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[REDACTED] TO THE VICTORIAN END OF LIFE CHOICES INQUIRY.**

*Suicide prevention and assisted suicide*

I believe that it is logical and appropriate for those of us who support suicide prevention to also oppose moves to facilitate assisted suicide in which such actions are legislatively endorsed by governments and the State.

I also have another strong reason to speak out about assisted suicide and its evil twin – euthanasia. That is because of my involvement as a patient advocate for the past 15 years with one of the most deadly of all cancers.

*Brain tumours*

In 2000 my late wife, Marg, was diagnosed with a *glioblastoma multiforme* malignant primary brain tumour and she passed away in 2001, eleven months later.

Unfortunately, the average survival period for this cancer has not increased very much from those eleven months, despite the introduction of a new standard of care in about 2005, which I campaigned for in both Australia and the United Kingdom.

Primary malignant brain tumours are one of the most lethal of all cancers and cannot be identified by screening or early detection because we do not know enough about their causes.

My wife's journey with her brain tumour occurred before the introduction of social media outlets such as Facebook and therefore in 2000 I created a public web diary to report on her progress. This was primarily for friends and relatives but was read by thousands of people from around the world, many of whom were in a similar situation and were anxious to know about the nature of the journey with a brain tumour.

My wife and I were not impressed by the lack of support and information in my city and country for people afflicted with this disease. After her death I imported brain tumour handbooks from the American Brain Tumor Association (ABTA) in Chicago and distributed them for free in Australia. This project was kept going by spontaneous donations from grateful recipients and the importation of handbooks continues to this day.

*Organisational development*

This activity resulted in my contact with carers and patients who wanted to establish a brain tumour support, education, awareness, and advocacy organisation in Australia and I was elected as its first national chair in 2003.

I soon realised there was no international organisation that linked together the various national brain tumour patient and caregiver groups in countries like Australia, the USA, Canada, the UK and Europe, and so in 2005 at a neuro-oncology scientific meeting in Edinburgh in the United Kingdom, I joined with a woman from Surrey in England (Mrs Kathy Oliver) whose son had just been diagnosed with a brain tumour, and we established the International Brain Tumour Alliance (IBTA) of which I was the foundation Chair for nine years during 2005-2014.

In that role I visited more than twenty-five countries and have spoken with many brain tumour patients and their caregivers and families from around the world.

### *Anxiety and depression*

Because of their terminal diagnosis and poor prognosis it is not unusual for such patients to think about their own death and what it means for them and their loved ones. Unfortunately, there is also a strong correlation between anxiety and depression with this disease and therefore patients are also susceptible to those conditions, which can impact on their thoughts.

### *How will I die?*

Over the years I have been approached privately by many patients and their caregivers asking me how they are likely to die. I tell them that one of the most comforting pieces of information that I received during my wife's journey was to be told by a fellow caregiver, who had asked his family doctor the same question - that brain tumour patients usually experience a very peaceful passing and the major body organs simply shut down one by one. This is what happened in my wife's case. The process might be straightforward but any death is also distressing for a partner and a loved one.

However, this is not to say that the journey with a brain tumour patient is straightforward. It is anything but and has been likened to a "roller-coaster ride" with dramatic and heart-stopping moments of terror when medical emergencies occur which can be followed by periods of relative calm.

In my wife's case she and I had a clear belief in what lay ahead. We both believed in an afterlife and that we would be united with God in Heaven after our death. My wife was very strong in her Faith and in this belief and, indeed, towards the end, was wondering why she was having to wait so long to access this new life, particularly as she had satisfied herself that I and the adult children living at home would not starve when she was gone because I had learned how to cook pasta and boil an egg!

I therefore have a good appreciation of the thinking and situation of people with this terminal illness, including those with a Faith and those without.

But there is another group of people who are prompted by their illness to think about their own death and, unfortunately, their thoughts turn to how they can decide how they will die, when, and where. They want to be in total control.

### *The 4 W's*

These people have been described as the “4 W's”, a title given them by the anti-euthanasia disability group “*Not Dead Yet*” in the United States. The 4 W's stand for – the White, Well-off, Worried-well.

Well, I believe I can understand the thinking of some of these people. I turned 73 years of age last June. I am white. I am adequately provided for in my retirement by a pension and I am one of the “Worried Well”. I take 16 tablets a day, which keep me on my feet and reasonably well and the occasional medical monitoring keeps my medical specialists in the lifestyle to which they have become accustomed.

The legions of the “worried well” are increasing exponentially. In the United Kingdom there has been a four-fold increase in the number of people being seen at specialist dementia clinics between 2010-2013. They are bombarding these clinics and are preventing genuine patients from accessing them. Many of these are described as the “worried well” – people who misplace their car keys and immediately suspect they are developing dementia.

The problem arises when you combine this natural interest in their end of life with a fear about not being in control of their lives. They are ready candidates to listen to appeals for assisted suicide and euthanasia.

The assisted suicide and euthanasia lobbyists, such as “Exit” play on the fears about a painful death and loss of control. Often, you will discover that their new recruits “know” of a “bad death” by a friend or relative but are also ignorant of the capacity of good palliative care physicians and health professionals to administer pain control and deliver good end of life care.

### *A fellow volunteer guide*

I am familiar with their thinking. For ten years I was a volunteer guide in the Old Parliament House building in Canberra and the shift I was on included the local secretary of the “Voluntary Euthanasia Society” as a fellow volunteer guide.

In our shift we rotated from location to location and at one stage we would find ourselves together in a large entrance hall of the building. If there were no tourists to welcome we would have interesting discussions. She knew where I stood on euthanasia and I got to know her stance. She was motivated by knowledge of a bad death by a relative in the distant past.

I did not suggest to her that the relative was probably inadequately cared for but that is what I suspected. Anyway, when her own death was approaching she chose to

enter our local Hospice which is run by the Little Company of Mary. She died a natural death there, looked after by the caring staff who follow the true principles of palliative care which, according to the World Health Organisation (WHO), “intends neither to hasten or postpone death”.

### *Susceptibility to anxiety and depression*

Returning to my experience with brain tumour patients, I mentioned earlier their susceptibility to depression and anxiety, probably brought on by the knowledge of their diagnosis and prognosis. This is well known among the treating specialists and they are encouraged to identify any such thoughts and treat them accordingly.

Indeed, several years ago I learnt that a UK neuro-oncologist was researching this connection and at a scientific conference in Yokohama, Japan, I put him in contact with a radiation oncologist from Sydney and both specialists collaborated as scientific advisors in the preparation of a special Fact Sheet published jointly by the national brain tumour support group and one of the major depression support organisations in Australia (Beyond Blue). It was also re-published by a brain tumour support group in the United Kingdom.

### *Brittany Maynard*

Into this mix comes Brittany Maynard, the 29-year-old woman with a brain tumour from California who, last year, moved to Oregon so she could take advantage of that State's assisted suicide law. She became the “poster person” for the so-called Compassion and Choices (C and C) organisation and, following her suicide, C and C have exploited her stance in a video starring Brittany.

I wrote an “Open Letter” to Brittany Maynard at the time. I do not know if she ever read it and, unfortunately, it obviously did not achieve the desired aim of asking her to reconsider her suicide plans.

What I focussed on was the way in which her suicide plans would have the effect of destroying the hope that her fellow brain tumour patients held on to.

I have to say that I was a latecomer to an understanding of the role of “hope” in the brain tumour journey and all cancer journeys. My UK colleague, when we were preparing our first jointly-authored publication for brain tumour patients and their families in 2008, was very keen to refer to “hope” and contacted Dr Jerome Groopman from Harvard in the USA, to obtain his permission to republish in our book a definition of hope that he had included in his publication “*The Anatomy of Hope*”. I was not so understanding at the time and agreed reluctantly.

Dr Groopman put forward this excellent definition:

“Hope is the elevating feeling we experience when we see – in the mind’s eye – a path to a better future. Hope acknowledges the significant obstacles and

deep pitfalls along that path. True hope has no room for delusion. Clear-eyed, hope gives us the courage to confront our circumstances and the capacity to surmount them”.

This is what Brittany Maynard was sabotaging and what groups such as “Exit” and their supporters do on a daily basis. They are destroying the hope clung to by all those with a terminal illness – *realistic hope*, in which they hope they will survive long enough to be the first to benefit from a new therapy, hope that they will last long enough to say things to their loved ones, to make amends, etc.

Brittany Maynard’s actions and the media’s support for her actions was a dangerous mixture to project upon brain tumour patients who are already susceptible to feelings of anxiety and depression.

### *Lecretia Seales*

Unfortunately, Brittany has inspired others to follow her lead and earlier this year, thousands of miles away in New Zealand, a 42 year old lawyer Lecretia Seales, who had a brain tumour, applied to the New Zealand Supreme Court for a ruling that her Doctor would not be prosecuted if the Doctor assisted her to take her own life.

Lecretia was fearful that she would have a disastrous death, experience intolerable suffering, and lose control of her body. As it turned out, the New Zealand Supreme Court denied her appeal and she died a natural death a few days after receiving the verdict of the Court.

I decided that those of us with experience of the brain tumour journey could not just stand by silently while the Judge was considering Lecretia’s request. I knew of a long-term brain tumour survivor in Australia who was the same age as Lecretia and she agreed for me to include her comments in an email message I sent to the Judge. Again, I do not know if he was influenced by it, or even managed to read it.

I would like to quote several paragraphs from this woman’s message because these words have been written by someone who has an absolute right to comment on this case, which was very similar to Brittany Maynard’s. My friend is a mother to four children. She wrote:

“Unlike Lecretia I do not think the solution to addressing our common fears is through access to assisted suicide via legislative change. We should not be passively waiting for what once would have been our inevitable decline and death. We must demand action from our Governments; such as funding for brain tumour research as well as patient and carer support.

“Cognitive and physical decline should not be accepted as inevitable outcomes of a brain tumour. With the emerging science of neuroplasticity people living with this disease should have access to neuro psychological assessment and treatment and the same forms of rehabilitation that is

accessible to people who've had a stroke or other acquired brain injuries. Cognitive decline should be able to be arrested or even reversed.

"There are inherent risks associated with what Lecretia is seeking.

"Firstly who will define "intolerable suffering" and the boundaries as to who could qualify for assisted suicide? There have been a number of periods over the past fifteen years where I have experienced what I considered intolerable suffering due to either my physical, emotional or mental pain. There have been lengthy periods during which I had wanted to end my life. The years where I didn't think I would live to see my daughter start school felt unbearable at times. I will see her start High School next year.

"Secondly, how will a person's mental competence be established? Impaired judgement and decision making occurs in the majority of patients with brain tumours at some point during their treatment. Sometimes this can be so subtle that we may not even be aware of it until it passes. For me personally I have been through different periods during the past 15 years where my judgement and decision making has been quite impaired although I would still have been considered mentally competent. These were during times of increased intracranial pressure or due to seizure activity. It is not unusual for brain tumour symptoms to change over time.

"Thirdly it is estimated that more than 25% of all patients with brain tumours suffer with major depressive disorder. Neither society, our health system nor our politicians believe that people living with a mental health condition such as depression has a "fundamental right" to end their own life. There should not be an exception to this for people with a brain tumour."

They are the words of a courageous and hopeful person and the outline of her thoughts and experiences provide a clear example of how campaigns initiated by the assisted suicide lobby, including their advocacy for Government endorsement of assisted suicide, could have a disastrous effect on the struggles of a vulnerable person with a terminal illness.

### *Suicide prevention and assisted suicide*

I stated earlier that I believe those who campaign for suicide prevention, often in the area of mental illness, should also be opposed to assisted suicide because in my mind they are all part of the one thing – suicide, the deliberate taking of one's life.

Those who oppose suicide and campaign for suicide-prevention can also be engaged in the campaign against euthanasia and assisted suicide. Fear of hindering their work for people with a disability has not stopped the disability advocates from involving themselves in opposition to assisted suicide. They can identify a potential threat to their welfare either from suicide, as such, or assisted suicide.

*There are always difficult choices*

There will always be an excuse not to be involved in community debate of these great moral issues. In fact, I know of very few occasions in life where you are able to avoid making difficult choices when you wish to pursue a moral approach.

Sometimes you are tempted by what, on the surface, appears to be a “charitable or humane approach”. Think about the pre-birth killing of an unborn baby diagnosed with Downs’ Syndrome, or the destructive use of human embryos in order to prove the efficacy of a promising medical therapy to cure a crippling disease.

Unless one develops and nourishes a consistent life ethic which embraces support for human life from conception to natural death you will be susceptible to the half-truths of the anti-life campaigners.