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Submission to the Parliamentary Inquiry into Voluntary Assisted Dying Committee

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Individual

Dear Committee Members,

1. Yes, I strongly support making VAD legal in the NT.
I'm a life member of Exit International, (previously VERF when Dr. Phillip Nitschke still resided here in Darwin.
2. It's difficult to cover all situations as individual experiences will differ vastly. However, I wish to bring to your attention the experiences of my late dearly loved partner John B and I. He started to fall over on his left side. It took his neurologist over five years to diagnose corticobasal degeneration, typical survival before death is six to eight years. He was eventually admitted to Tiwi Aged Care, now Regis, in a wheelchair and deteriorated rapidly. I fed him evening meal five evenings a week, (Golden Glow assisted him the other two), gave him his medication, and insisted on his medical care. I would sometime still be there at 9 p.m. waiting for staff to change his dressings. They were woefully understaffed. His medication was for Parkinson as there is no treatment for CBD and it's extremely rare.

He was eventually *unable to even move a finger to press the call button*. Fourteen months after his admission, after breakfast on a Sunday morning in August ten years ago, he passed away, emaciated, a shadow of his former self. **All alone.** It sits with me; it never leaves me. How much better it would have been for him, myself and members of his large family to have been with him, if he had had the choice. This was the 'care' afforded a hard-working decent man of only 65. I witnessed him signing the form excluding intravenous feeding from his care. He didn't want to continue living at *all* costs. I wasn't allowed to stay overnight ever at Tiwi, how different from the caring situation at palliative care.

In 2000 he survived a triple bypass in Adelaide returning with a long 'zip' down his chest and front of both femurs. He went to Adelaide again where they operated on his neck, this was for undiagnosed CBD? You'll grab at any straw to survive; survival lived powerfully within him.

Consequently, the criteria, to administer one's own lethal medication is insufficient in some situations. If the person has absolutely no quality of life whatsoever and wishes to use VAD it should be available. However, in the case of extenuating circumstances for more help to be offered as some diseases rob you of nearly all physical movement. Speaking and chewing were getting difficult towards the end. As there was no time frame

regarding his lifespan, he didn't qualify for palliative care which in my opinion as time went by, he was eligible for. He was as thin as a rake when he died but totally compos mentis. The part of the brain which moves muscles stopped working, not the part which stopped him being lucid. I agree with Marshall Perron that *setting timeframes cruelly excludes patients with some diseases such as Parkinsons from accessing VAD due to the unpredictability of disease progression*. Add CBD to this list.

3. Maybe set up a separate VAD building where information, education and end of life care are available to all, education is the key. For all to understand that VAD is a personal choice, that you and you alone decide what happens to you. Already the medical situation is that you sign a consent form for certain procedures. Aboriginals and Torres Strait Islanders and others of different cultures need to understand this. That one culture could possibly dictate to another culture is wrong. It's a personal choice; to disallow others because of your beliefs is reprehensible in my opinion.
4. By keeping it completely separate from other care, having a separate building, maybe in the grounds of RDH similar to palliative care.

I supported VAD long before this lifechanging situation. It has only caused me to be even more pro assisting someone to end a life that is unbearable, if that is their wish. I'm imparting this private history as I want this committee to be aware that situations such as this are a reality, here, now, in the Northern Territory.