

ACT Legislative Assembly Forum 15/4/2025

Submission by Gail Ford

Read by Tony Whelan (Treasurer, Death with Dignity ACT):

Introduction by Chairperson Nicole Lawder:

Good morning everyone. I would like to introduce Gail Ford, whose working life combined teaching and travel. She grew up in Melbourne, taught in Victoria and Canada and made her way around South America, Europe, the Middle East and other parts of Asia. In the late 1980s Gail set up an exchange with Russia for students and art and music enthusiasts, visiting the country almost annually from 1989 to 2013. To record her experiences in Russia over this pivotal period in its long history, she wrote a book, which was launched in 2010. She raised her family in Canberra.

We thank Gail for agreeing to share with us her experience of Parkinson's Disease and her hope of achieving a peaceful and dignified death.

Gail says the biggest impact of the disease for her has been extreme difficulty communicating, especially speaking. I am therefore going to read prepared notes on Gail's behalf

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Gail has probably had Parkinson's Disease for 20 years or more, though it was not diagnosed until 2010. There are no specific tests for Parkinson's, but hand tremor is often mistakenly seen as a definitive symptom. Gail showed no signs of this, but years before had reported two other early signs of Parkinson's – loss of smell and an inability to write clearly.

The latter she still finds really annoying, as anything she attempts write by hand becomes meaningless squiggles - even her signature, short as it is, is completely unintelligible. Until you can NOT write anything by hand you don't realise how often you need to do so – jotting down facts, names, numbers, writing addresses, etc. it's endless, and becomes a real limitation, *not* just a minor inconvenience.

Using a computer as an alternative however, is extremely problematic for Gail, and takes an inordinate amount of time. Fluttering fingers hit keys they shouldn't, issuing unintended commands; in almost every second word two letters are transposed; and she only has full use of her left, very non-dominant hand, so using a cursor and mouse become difficult and very time-consuming.

Even more distressing than writing, particularly in relating to people, are the problems Gail has with her speech, making her very difficult to hear, and understand. This has forced her to give up organising or being part of various groups, and also inhibits her from taking part in most social activities, which eventually becomes isolating.⁴

Gail's life has been built around communication - speaking and writing.
Robbing her of her ability to communicate is the harshest of blows.

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About 8 years into her Parkinson's Gail found her medication was becoming unreliable and she was having lots of 'offs'. She looked into alternative treatments, seeking advice in Sydney, and decided on Deep Brain Stimulation (DBS). She is very positive about this. It a surgical procedure in which two electrodes, powered by an implanted battery a bit like a pace-maker, are strategically placed in the brain and programmed to supplement other medication. Gail has had DBS in place for over 8 years - there seems to be no limit- and by stabilising her it has given her a new lease of life, and allowed her to reduce her medication. (NB Gail has some more information on her experience with DBS for anyone interested)

Gail says that she paddled along reasonably well until 2024, when she had a king-sized fall resulting in a badly dislocated shoulder and a hip broken in two places. This led to months in hospital , much of it in searing pain because of a problem with morphine. Whilst trying to get her shoulder back in place a nerve was severely damaged, and she now has very limited use of her right arm and hand. The three middle fingers also buzz constantly, like having acute pins and needles; contact with the computer keyboard is barely possible; and she can't hold a pen, or cutlery in her right hand.

Less than a month after getting home Gail fell again, fracturing 7 ribs, and whilst still in hospital fell on her right wrist, breaking that. Her right side is therefore pretty useless.

Gail attributes all of these falls directly or indirectly to Parkinson's Disease, not age.

Falls are the biggest risk for most people with this awful disease. That's what Parkinson's people do! They fall. And that's what KILLS them - not the Parkinson's itself but indirectly, by falling and dying from something caused by the fall. This is no doubt why Parkinson's is not included as a terminal illness in the documents of any Australian State. This greatly

reduces the opportunities people with Parkinson's to qualify for VAD in any of the States. It may be indirect but is the falls, caused by Parkinson's Disease, that are the killer, and therefore Parkinson's is terminal – but indirectly!

Any illness can beset the Parkinson's patient but all seem to be exacerbated and complicated by it. One special bit of Parkinson's 'fun' is difficulty swallowing. The risk of inhaling fluid or food into the lower respiratory tract can lead to aspiration pneumonia. This reportedly accounts for 70% of all deaths of people with Parkinson's disease. Then there are its charming traits, like dribbling, and as for bladder and bowels – they're an unending drama!

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When a number of health problems hit together, life can get grim. You start assessing how long you really want to hang on, and what the future holds. Some things may improve with treatment, but Gail feels that the biggest influences on her health and her life are her 84 years of **age**, and her 20 plus of **Parkinson's**, and that whatever she does these will keep up their relentless, irreversible decline. Her aim is to jump the gun and get in early, rather than waiting too long and condemning herself to a painful, undignified death.

But where is the tipping point? That is the hardest decision. She has her own 'plimsoll lines' and if she goes below these... it's time! They include the indignity of physical needs such as having to be fed like a baby, and not being able to wipe your own bottom, and wearing a nappy, but they also include things that reflect state of mind and the will to go on :are you, for example, interested in or looking forward to anything?

However Gail thinks that it seems difficult to commit suicide successfully, except by violent means. If, for example, you are using an illegal drug, how do you know the quality? And how can you ensure that by ending your own life you don't potentially implicate someone else's. by participating with you or finding your body, and getting questioned and charged?

Wanting everything to be done properly, legally, and with dignity, Gail had decided that her only option was to go to Switzerland, the one country where VAD is available to foreigners.

It would of course be simpler, and less financially onerous, not to have to do this.

She now hopes that she will be able to access VAD in the ACT under the law that will come into place on 3 November. However, like the equivalent documents in the States, the ACT Act says that to qualify a person must be suffering from a condition expected to cause death. This is where Parkinson's seems to be in a grey area , as death from this complex illness tends to be indirect, hough in many cases it is undoubtedly the chief cause.

Gail is hopeful that as the implementation of VAD progresses, there will be a clear policy guideline for practitioners that will include long-term neuro-degenerative conditions such as Parkinson's Disease, and will focus heavily on the relief of suffering rather than any "close-to-death" opinion.

She is still afloat just above her plimsoll line, but she does not want to lose the right to determine her own future and so plans to prepare submissions to qualify for a VAD both here in Canberra, AND in Switzerland .

In her many travels Gail always believed in thorough but appropriate advance planning, covering lots of variables. In organising this journey she would rather go too soon than leave too late and miss the proverbial bus. The bus itself is inevitable, and if the time-table doesn't suit, you may even be able to flag it down. Gail would prefer however, to seek out the more established stops, and the demands each makes on its passengers.

My sincere thanks to the Assembly , and especially the Attorney- General Tara Cheyne, for their assistance in this quest.

Gail Ford
(14/04/2025)