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To: [LA VAD](#)
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Subject: VAD - my story
Date: Thursday, 14 August 2025 10:58:06 AM
Attachments: [REDACTED]

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| Good morning.

I have rung and left a message this morning, but thought I would also send in my story to support VAD here in The NT.

I am hoping to submit my story about why I support and, unfortunately one day I may need to access VAD within the NT.

Please take the time to read my story. I don't want pity or sympathy, I just want to right to access VAD when the time comes., plus the right for others to access VAD if needed. The right for when I can no longer live with the pain and the hell that I live every day with this terminal disease that has no cure and no treatment. The right to die with dignity surround by my family, animals, friends and medical team.

My family, medical team and friends support my decision as they also live this 'hell' with me. Watching my body deteriorate and the pain I go through everyday, not being able to do anything for me except support me.

Next Saturday the 23rd August 2025, I will honour a long time friend and her family living in NZ. This is the day Lynn with her family, have chosen to stop her suffering after a long and horrific fight with cancer. She has been blessed with the support of her family and medical team, as she is accessing VAD in her own home, surrounded by her family and close friends. She is so blessed.

Living life on her terms.

Like a few others in our position, my husband and I have been forced to purchase a property in QLD where VAD is legal. I am originally from QLD and my specialist team are already in QLD and fully support my decision to access VAD when, or if needed in the future. How sad to think we have had to think long term, but when living with a terminal disease that has no treatment or cure you are forced to look at the future and all the long term medical needs.

If I was to access VAD in QLD I would not be able to be supported by my family and friends that I have here at home in Katherine NT. My husband will also have limited support in Qld as his friends are all based here in the NT. How sad to think we had to think long term, and spend money in another state we don't live in, just so I am able to access VAD when or if the time comes, adding so much more stress on me and my husband that we don't need.

Leaving the NT is not an option I want to access, but on the same token, I don't want to find another option for stopping my daily suffering and hell I live in. Unfortunately one of my husbands work colleague, who had been fighting terminal cancer for years, suffering unbearable pain for years and exhausting all medical treatment, knew he didn't have any

other medical options. He was just waiting to die a very cruel death.

He didn't have the option we do, with moving interstate where VAD is legal. His only option earlier this year was to send his wife into town, take one of his guns from his gun safe and proceeded to ring the police to let them know what he was going to do. He lived out of town, so by the time they were able to get to him on his property he had already taken his own life.

How sad, to think he didn't have any other option than to die alone, without any dignity and without the support of his loved ones, friends or medical team.

I can't imagine the fear he went through in his final moments on earth.

I honestly hope that whoever is reading this never has to consider talking to their medical team about access VADs. I hope you or your family and friends never have to consider this as an option for themselves or loved ones.

It should be my right to die with dignity and with the full support of my amazing family, friends and medical team. My right not to die alone, committing suicide because I have no other options as I can no longer suffer and live with this cruel terminal disease.

I am very happy to speak to anyone on my views and my opinion about my support with bring VAD back into the Northern Territory.

Yours

Sam) Wilson

To Whom It May Concern,

I am writing on behalf of myself and my position on VAD.

I have a rare form of muscular dystrophy called Fascio Scapular Humeral Muscular Dystrophy or FSHD. There are over 40 types of muscular dystrophy and all manifest and affect the body differently. Most are hereditary, just like FSHD but unfortunately 2% of those diagnosed with FSHD do not have it in their family.

It has been a hard 54 years of being called lazy as I have always tired easily and my shoulders have always been rounded. I have been given many exercises and devices to wear to help correct my 'laziness'. I must note here none worked.

I was always active as a child and teenager competing in competitive tennis and swimming. I was very good at freestyle, breaststroke and backstroke but butterfly always seemed to be a struggle. Now many years later it all makes sense as my back, shoulder and stomach muscles became affected by this disease.

When I came to live in the territory in 1993 I noticed many things with my body strength but as usual put it all down to being lazy and not exercising enough.

I learnt to adapt how I did simple things like reach up to tall shelves or putting up my hair while laying on a bean bag as my arms didn't go above my head.

The lovely medical profession here in Katherine gave me so much hope. I went in over the years with my concerns even got sent to many neurologists over the years in Darwin. They all did testing, looked at my winged scapular and listened politely to my concerns. They all asked lots of questions about my family history and did many blood tests but because I don't have muscular dystrophy, motor neurons, multiple sclerosis in my family they weren't too concerned. My bloods for muscular dystrophy kept coming back normal....?? What ever that means.

I must admit having a local doctor in Katherine write on my chart 'It is all in her head' didn't help. I got to a point with my health where I was so frustrated, but I found a wonderful doctor in Darwin who listened and helped navigate through the process of eliminating one disease after another. Unfortunately they moved on, and I was given another doctor who didn't give up on me.

All my blood tests over the last 7 years didn't make any sense and I went from one diagnosis to another and back to square one before they found a tumour on my pituitary gland growing up into my Brain.

I went to Brisbane to a neurosurgeon to have 'Igor' removed in about 2013. I still have 5% of Igor living in harmony with me and he continues to 'sleep'.

While in hospital I saw an endocrinologist to sort out a multitude of issues caused by Igor. But as he was nearly all gone most of my bloods went back to normal.

I went back to see my neurosurgeon after 6 months and told him I was feeling 150% better than I was before my tumour was removed but I still struggling with walking up stairs and lifting my arms up above my shoulders. Any sort of exercise was like I was running a marathon and took me days to get over.

He was able to get me an emergency appointment with my neurologist in Brisbane

before speaking back to the NT.

After years of being told it was all in my head I was being listened to and was hoping to get some answers. Unfortunately, I got answers and a horrible look into my future. I was told there are 8 really bad types of muscular dystrophy and after many tests like muscle biopsies, electrodes and of course blood tests to rule out the different types of muscular dystrophy.

I was diagnosed with FSHD and of course did a lot of googling to see what the future held. How this disease affects you is unknown. There is no cure and no treatment other than to treat the symptoms and constant pain.

I live with pain 24/7. I live with humiliation of not being able to do what everyone else can do. The humiliation of using a walking stick every day and looking like a penguin when I walk or waddle.

The humiliation of people staring at me as I walk towards them. The pity in their eyes is always there.

I am now using my wheelchair when shopping in Darwin but I am too embarrassed to use it here in Katherine.

I have had to retire early from my teaching position after over 30 years as it is too exhausting to keep working each day. I love my job but this is just one more thing this disease has taken away from me.

This disease is a living nightmare and the end whenever that will be isn't. A pretty one for those living the hell.

Imagine a life not being able to move, having someone do everything for you.

Being a brain in a body that doesn't work. That's my future, bleak look into hell.

I understand those with cancer or other disease similar, are, at some point in their treatment, they are given a timeline as they are terminal. Those with my disease don't get a timeline. Every case is different, every timeline is different, every course of treatment is different. But at the end of the day and the end of my life, I want to be able to decide when and where I go. I don't want to be in a bed on a ventilator, being tube fed. Prolonging the hell for whatever reason someone else has decided is my path in life and the end is controlled by others. Living life as a Brain on a bed.

This disease has destroyed or changed so much in our lives. It has taken so much away from not only me but from those around me.

My family have given up their property in Qld to move onto our property to help out wherever they can, but more importantly they are here so my husband can still work out bush and maintain some form of normalcy on his part.

I am unable to get up if I fall. I'm unable to cook dinner anymore as I can't stand for long periods of time or use a knife for long. I am unable to wash and hang out my own clothes or broom and wash my floor. Things everyone else takes for granted. But I do know, I won't give up on my life and my rights on how I live it and my right to decide when it is time to make the hard decisions on ending my life with dignity and with my family around me.

Not everyone fits into the same bucket with their diseases. We are all different and deserve to have a say on our bodies and how we are treated.

Everyone going through the hell of FSHD is riding their own wave of hell.

This disease has taken away my rights and everything other than my family and friends. Please, please, please don't take away my right to choose when and how I die when the time is right.

VAD has been a discussion I have had with my medical team, friends and families over the years, especially the last few years as my disease has progressed. I don't make any decisions on my own but I do know the final decision should be mine and mine alone once I have all the information needed to make an informed choice.

Not everyone fits into the formula of being terminal and only have weeks or months to live. Some of us are terminal and may live for months or years. Living in hell of constant pain and humiliation every day.

I am happy to discuss my opinion on VADs and my right to make the decision on my own life while I am able to.

Yours

Sam 

28/8/2024