Assisted Dying Bill 2021***,** stem from my many years of medical practice. Patients have fears that are often based upon stories they've heard about the poor medical experiences of others. They have a fear of losing control and becoming a burden. These fears can be overcome by timely education of the patient and improving the education of all doctors providing supportive care towards the end of life. It is patently clear that

[1] Any opinion expressed by me is a personal opinion, and is not expressed on behalf of the Liverpool Hospital, nor the Sydney South West Local Health District.

despite their best intentions, doctors make mistakes, and thus assisted dying could be performed under a false premise. Incorrect diagnosis and/or prognosis can readily result in the untimely death of a patient.

4. I share three cases that highlight the reasons behind my concerns.

1. Doctors get the diagnosis wrong

Case 1**

5. A 66-year-old man presented with a first episode of seizure and word-finding difficulty. His medical background included a 6-year history of Chronic Lymphocytic Leukaemia (CLL). He also had an abnormal skin lesion excised from the upper back 18 months earlier. Histopathology of the skin lesion confirmed melanoma in-situ (a non-invasive pre-malignant lesion) with clear surgical margins. **Due to the incorrect propagation of information, including multiple episodes of "cutting and pasting" of the medical history, this was documented on many subsequent occasions in the patient's electronic medical record as being "melanoma".** This was factually incorrect. Upon presentation to hospital a computed tomography (CT) scan of the brain was performed. This showed multiple cerebral enhancing lesions with associated vasogenic oedema suggestive of metastases. The patient proceeded to have complete staging CT scans of the chest, abdomen and pelvis. These showed widespread lymphadenopathy and splenomegaly consistent with a known diagnosis of Chronic Lymphocytic Leukaemia, right upper lobe of lung subsegmental collapse/consolidation, a 5mm pulmonary nodule and subtle bony lytic lesions in both iliac wings and the L4 vertebral body. He went on to have a Magnetic Resonance Imaging (MRI) scan of the brain which echoed the cerebral CT findings. **As the history of melanoma was incorrectly provided, metastatic melanoma was thought to be the most likely aetiology of many of the reported scan abnormalities.** Due to the uncertain diagnosis and ultimate correction of the incorrectly propagated history of invasive melanoma, he underwent neurosurgical intervention. An abnormal area of tissue was identified and

samples confirmed the **diagnosis of aspergillosis (a fungal infection) that resolved with appropriate antibiotic therapy**.

Case 2

6. In 2015, a 62-year-old man presented to hospital with fevers, chills and rigors and a background history of oesophageal cancer for which he underwent oesophagectomy in 2003. A CT scan was performed and reported to show multiple necrotic masses within the right lobe of the liver, consistent with metastatic disease. He was admitted under Medical Oncology for ongoing management. "Biopsy" of the liver revealed the presence of liver abscesses. Antibiotic treatment was administered, and the **patient remains alive and well 6 years later**.

2. Doctors get the prognosis wrong

Case 3

7. In July 2017, a 53-year-old woman underwent surgery for a cerebellar metastasis from a primary breast cancer initially diagnosed and treated in 2008. Following the brain surgery, she remained well until January 2018 when she had clinical and MRI evidence of a recurrence in the tumour bed. She therefore received stereotactic radiosurgery. Upon further progression in March 2019, she commenced palliative chemotherapy. In August 2019, she was reported to have progression on MRI and was noted to be physically declining on chemotherapy. Treatment was therefore discontinued. It was expected, at that time, her survival would be several months at best. Her condition improved off treatment (the MRI findings in retrospect being due to radiation necrosis, rather than disease progression). She remained reasonably well until May 2021 when she developed new neurological signs with confirmed multiple sites of disease progression on MRI. **Her survival, with reasonably good quality of life, has been >24 months longer than predicted by several experienced Oncologists and her Neurologist**.

Eligibility Criteria

8. The proposed eligibility criteria are contained in s 16 of the Bill. Section 16 provides:

16 Eligibility criteria

(1) The following criteria must be met for a person to be eligible for access to voluntary assisted dying—

(a) the person is an adult,

(b) the person—

(i) is an Australian citizen, or

(ii) is a permanent resident of Australia, or

(iii) at the time of making a first request, has been resident in Australia for at least 3 continuous years,

(c) at the time of making a first request, the person has been ordinarily resident in New South Wales for a period of at least 12 months,

(d) the person is diagnosed with at least one disease, illness or medical condition that—

*(i) is **advanced, progressive and will cause death**, and*

*(ii) **will, on the balance of probabilities, cause death**—*

*(A) for a disease, illness or medical condition that is neurodegenerative—within a period of **12** months, or*

*(B) otherwise—within a period of **6** months, and*

(iii) is causing suffering to the person that cannot be relieved in a way the person considers tolerable,

(e) the person has decision-making capacity in relation to voluntary assisted dying,

(f) the person is acting voluntarily,

(g) the person is not acting because of pressure or duress,

(h) the person's request for access to voluntary assisted dying is enduring.

Diagnosis

9. The *Voluntary Assisted Dying Bill 2021* **pre-supposes that two experienced doctors will get the diagnosis right** for every person regarded as "experiencing suffering that cannot be relieved in a way the person considers tolerable" in the terminal phase of their illness. In my experience, from the cases stated above, and many other cases, **it is not uncommon for medical error to occur** when "anchoring bias" leads doctors to accept pre-determined clinical diagnoses and diagnostic reports of advanced malignancy. Cases 1 and 2 summarised above (seen by many experienced doctors) were definitely suffering at the time of their incorrect diagnosis and would unequivocally have qualified for voluntary assisted dying, despite the fact that they did not have metastatic malignancy.

Prognosis

10. **Prognosticating in advanced cancer is notoriously difficult**, the longer that someone is likely to survive. As a Medical Oncologist, I can almost always predict when someone is in the last few days of life and usually identify when someone is within the last 3-6 weeks of life, but **rely on statistical evidence to predict who is likely to die within the next 6-12 months**. The Voluntary Assisted Dying Bill 2021 pre-supposes that medical practitioners can reliably and accurately predict life expectancy. **It is my belief that if the Bill is passed, difficulty in prognostication will ultimately mean that people will be assisted to die that may have significantly longer to live than might be anticipated by the certifying medical practitioners.** The key to resolution of this dilemma is to alleviate people's suffering with high quality palliative care so that they regain the will to continue with life, not to end their life prematurely.

11. My experiences as a Medical Oncologist do not reflect the "safe framework" proposed by The Hon Alex Greenwich MP in the *Voluntary Assisted Dying Bill 2021*. I completely reject the assertion that "the rate of death by suicide among

people who are terminally ill with cancer is high". Those few patients of mine that have committed suicide have almost invariably done so because of a concomitant severe depression, not uncontrolled physical suffering.

12. **As a society, we need to substantially increase our palliative care services to "ease the burden" on individuals with terminal illnesses, and maintain the role of medical professionals as "healers", not agents of "voluntary assisted dying".**

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Medical Oncologist

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