



**LEGISLATIVE ASSEMBLY**  
FOR THE AUSTRALIAN CAPITAL TERRITORY

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SELECT COMMITTEE ON VOLUNTARY ASSISTED DYING BILL

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## Submission Cover Sheet

Inquiry into the Voluntary Assisted Dying Bill 2023

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# Inquiry into the Voluntary Assisted Dying Bill 2023

A submission regarding stage 4 brain cancer:  
glioblastoma

Select Committee on the Voluntary Assisted Dying Bill 2023  
Chair Ms Suzanne Orr MLA,  
Deputy Chair Ms Leanne Castley MLA,  
and Committee Members

via: LAcommunityVAD@parliament.act.gov.au

**RE: Submission to the Inquiry into the Voluntary Assisted Dying Bill 2023**

Dear Committee,

I humbly request that the Committee consider accepting my late submission in relation to the current inquiry into the Voluntary Assisted Dying Bill 2023 (the "Inquiry").

This submission advises the government on concerns faced by brain cancer (glioblastoma) patients and provides two people's perspectives on the issue of voluntary assisted dying.

Yours sincerely,

Lara Kaput

*“...just push me off a cliff...” or “ ...take me to the back paddock and shoot me.”*

As written by Mr Daniel Beacom in his Advanced Care Directive

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## Foreword

The late Mr Daniel Edward Beacom died on 22 October 2022, and so his lived experience is being told in first person by his partner, Lara Kaput, based on her observations as Mr Beacom's Carer and conversations they had. Due to Mr Beacom's death from glioblastoma (stage 4 brain cancer) progression, there are things that we will not know that he experienced. Lara will be making this submission on behalf of Dan and with respect to all individuals with stage 4 brain cancer who are no longer here to tell their own stories.

Even though I am unlikely to choose it for myself, I respect Mr Beacom's wishes and those that similarly suffer. **It is my submission that I endorse legislation allowing voluntary assisted dying for all of people who need it – no matter how old they are.** Further, I would take up any opportunity to participate in a public hearing, focus groups or roundtables for the benefit of the Inquiry into the Voluntary Assisted Dying Bill 2023.

- Lara Kaput

## Executive Summary

I described my tragic and rather horrific experience with the health care system as ‘death by a thousand cuts’. Subsequent to my glioblastoma diagnosis, I acquired eleven disabilities within 12 months rendering me unable to care and advocate for myself.

I suffered disappointing treatment by professionals across an acute health care provider an NDIS registered provider, a Neuropsychology service, an Occupational Therapy service and two tradesmen, which I have not detailed here. My Carer identified four missed opportunities to extend my life. Complaints were made directly to the organisations and/or to the responsible governing bodies and are not relevant to solve for this Committee, but they describe the context of my situation.

That my brain cancer caused cognitive and functional defects as well as a greatly shortened lifespan meant that did not stop me living with some quality of life until a week before my death. What I wanted in the end – after the two of us having tried every possible option to keep me alive – was to access voluntary assisted dying. I authorised for Lara to use my story to help others change the system – to choose the time and place of their end, and not be stuck in a bed like I was, declining with loss of autonomy. For the fiercely independent person such as I was, this was intensely undignified and fearful for me, and deeply traumatising for my family and friends.

## Background

I was a 62-year-old introvert and an uncharacteristically fit and strong retiree. I always paid my taxes and I didn’t break the law. I never tried drugs, didn’t smoke, drank very little alcohol and was rarely sick. I ate mainly fruit and vegetables. After my early retirement, I volunteered on camera-trapping projects for Parks Victoria and with Bushwalking Tracks and Conservation at Bushwalking Victoria. I was politically active and a socially responsible citizen who donated to dozens of charities. I enjoyed banter with my former colleagues, dearly loved my family, kept deep friendships with fellow mountaineers, and I had a loyal and loving partner.

I had a pre-existing **vision impairment** (short-sightedness) which was well-managed and (suspected) **enochlophobia** (fear of crowds). Prior to extensive and debilitating disabilities caused by glioblastoma, I led a very active outdoor life with my partner, Lara, who became my primary Carer.

## A. Pre-diagnosis

Approximately one month prior to my diagnosis, my partner and I had **moved interstate** with no family supports. I had bought an older house in Canberra that needed repairs and

maintenance. However, we didn't realise that it would become my 'forever house', or the extent of the required maintenance and repairs required at the time.

Due to the extensive Covid lockdowns in mid-2021, I had been socially isolated for two months and prevented from visiting my family or crossing the border. During this time, I had become regularly tired and unusually fixated on certain topics, e.g., hourly Covid statistics. The isolation meant that my change in behaviours were mainly unnoticed by people who knew me. As soon as I was legally allowed to, I visited my mother and then left Victoria to travel to my new house interstate. Upon arrival in Canberra, we started to create our new life together. My partner was socially isolated also, as she had been raised with the fundamentalist Jehovah's Witness religion, and when she had left, she was disfellowshipped and shunned, thereby losing all of her childhood network of family and friends.

However, one day, after going for a long walk, I was uncharacteristically and extraordinarily tired. I had suffered a headache for two days which I described as an "aneurism headache". Additionally, my Carer detected that I did not seem to be talking normally. She encouraged me to go to the doctor that day. I got my appointment time mixed up and by the time I got to the clinic I was unable to speak normally. My General Practitioner gave me a referral for an urgent MRI brain scan. I took this home, showed Lara and we made plans to get the scan the following morning.

On the way to get the MRI, Lara became very concerned I was potentially having a stroke as I was not making sense. She took me directly to Emergency Department. We explained we had been on our way to get the MRI when I deteriorated. However, in triage they advised that it would be quicker to get an MRI privately; they sent me to Canberra Imaging.

## B. Diagnosis with stage 4 cancer (glioblastoma)

After I had the MRI, Canberra Imaging rang Hospital. I was fast-tracked through Emergency to Neurosurgery. They met with us and advised that they suspected a brain tumour.

I may have been diagnosed earlier if I was not cruelly isolated by Covid restrictions. I might have had my craniotomy earlier and they may have been able to remove more of the tumour. This was the first missed opportunity to extend my life.

In September 2021, I was diagnosed with an **acquired brain injury** subsequent to glioblastoma, or GBM. Glioblastoma has a **median lifespan of 14 months**. Prior to this diagnosis I was in almost perfect health.

It was very confronting to see the scan. My partner asked how long I had, "5 years?", she offered. "Considerably less than that", was my neurosurgeon's response. We were both devastatingly hurt by this prognosis and we cried for weeks after this. One day I got up and told



her that I would not be focusing on my death, but on the remaining time I had left.

## C. Post Diagnosis – gradually increasing loss of function

During treatment for glioblastoma, we travelled interstate approximately monthly, as I wanted to see my mother and my Carer was also caring for her father, who lived interstate with eleven disabilities. We also hosted interstate visitors (at first monthly, then fortnightly, then weekly) to spend quality time with me and then assist with caring for me as my disease progressed.

### Eleven disabilities caused by glioblastoma

At my death, my **twelve** disabilities were:

1. **enochlophobia\*** (suspected). I did not like socialising with groups of people;
2. **atrophy** (and subsequently **sarcopenia**). I lost muscle mass due to extended use of dexamethasone, the steroid prescribed to reduce brain swelling. Eventually I was unable to lift myself out of bed;
3. **loss of balance**;
4. **cognitive loss**. For example, my brain had a slower processing speed. I also became progressively agitated. One day I became delirious and tried to escape from my house by violently shaking the doors to leave; I was in my underwear and it was raining and dark outside;
5. **dyscalculia** (difficulty in understanding numbers);
6. **dysphasia** (word-finding difficulty - **a language barrier**);
7. **extreme fatigue**. During radiotherapy, chemotherapy and due to the tumours, themselves, I was abnormally tired and this worsened as the months went on. Eventually I was sleeping for 22-23 hours a day;
8. Alzheimer's-like **memory loss**. For example, I would be stuck in repetitive loops such as constantly repeating to my Carer, "I'm blind" and "Don't you know I'm blind?";
9. **pre-syncope**. As my tumours progressed, I was 'presyncing' when I leaned forward or backwards;
10. (left-sided) **palsy**. I experienced **facial numbness** and had to masticate my food with my fingers. I had to use an adult bib and wide-mouthed drinking cup with straws. I also had **tosis and** experienced nightmares about my face closing in and being unable to breathe. Eventually I was unable to smile which made me feel locked in. My partner was scared I might choke to death;
11. **urinary incontinence**; and
12. **vision impairment**. I was **virtually blind** as I could not see at all to my right (**homonymous hemianopia, short-sightedness**. When I visited the Canberra Regional Cancer Centre, I was unable to see a bright red fire hydrant mounted on the wall at

head height when it was on my right-hand side. Eventually, my world became compressed to what I could see within 30 cm of my face. I suffered

- a. **epiphora** (constantly watery eyes)
- b. **metamorphopsia (blurriness and visual distortion)**, such as a straight wall appearing curved, like a watch in a Salvador Dali painting)

The vision impairments meant that I had to wear glasses, an eye patch and a mask during Covid lockdowns. I experimented with a head-mounted side mirror to see to my right for a while and I had to manage all of these together, with the eye patch often becoming dislodged by medical staff or my Carer and accidentally snapping back onto my eyeball.

\* enochlophobia was pre-existing

## D. Post Diagnosis medical treatment

The Canberra Hospital temporarily saved my life. For that, my family and I were eternally grateful. However, there were several issues worth noting that occurred during this time. These issues were raised with The Canberra Hospital and are not a concern for this inquiry.

### Craniotomy delayed due to broken equipment |

I was scheduled for a brain surgery with to debulk the tumour which removed 85% of the mass. However, the initial date for my surgery by was delayed for over a week due to the interoperative MRI (iMRI) machine being broken. My surgery proceeded after it was fixed, however with such an aggressive condition, time is important. This was the second missed opportunity to extend my life.

### First and Second Line Treatment | Canberra Health Services

I was provided the Standard of Care for glioblastoma, including radiotherapy (60 gy over 6 weeks), and concurrent chemotherapy (monthly temozolomide for 6 months). I had a recurrence after becoming resistant to first line chemotherapy. As my glioblastoma became resistant to first line therapy, I was started on second-line chemotherapy treatment and Procarbazine, Vincristine and Lomustine, known as PCV and a biological therapy (Avastin). I have no complaints about this aspect of my treatment.

I believe that if I would have been treated with second line chemotherapy earlier, they may have been able to slow the tumour sooner. This was the third missed opportunity to extend my life.

#### Consistent second opinions

I became concerned that I wasn't being given the best care. Subsequently I received five second opinions to be sure that no stone was left unturned, however in the main the second opinions in Australia were of little added value:

- Second Opinion 1: – **no hope given**
- Second Opinion 2: – **no hope given**
- Second Opinion 3: – offered oncomagnetics and viral oncotherapy
- Second Opinion 4: – **no hope given**
- Second Opinion 5: – support provided but **no hope given**

**You can see from the efforts we went to that my prognosis was consistent.**

#### Lack of access to clinical trials

It was intensely disappointing to find there were no relevant life-extending clinical trials available in Australia. Other countries like Germany, Japan and the US have many immunotherapy-based clinical trials, such as CAR T cell therapy and various GBM vaccine trails, but these weren't available to me except at great cost financially, and in time and effort. Nor

was a proven FDA approved therapy called ‘Tumour Treating Fields’ available in Australia. My Carer spent over 9 months searching relentlessly for relevant clinical trials internationally, and as there was no government service to do this for us, this took hundreds of hours from my shortened life. Additionally, my Carer asked again and again how we could obtain genetic testing of my tumor.

If had been monitoring relevant international clinical trials, they may have been able to recommend somewhere else I could go. If the Australian health care system had funded relevant national clinical trials, one may have been available to me. This was the fourth missed opportunity to extend my life.

## E. Comfort Care and Voluntary Assisted Dying

### Palliative Care (home-based) | Clare Holland House

I had wanted home-based palliative care; I wanted to die at home. However, within the required timeframe it wasn’t possible as:

- Home-based palliative care staff from the Canberra Regional Cancer Centre (based at Clare Holland House) did not have sufficient resources to support me to stay at home;
- we were unable to find sufficient suitable NDIS-based Support Workers;
- my house was not able to be modified to support me;
- my primary Carer was not sufficiently skilled;
- we did not live near our support network.

I was incredibly tortured by my loss of capacity. In the last two week of my life, I was actively dying. For days I barely ate and didn’t want to take my medications.

I mostly slept. I was stripped down to my underwear after an incontinence episode. It was raining and it was late. I staggered around the house shaking every door in an endeavour to escape the house. When I realised that I couldn’t get out, I begged my Carer to take one of the pickets from the fence and to end it for me. She said she couldn’t help me. That it was illegal to kill me. That she didn’t have the skills to do it and couldn’t risk me being further harmed. Instead, she organised for me to be taken to hospital and then to be transferred to Clare Holland House for palliative care. I did not want to go on. I never wanted an institutionalised ending. I wanted to be out of my suffering. I had been brave and I had been compliant; I deserved to be allowed to end my immense suffering. But no one would let me.

Instead, I was sedated by three paramedics in my home and transferred to hospital by ambulance. There I tried to escape my bed but I didn’t have the strength to get up. I wanted everyone to go away. I wanted to be back in my own home. Instead, as my tumour kept progressing, I became non-responsive and was reawakened with steroids. I no longer wanted

food and drinks. After a family meeting where my family and partner collectively reaffirmed my wishes, all cancer treatment was stopped.

### Palliative Care (inpatient) | Canberra Regional Cancer Centre

I was transferred to the cancer ward where I was placed on comfort care (no active treatment and midazolam and morphine doses) while cleaners and meals came and went. Needles kept being stuck in me. I had bed baths done by strangers. I slowly declined over five days in a semiconscious state. My documented view was that I wanted someone to “...just push me off a cliff...” or “...take me to the back paddock and shoot me...”, if I got to this stage. My Carer called it peaceful and a “good death”. She said, staff in the cancer ward were incredible at providing me a safe, secure, private and quiet space to be at peace. But for me it was everything I never wanted – the final indignity and theft of my self-control.

### Voluntary Assisted Dying (VAD)

Prior to moving to the ACT, I had been a resident of Victoria, where I was a very vocal proponent of Voluntary Assisted Dying. After the life-changing deaths of my father from blood cancer, and my best friend Malcom, of melanoma, I had prepared end of life documents including my Will, with Medical Decision Makers and Powers of Attorney in place, and a very clear Advanced Care Plan which I had communicated to my friends and family.

After first and second-line treatments had failed for me, and this was clear from my ever-accumulating disabilities, I ascertained that I would no longer be able to function with any quality of life. I wished to die. I told my Carer two weeks before my death that I was dying. I told her a week before my death that I was ready to die. In fact, I agitatedly demanded her to end it, at home. I wanted it over. My Carer was unable to help me. Now a resident of the ACT, I was unable to return to Victoria and in any case, I had not been under the care of Victorian medical care. Hence, there was no ability for me to access voluntary assisted dying there. And worse, it was illegal here - the ACT did not permit me to be euthanised.

### Recommendation

**Recommendation:** The Australian Capital Territory government should prioritise changing laws to permit Voluntary Assisted Dying for people diagnosed with aggressively debilitating stage 4 brain cancer, specifically glioblastoma.