

May  
2024

## The Dementia Q? A Special Edition

**It is the diagnosis no family wants. 'Your mother has dementia'. Yet this is the reality for hundreds of thousands, if not millions, of families throughout the world. The longer life course has given much, including higher rates of dementia. The longer you live the more likely you will get it. The world is stuck with a problem for which modern medicine has no answer** by Fiona Stewart

a decade ago, I have tried everything in my power to stay connected to my parents. It used to be that my mother would email from the home computer. I knew exactly where the big machine sat in the study of my childhood home. I used to imagine her sitting there, late into the night, typing away.

Back then, I'd get a weekly report of who said what at the yacht club, tales about her grand kids (from my brother) and always accounts of this or that music concert that she and my father had recently attended.

### My Dementia Story

My dementia story begins, or rather the story of my mum Pam's dementia, began several years back. For me it started when Pam disappeared, almost overnight, from my WhatsApp feed.

Bit by bit her emails ebbed away. I never really knew why. On one trip back to Melbourne, I suggested we change to the more immediate medium of WhatsApp. I bought her a new smartphone, showed her how to take and attach photos. For several years this worked a treat, and we were in constant contact, sharing our separate, but interconnected, lives from opposite sides of the world.

But let me tell you a bit about the time before that. Since moving to Europe almost



Pam & Fiona in Melbourne, February 2024

exit  
international

### THIS ISSUE

- 1-4 The Dementia Question - Special Edition
- 5 Exitorial
- 6 The Dementia Question - Special Edition - continued
- 7 The 93-Year Old Murderer
- 8 Peaceful Pill eHandbook  
Updates: Nitro, Nitrite & the new Exit Swiss Friend Program

### Diary Dates

#### LONDON WORKSHOP

Saturday 11 May 2024 @ 1-4pm  
Dragon Hall, 17 Stukeley St, WC2B 5LT

#### MELBOURNE CHAPTER MEETING

Tuesday 7 May @ 12.45pm  
Boroondara Hawthorn Library  
584 Glenferrie Rd, Hawthorn

#### CANBERRA CHAPTER MEETING

Monday 13 May @ 11am  
Raiders Club - Belconnen

#### PERTH CHAPTER MEETING

Monday 13 May @ 12.30-3pm  
Wembly Community Centre

# The Dementia Question

## Special Edition

Then, about 18 months back, the WhatsApp messages stopped too. At first, there were the excuses 'oh your mother lost her phone' or 'the phone is always flat'. I was disappointed but understood, it can happen to anyone.

It was only once I was able to speak directly to my father that I began to understand the reason for her increasing absences: she had forgotten how to send messages. Something was happening and no one was really sure what. Doctors' appointments were eventually arranged the dreaded diagnosis was confirmed.

A year and a half on and our communication is down to phone calls which are, more often than not, a one-sided exchange. I ask the questions and she gives me the answers. The weather is a constant source of discussion: I guess because it is recent and obvious, just look out the window.

On a good day my phone calls with Pam are almost as they used to be. Sometimes she even throws in a bit of unsolicited detail of who said what, where and when. More often than not, though, my questions are met with 'oh thingamajig you know' or 'I can't remember'.

### Difficult Conversations

In some ways I feel a sense of guilt writing this down; a sense of betrayal. But this is my experience too, not just hers, and not just my family's at home in Australia. Her dementia has affected us all. Talking about the diagnosis should not be taboo, about that I am sure. I have already missed the chance to talk about that other great elephant in the room with her, how she might want to die.

It may come as a surprise to many that I never had *that* end of life choices conversation with Pam (when she was still able).

We once talked about what we would want done with our ashes. She was surprised that I wanted mine scattered at the local surf beach. I was surprised that she didn't care what happened to hers.

Despite my two decades of work with Exit, my conversation with my mother about 'the end' never went any further.



*My parents rocking it, 60s style ...*

And now it *can't* go any further. There is no psychiatrist on the planet who would now attest to my mother having the mental capacity to take her own life: with or without help. And besides, that may not be what she wants.

A few weeks back in the weekly Exit Email Newsletter we highlighted a recent opinion article by Jessie Dezutter who is Professor of existential geriatric psychology at KU Leuven in Belgium.

Her article had been originally published in Dutch in the newspaper *De Standaard*. The piece was about the efficacy (or not) of how in the Netherlands and Belgium you can include a request for euthanasia in your advance directive.

Had my mum lived with me in the Netherlands, she could have made a request for help to die, before she got her dementia diagnosis. This written request would mean that a doctor could lawfully kill her even though she was demented and may not know about it.

But how does this lawful practice actually work? It doesn't really. Take the 2019 case of the Dutch doctor who sedated a 74-year old demented patient with sedatives in her coffee prior to the lethal injection. The doctor in question was eventually cleared of breaking the Netherlands' euthanasia laws but not before a long-drawn-out trial was endured by all.

# The Dementia Question

## Special Edition

Exit's Philip Nitschke (my husband) has long been critical of the inclusion of a voluntary euthanasia/assisted suicide request in one's advance directives. He is of the opinion that a decision to die should never be outsourced. He says that you would only advocate for the inclusion of a request to die in an advance directive when you don't want to engage too deeply in the problem.

### Super Human Oversight?

Here in the Netherlands, a doctor's legal ability to kill a demented patient remains a deeply unpopular concept, with almost all of the medical profession hostile to the practice. Clearly, the problem is more complex than words on a piece of paper.

Just say, for the sake of argument, that Pam had completed her advance directive a few years back and we had discussed it thoroughly (and regularly) ever since (thus ensuring it was still relevant to her wishes). An ideal situation you would say. Would I then support the actions of a benevolent doctor in 'helping her to die'. At what point would I, or any other family member would deign to speak for her?

At the current time, my mother is a little bit demented and, yes, there is steady deterioration. But would 2024 be the year when she would want to go?

Pam is just back from a cruise around Japan where, by all reports, she had a great time and marvelled at the cherry blossoms. However, because my mother no longer has mental capacity who else could claim to know enough about her (if that is the criteria) that they could decide with authority and surety that *now* is her time to die? Certainly not her geriatrician, nor the family doctor. And almost certainly not my father.

The whole human situation demands super-human oversight. And this is one reason why assisted dying/euthanasia requests do not belong in Advance Directives.

What may sound good in theory, can create more problems than it solves. In her article on dementia and euthanasia, Belgian Professor Dezutter writes:

*Dear person with dementia,*

*We often talk about you. Less often we talk to you. That may be because you hold up a mirror to us. A mirror of what our lives might be like in the future. A life that frightens us ...*

*The question of freedom plays especially hard when we talk about you, a person with dementia. It is, after all, about our freedom ...*

*Our freedom to decide that we don't want a life like yours, don't even want to risk such a life. Our freedom to end our lives if we were to have a life like yours ...*

*Our freedom to seek help to do so from the medical profession to assist us in that autonomous and freely made decision. The decision to choose euthanasia.*

*We decide now that future life will not be worth living, even though we do not know if we will feel the same way as a person with dementia ...*

Dezutter's article is one that I keep returning to again and again, as I mull over our family predicament. In some strange way it gives me solace, as I prepare myself for my mother 'going into care'. We didn't have that conversation either. It is the flip side of the same





# The Dementia Question

## Special Edition

coin: what were her boundaries - what are her red lines about a life worth living.

More often than not Exit members say 'I'm not going into a nursing home'. Or 'when I can't clean up after myself that is the time to go'. My mother didn't say any of that, at least not to me, and now she is stuck. But is she?

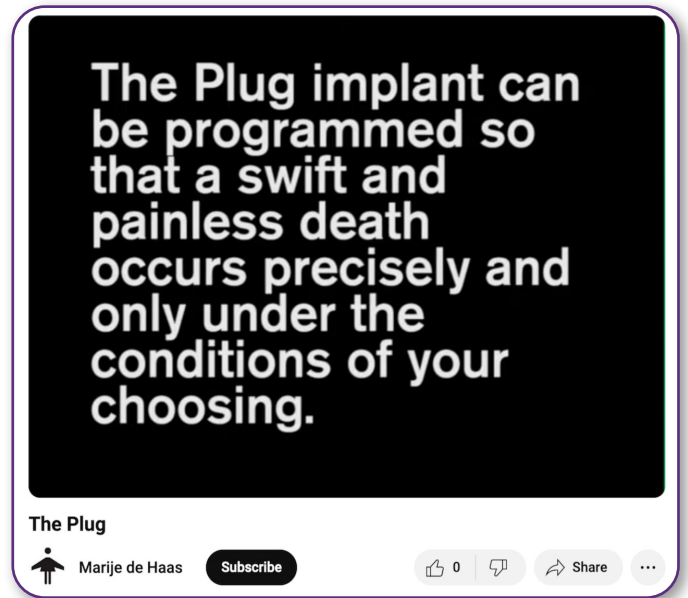
I have a gut feeling that - assuming she is aware of her living situation - Pam may not mind the proverbial dementia unit. She is social by nature. She likes to sing and she loves her handicrafts. At least she used to. And that's the point. While I don't appreciate the mirror that she - in her situation - holds up to me and my life, it does make me question my feelings of regret of not having discussed what she might want should she find herself in this situation.

From where I stand now, I keep saying that I will be organised and, unlike my mother, I will get out while the going is good. But will I?

As a longtime Dutch resident I can include a request for voluntary euthanasia in my advance directive but I haven't done this yet. And I doubt that I will. So what else is there out there for me when my time comes? What is there for Pam?

## A Technological Fix?

As most Exit members are aware, Philip is an ardent follower/ creator of new technology, especially as it relates to the end of life. At the online NuTech conference held during the pandemic, one of the keynote speakers was Marije de Haas. De Haas has developed a thought-bubble experimental film called 'The Plug'. (See: <https://bit.ly/3ULiRle>). This short film documents 'the Plug': a microchip that will kill you when dementia sets in. A 'reverse pacemaker' if you will.



In interviews with its recipient and the man from The Plug Inc., it is explained that you do not have to live your final weeks, months or years with a 'stranger' who coopts your thoughts and wears your clothes, all without your explicit permission. The Plug is a device that, once activated, will kill you. Important to note, is that if you do not develop dementia, the Plug remains a benign presence under your skin.

For some years now, Philip has been reading widely and thinking deeply about how to make the Plug a physiological reality. In his chase down this rabbit hole he has befriended biohackers on several continents, so intent he is on talking the issue through. And he is not done yet.

The proposal is intriguing, if it could be made to work, is it not? An implant would relieve the medical professional of an uncomfortable obligation (were help to die to be widely included within advance directives). It removes loved ones from having to 'play god'. So how would it work?

In Philip's thinking, the Plug would be a chip or some such that is implanted under the skin. Subcutaneous devices are already a reality for any number of treat-

Cont p. 6

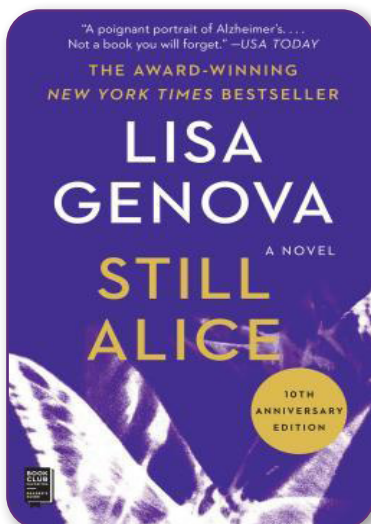
# EXITORIAL with Philip Nitschke

## Still Alice

In the film *Still Alice* (based on the book by Lisa Genova), the character 'Alice' is diagnosed at 50 with Alzheimer's Disease. Not long after she writes herself a letter. She intends for the letter to come in handy at an undetermined date in the future: at a time when she is demented. In the letter she self-instructs on what to do to kill herself.

This self-care advance directive (of sorts) by Alice is a non-technological attempt at taking responsibility for her life and death decisions when she has lost mental capacity. Leaving aside the utter unlikelihood that she would have a bottle of pills that could kill her (modern sleeping pills are not lethal), the problem that is recognised in this story-telling is that which has been written about by Fiona in this edition of *Deliverance*.

My response to *Still Alice* was, and still is, that we should be able to use technology so the Alices of the future can take responsibility for what happens to them when their dementia has stripped them of all other means of self-determination. There is so much more to be said about the problem of dementia in the end of life choices debate. I ask readers to treat this special newsletter edition as the starting point for an ongoing conversation at all levels.



## The Sarco Project

In the coming weeks, we are finally due to take delivery of the Sarco after several months of delays with the painting. This is an exciting time as we will get to see what the final Sarco will look like, and how it will function.

Several months of testing are now planned, as no aspect of the Sarco's operation can be left to chance. I am very fortunate to have a very skilled team of technicians and designers working alongside me on the project here in the Netherlands. This endeavour has truly been a joint effort. I will report more on Sarco plans in coming editions of the Exit Internationalist Email Newsletter. Watch this space.

## The Dutch Trial of CLW

As I write this Exitorial six former members of the Cooperation Last Will association - the Netherlands foremost end of life choices activist organisation - are in court arguing for their freedom. They stand accused of distributing Middel X (sodium azide) to their members. An intolerant public prosecutor has decided to make an example of this type of activism. The deterrent factor will figure big in the sentencing.

While the Netherlands may have had over two decades of euthanasia legislation, and it may seem a liberal place in that it allows children and the mentally ill to use the *Terminal of Life upon Request Act*, the country is increasingly intolerant of anyone who seeks to push the boundaries. Far from being the 'wild west' of the end of life choices debate, this land of tolerance and freedom is anything but.

The 'Completed Life' bill (a law which would allow elderly but not seriously ill or unbearable suffering people access to a good death) is going backwards in the Dutch parliament as more and more 'safeguards' are applied. The CLW verdict is due in July. I wish CLW all the best with their struggle. Exit is right behind them!

# The Dementia Question

## Special Edition

ments from slow release birth control to drug administration. The implant would need to be regularly engaged with, to keep it in working order. In this situation, working order would mean ticking along with no action planned.

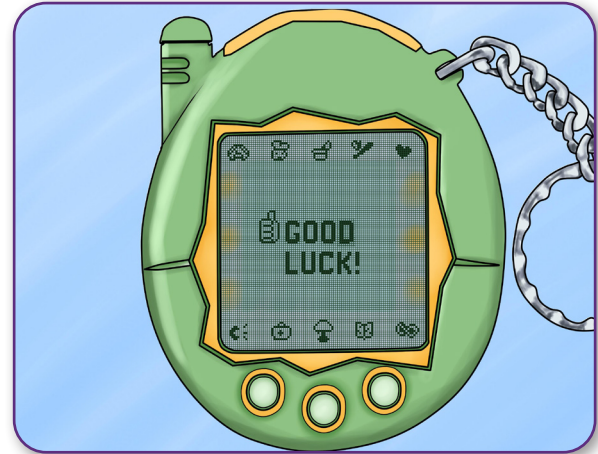
Re-activation would require its owner to remember to 'care' for it: 'tamagotchi style'. The Tamagotchi was a Japanese invention in the 1990s: a so-called 'hand held digital pet' that, upon activation, could interact with its owner.

In terms of an implant, every year (or other defined period of time) there could be a series of notifications to re-activate. If, on the third reminder, no action was taken by its owner, a lethal drug would be dispensed and the person would peacefully die. This, Philip says, is the most difficult part. Which drug, in what quantities, with what safeguards against abuse by third parties. How could the drug be stored? What type of government regulation and oversight?

The rationale of such an implant is that a person with mental capacity would know to respond to the multiple invitations for re-activation. The three-alert system would be the safeguard. A person slipping into dementia would have no awareness of the implant and would have no knowledge of what type of re-activation would be required to keep on living.

By default, the person would die of their own hand. Of course, this is not a perfect system but it is *something*. I like it because it relieves anyone other than the 'dear demented person' from having to exercise control and/ or decision-making over their end of life. The responsibility stays with the user. There is no outsourcing. I also like it because it represents a circuit breaker in the inevitable, endless spiral into dementia oblivion.

Around the world, communities are having conversations about what to do about dementia. Care homes - if they weren't already - are now mega busi-



A Tamagotchi

## Final Words ... for now

nesses, as are medical breakthroughs. Neither brings much comfort for my family.

In the past year, two members of our team at Exit have had their elderly fathers die of dementia. One was institutionalised, the other was cared for at home (with extra local government help). Both fathers died within the past 6 months. Both of these men 'slipped away' in their sleep. Both men struggle to be remembered beyond their demented final selves.

The three of us mourn for our parents as we are brought before the mirror of life. We have plans for a group talk about what we might want for ourselves given how it looks to live life in the shadow of a disease that has little treatment and no cure.

While some may think that Philip has finally 'lost it' devoting his attention to some hair-brained sci-fi plan, nothing could be further from the truth. Rather, what is happening is that he is taking a stand against the increasing trend at the end of life to outsource death to the professionals. No one wants to be the executioner of another.

Given that modern medicine has no solution for the problem of dementia, surely the role of technology deserves serious consideration (and investment)?



# The 93-Year Old Murderer A Wakeup Call of Sorts?

This month, Donald Morley (93) from Canberra, Australia was sentenced to life in prison for the murder of his wife of 69 years, Jean Morley (92).

This is a guilty verdict that has struck a cord within Australia, and the world. The apparent plan had been for Donald to kill Jean and then to kill himself. He had told a community worker that they had 'lived long enough'. Jean was suffering from dementia. Donald was her carer.

There are not many couples who live long enough to stay married for seven decades. There are even fewer who put plans in place of lawfully dying together. If Jean had not had dementia, the Morleys could have made their plans using any of the methods in the Peaceful Pill eHandbook. Given that Jean had lost capacity, an unnatural death was always going to come down to murder.

When Exit first heard of Jean Morley's death, our first reaction was to check our records. Were they

members of Exit? Because, if so, what had gone so horribly wrong that Jean was dead and Donald was left to face the full force of the criminal law. They were not members. Perhaps it is to be expected that Donald survived his attempted suicide. You need to know what you are doing if you are not going to 'make a mess of it', so to speak. Had Donald been well informed of his end of life options, Jean may have died in way that was more dignified and less violent than a pillow in the face.

Being prepared is not only the motto of the global scouting movement, it also applies to the end of life. Get yourself organised, and then get on with living in the comfort of knowing that if things get 'too bad' then you have an Exit Plan. These words are cold comfort to Donald who is now destined to spend his remaining months or years incarcerated. The law has little tolerance, it would seem, for compassion for those who believe that they have 'lived long enough'.



*The Morley home in Canberra, 2024*

# Peaceful Pill eHandbook

## Nitro, Nitrite & Swiss Friend Program



The *Peaceful Pill eHandbook Essentials* continues to be the world's leading practical guide to end of life choices. Authored by Drs Philip Nitschke and Fiona Stewart, the online edition is regularly updated. Indeed, in the month of April 2024, three updates were made. These updates focused on:

- **Nitrogen hypoxia**
- **Sodium nitrite**
- **New Swiss Friends Program**

The first two updates feature new workshop footage that was shot live at Exit's February 2024 Sydney Workshop. The third update focuses on the rebranding of the Exit ID program - now called the **Friends Program** - for those who travel to **Switzerland** and wish to have a guiding hand upon arrival.

Nitrogen was also the topic of the January 2024 Update. This update provided an analysis of the execution of Alabama prisoner, Kenneth Smith. By all accounts, Smith's death looked tortuous. But his degree of actual suffering is difficult to establish. What did become clear is that for **nitrogen hypoxia** to provide a peaceful death, with or

without a mask, cooperation is required. Kenny did not want to die and he did not cooperate. The result was not pretty. Following on, the February 24 Update focused on the dilemma that faces **couples who want to go together**.

This update was triggered by the joint death of the former Dutch Prime Minister, Dries van Agt, and his wife Eugenie. Theirs was an 'euthanasie' death as both were seriously ill. Their deaths generated much discussion within the Exit community, raising 'false' hope that dying with your long-term partner is simply a matter of asking.

Sadly, this is far from the truth. The van Agt's got lucky because both were sick at the same time. More often than not, it is one member of the couple who gets sick, leaving the other to outlive them.

A couple death takes a great deal of planning!

Videos about the DIY deaths of: Don & Irish Flounders (died at home), Peter & Pat Shaw (died at home) and Athol and Beverley Whiston (who died in Peru) can all be found on the Exit Blog at: [www.peacefulpill.com](http://www.peacefulpill.com)