Submission No 106

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

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Submission to NSW Parliamentary Inquiry into Voluntary Assisted Dying from Janet Cohen, 68 years old, terminal lung cancer, regional NSW.

This morning, 12<sup>th</sup> November 2021, my first waking thought was "Today is the day that NSW Parliament starts debate on the Voluntary Assisted Dying Bill." It's hard to describe the turmoil of hopes, fears and anxieties that accompany this thought and the current debate.

On Monday 15th, I start radiation to treat a cancer clone, very close to my aorta. It's a risky procedure. I'm frightened of the consequences and more anxious that it might not work to hold the spread of cancer, in which case the next 'treatment' will be end of line, palliative chemotherapy.

No matter what happens next week, I now face the reality of my death within a couple of years.

Since 2013 when lung cancer burst into my life like a gale force storm, my death has plagued my thoughts. For an active, fit, pre-retirement, 60 year old, non-smoker the terminal diagnosis was and still is, horrifying. But I've been one of the lucky ones.



On this journey, my partner Glenn and I have had many patches of smooth sailing thanks to new, targeted medications.

However the tempests of major lung and brain surgeries, cancer mutations and invasive body and brain scans have constantly challenged our resilience and our ability to stay afloat and maintain quality of life. We've done well in very stormy weather.

Glenn and I at Glenn's son Julian's wedding 2017

I'm so grateful to still be alive and I will cling to life, but the weather has changed again with the discovery of a new, untreatable cancer clone, signalling that we have now turned towards the end of my journey and our time together on this beautiful, fragile vessel called life.

In 2013, we knew, when trying to chart a navigable course through these treacherous shoals, that one day we would meet the tsunami of terminal illness and would need to find a 'safe harbour'.

I found one, unfortunately not in Australia but in Switzerland, where sadly many foreigners with no VAD laws in their own countries chose to die. Back then, no Australian jurisdictions had passed VAD laws, although in 2017 NSW came so close.

In 2015 I qualified for provisional pre-approval for a voluntary assisted death with Dr. Erika Preisig of Eternal Spirit - Life Circle, Switzerland. I may take this option if the laws don't pass in NSW or if they pass and I am very unwell before they take effect.

For a long time, I even considered moving to Victoria or Tasmania, but this would have been even more disruptive and challenging than travelling to Switzerland. Long term anxiety about the very real possibility of a drawn out, painful death is a dark cloud casting shadows across our lives, dimishing the quality of my final years and our last years together.

I wonder if you can imagine how dearly the lack of VAD in NSW has cost my partner and I in terms of our psychological peace, comfort and well being?

I should not have to travel across the world to achieve a peaceful, dignified death. I don't want to leave a legacy of suffering to those who care about me.

I can't overstate how comforting it's been to know that if my pain and suffering can't be relieved by palliative care, which is the case for a signficant number of Australians, I don't need to keep struggling and battling, that I have the option, albeit only available to me overseas at great financial cost and personal effort, to experience a dignified and peaceful end to my life. VAD is a palliative care option and should be available as such.

Since 2017, I have publicly advocated for people with a terminal illness in NSW to have greater end of life choice which should include palliative care and VAD.

Campaigning on this issue has taken a significant toll on me and my partner, but I hope that my experience and story will make a small difference.

Please open your hearts and minds. Don't destroy my faith in human kindness and compassion.



Of course, rather than writing letters to MPs, giving interviews and penning submissions, I would have preferred to relax with friends, or like on this beautiful morning have a swim at Pilot Beach, rather than spending hours writing this submission.

It's been shocking for me to realise that compared to other States, NSW Parliament appears to be so out of touch with the wishes of the overwhelming majority of NSW residents.

It has saddened me to see representative democracy take such a thrashing in favour of party-political game-playing and to watch some of our key representatives take personal and factional positions on this issue rather than considering the needs of others and

the benefit to the wider community. Isn't an MPs job to represent their constituents?

Can you imagine how distressing it has been for me and others like me to witness all other States pass VAD Bills while NSW appeared to sit on its hands?

Can you understand how frustrating it is to have witnessed the delaying tactics and shenanigans that ensued when the 2021 Bill was introduced into NSW Parliament? NSW politicians displayed the worst of party political games while people like myself watched on in increasing despair.

I can assure you, that as a person with cancer for more than eight years, I have earned my PHD in Suffering.

Why would Parliamentarians vote to condemn me to suffer more in my final months?



I face an uncertain future without VAD laws in NSW

I'm pinning a lot of hope on the NSW VAD Bill passing as soon as possible without further unnecessary delays.

VAD is the light at the end of my narrowing tunnel of choices. Every day's delay means the light grows dimmer and people like me suffer.

I hope I have time to access VAD in my home state. I've been waiting for this reform for far too long.

If MPs fail to pass the Bill, I may have

no option but to access the Swiss system if I am physically able to. I don't want to die in Switzerland, please give me a choice. Finally, I would like to add:

- Terminally ill residents in NSW are disadvantaged in comparison with residents in all other Australian states by being denied this service. We deserve equal access.
- Independent survey after survey show that over 80-85%% of NSW residents across all social demographics, political persuasions and faiths support the passing of VAD laws.
- There is sufficient evidence worldwide and now right here on our doorstep in Victoria that this legislation and the VAD program work and are safe.

I and others suffering with terminal illnesses, literally can't wait for the NSW VAD Bill to pass.



Glenn and I (far right) with family at Cradle Mountain

Please let compassion and the will of the people of NSW be your guides when considering this Bill. Please, please just get this done for all of us and don't condemn us to more suffering.

Janet Cohen, Glenn Brewer and extended family

12 November 2021