SUE WADDICOR 09 Jan 1961 to 18 July 2024

## PROLOGUE

Sue and I separated in 2006, although we stayed in touch ever since. In April 2022 Sue self-diagnosed with MND. Later that year her speech became slurred and her hands and limbs became less dexterous. She first rang her GP in August 2022 when she was referred to Ear Nose and Throat (ENT) Department where she was (eventually) seen in February 2023. Darcey and I spent our last Christmas with Sue in 2023, not knowing, although we found out shortly after that. She had an official diagnosis in April 2024. She wanted control of her own destiny, and having started Voluntary Stopping Eating and Drinking (VSED) – without fanfare on 1 July (after she'd managed to finish her tapestry project). She died 18 July 2024. The story is pretty harrowing, but I felt it appropriate to say something while all the 'Assisted Dying' deliberations are occurring.

## INVESTIGATIONS & FINDING OUT

In April 2022 Sue self-diagnosed herself with MND although she had noticed difficulties with her articulation and speech for a couple of years before that. Sue also had subtle but progressive weakness and loss of coordination of her muscles and choking fits. Investigations started in August 2022 after she had noticed her difficulties in swallowing and her speech becoming slurred. She investigated possible causes using an NHS Symptom checker which had suggested that Motor Neurone Disease (MND) maybe likely.

In Spring 2024, a number of investigations were instigated, examining the cause of these difficulties, including an Ear, Nose and Throat (ENT) examination to investigate the cause of swallowing and speech difficulties; Magnetic Resonance Imaging (MRI) scans of her brain and cervical spine; and electromyogram (EMG) investigation to determine if MND was the cause. The ENT and MRI didn't determine any cause, but the EMG confirmed MND was the cause.

I found out by email on Monday 15 January. I went down to Manchester 17 January for a few days. During this time Darcey and I went out for a meal, and during the meal she was enthusiastically describing all the stuff she was planning on doing with her mum later in the year. She didn't know. Sue wanted to tell Darcey face-to-face so Darcey found out from her mum later in February.

## WILL AND POWER OF ATTORNEY

It's the practical things that are easiest to deal with in such scenarios, and this is where the Will and Power of Attorney came into play. This sort of stuff diverts you from the realisation of having to deal with the personal nature of MND, cancer, etc.

## THE DOG BRINGS IT HOME

What brought it home to me and Darcey was the realisation that at some point Darcey will need to look after Pixie, her dog. Pixie was Darcey and Sue's companion since early 2017. In late February Darcey started thinking about what to do with Pixie, shortly after Pixie had been found to have a tumour. Darcey didn't want to lose both. Around late May, early June Sue explained to Darcey that she could no longer lift Pixie into the car, so she was going to have to bring Pixie down to Manchester. However, Pixie gave Sue a reason for living without Pixie Sue would have just stayed in bed, so Darcey went home to look after her mum.

## MND SCOTLAND & NHS GALLOWAY

During these months I contacted MND Scotland with a view to finding out what can be done to help Sue with pain relief, etc. should it be required during her last few days. There was not much they could do. They offered advocacy but nothing from a clinical perspective, advice on pain relief (if needed, etc).

## DEATH SENTENCE

Sue and Darcey decided that they wanted me to be with Darcey for support as she cared for Sue in the last few days. She would wait to pursue VSED until I arrived. I got the train down to Dumfries on 28 June 2024. Darcey picked me up in Dumfries and took me to Sue's house a couple of hours drive. Gloriously sunny.

Over the weekend life was as 'normal' as it could be. A few things. Sue had typed up a 'Living Will'. We managed to persuade her to handwrite this to give clarity to her lucidity. She also completed a Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) document in which Sue stated that she did not want any life prolonging treatment, did not want antibiotics in the event of a chest infection and that she didn't want to be any more dependent what she currently was. She stated that in the event of the deterioration of her condition she wished symptom control and comfort to be her priority. She did not want ventilatory support or artificial nutrition or hydration.

We discussed the subject of pain relief. Although I had ibuprofen and naproxen for my own ailments Darcey/I could not administer NSAIDs (Non-Steroidal Anti-inflammatory Drugs) to Sue in her weakened state. This was just in case it triggered a 'premature' death. Sue wanted to buy such meds online, but Darcey and I argued against this on the basis we could be implicated. It was all very traumatic.

Sue finished her tapestry.

On Saturday 29 June Darcey and Sue watched Coldplay headlining at Glastonbury live on television. They'd been talking for years about going to see Coldplay live, but they never got to.

## THE ASSESSMENT

On Monday 01 July, Sue came down as normal and without fanfare started pursuing VSED. To an extent the first few days were normal. Sue and Darcey had been in touch with the Palliative Care Nurse (PCN) who had asked if they could 'pop by'.

The Thursday 04 July the PCN visited Sue with Darcey in attendance. As part of this visit they recommended that Sue be visited and assessed by a psychiatrist. Darcey and Sue also asked if it would be possible for Sue to be administered pain relief should be required. The PCN would revert.

On Friday 05 July the Psychiatrist arrived. A lot of the following narrative was paraphrased by the psychiatrists' interpretation of Sue's responses.

When asked why Sue wished to end her own life at this point in time, Sue replied,

"*I planned this when I knew that I had Motor Neurone Disease. There is no way I could end up with an unimpaired brain inside a useless body. To me that isn't a life — it is an existence that would be unbearable. I live alone. I am fiercely independent. The thought of being dependent on someone to dress me is something I cannot bear.*

*I am an active person. I can't just sit and watch TV. To me that would be a Hell on earth (Author's note: it was not the sitting and TV part: it was Sue's being alive with her mind trapped inside a useless body that would have been Hell on earth). I knew that I couldn't walk or I couldn't eat, that would be the point where it would be too much*".

When the psychiatrist reflected that Sue had made the decision to end her life at the point where she was still able to eat and walk, she stated,

"It may be I am just a different mindset to other people. When you can't do up your buttons or can't get dressed I can't tell you how frustrating that is. I have a large garden and this is becoming overgrown and I can't do it properly... it's about going out whilst I am still me.

Sue felt that the time was right because Darcey was able to be present to support her.

She explained to the psychiatrist that,

"*Quality of life is so important. People who talk to us about assisted dying aren't experiencing the problems themselves.*"

And,

"*A short period of suffering for me means that I won't have to go through a much longer one. This is a short period of physical suffering. If I didn't do this I would have the double whammy of physical suffering and mental torment that would go on for much longer*."

Sue's argument was that VSED was to reduce here suffering, not an effort to shorten her life.

The psychiatrist subjected Sue to a couple of tests – Hospital Anxiety and Depression Scale (HADS) test, and a cognitive test known as the Montreal Cognitive Assessment Tool (MoCA). The results of these tests indicated that nothing was untoward.

During the early stages of VSED Sue had found it 'easier than she expected' to cease eating. This was largely because she was already finding it difficult to swallow. Since having MND she found the time and effort required to eat to be prohibitive. Cessation of drinking fluids was a lot more difficult, and she spent a lot of time thinking about how she would like to drink more fluids but she resisted the urge because it would prolong the process of dying. When Sue asked a stand-in PCN whether merely swilling juices around her mouth would prolong the process of dying he/she was unable/unwilling to provide information.

Sue was interviewed by the psychiatrist both with and without Darcey present. Darcey was also interviewed on her own. On her own, Sue clearly restated her opinions, and Darcey restated that she would support Sue because it was Sue's decision. Darcey was not encouraging Sue to end her own life.

They also discussed the process of dying. Sue wasn't sure how long it would take, but to give Darcey and me an idea and to prepare ourselves, we looked online. Estimates suggested in the region of 10-14 days; a number of factors influence the duration.

In order to intervene to prevent Sue from ending her life using VSED, two types of legislation could be used. These are, the Mental Health (Care and Treatment) Scotland Act (MHSA), or the Adults with Incapacity Act (AIA). There are certain criteria that are required for the NHS to step in with either of these two pieces of legislation:

1. You have a mental disorder;
2. There is a treatment available for your mental disorder;
3. Without the treatment there would be a significant risk to your own health, safety and welfare; or to the safety of another person;
4. There is a significant impairment in your decision-making ability, and
5. It is necessary to proceed with the use of the Mental Health Act because no less intrusive option is available to support you.

The assessment concluded that MHSA criteria 1-4 were not met. With regards to the AIA, one or more of the following criteria would need to be met:

You should be unable to:

1. Act
2. Understand the decision that is required to be made
3. Make the decision

4. Communicate the decision; or,
5. Retain a memory of that decision.

Sue was assessed as being able to pass all of the tests necessary to demonstrate (mental) capacity.

Both pieces of legislation specifically exclude actions or decisions that *a prudent person would not make*. This exclusion allow space for an individual to make a decision and for the decision to be respected even if is not felt to be a wise decision by those assessing it. This means that the assessor does not need to agree with the decision in order to respect it.

The assessment concluded that Sue did not have a mental disorder and that she did not lack capacity in relation to making a decision to withdraw nutrition and hydration even though this would shorten Sue's life.

On Friday 05 July the PCN wrote an email to Sue. Due to legal advice the PCN would be unable to assist in providing pain relief should it be required. We were left on our own, not knowing what to expect. We were pretty much abandoned by the NHS.

For a few days Sue came down to watch England play in the Euros. However, Sue's condition worsened and after about 10 days shortly after the England vs. The Netherlands (football) game on 10 July she became bed ridden, with Darcey doing the day-to-day caring. Sue listened to the Euros final on the radio because she couldn't get out of bed. To try and ease her suffering (at Sue's request), we bought all manner of juices that Sue could swill around her mouth: pear juice, apple juice, pressed orange juice, tonic water, blueberry juice, squash, lots of ice cubes and even champagne – something that Sue didn't normally drink. This frothed a bit, though which didn't help.

Darcey (and Pixie) went for walks. Lots of walks. Sometimes we went together. Darcey and I read. Lots. Including (me) "Gulag: A History" by Anne Applebaum that I found in a second-hand bookshop in Wigtown. Not exactly light relief. We argued too, although thankfully this was and is an extremely rare occurrence. It was a very stressful time for both of us.

I made a few notes:

Day 1 - no change in condition

Day 2 - no real change

Day 3 - stomach pains. Took a couple of ice cubes

Day 4 - lower back pain; likely just fatigue, weakness. Took an ice cube overnight. PCN called round. Prescription for laxatives and mouth spray.

Day 5 - psychiatrist to confirm Sue isn't insane and is of sound mind. Check for psychosis, depression, cognitive function. Verbally – most compelling case for end of life / assisted dying that they'd ever come across in their whole career. They had not had a case like it. Ever.

Day 6 - no change; weaker.

Day 7 - weaker. No pain. Eyesight worse.

Day 8 - much weaker. Nauseous. Can't swallow. Very sleepy. But couldn't / didn't sleep

Day 9 - much weaker. Legs wobbly. Blistering lips. Lying down a lot more.

Day 10 - weakness continues. Nauseous. Lying down a lot. Wind. Uncomfortable.

Day 11 - Sue spent most of the day in bed. Can't sleep despite being tired. Thirsty.

Day 12 - no change in Sue's condition. Very weak. Can't stand for long. Maybe 2mins.

Day 13 - much, much weaker. Still suffering from insomnia.

Day 14 - can't breathe through nose. Shallow breathing. Jaw muscles too weak to chew gum. Feet painful - cold.

Day 15 - Sue can hardly talk. Rasping in her breathing.

As time wore on, Darcey was becoming more and more tired. Sue will also have been knackered, but she *couldn't/didn't sleep* the whole time, and Darcey was getting less and less sleep. I 'helped' with the care over the last few days. It was difficult, with Darcey getting more and more frustrated, because she couldn't understand what Sue wanted. Sue was no longer intelligible, her speech become more and more slurred. We created and went through a list of what Sue might be wanting. For days and nights we could hear Sue emitting soft moans but there was nothing we could do. A few occasions we had to lift Sue back onto her bed because we found her on the floor. Sue was so weak, we don't really know how she got there. This did lead to us putting cushions adjacent to any hard furniture to ensure Sue didn't clatter herself when falling out of bed.

Day 16 - Darcey can't understand what Sue wants anymore. No sleep. Really frustrated. Sue tells D she's bored. Darcey phoned stand-in PCN, (Author's note: The PCN had who had been allocated to Sue had gone on annual leave without letting us know). Who was legally unable to answer if nutrients are absorbed from fluids flushed around her mouth. Sue had fallen out of bed. Helped Darcey lift her back in. Painfully thin. Losing her sight and going deaf. Radio on a lot louder than it used to be.

Day 17 - Sue fell out of bed last night. Twice. Darcey & I lifted her back in. Darcey dabbed her lips with apple juice. Painfully thin. Fell out of bed again 10:40. Fell out of bed again around 15:00.

Day 18 - just after 00:00 checked in on Sue 5x between 00:00 and 03:00. Fell out of bed about 02:30. Put her back into bed. Not so much moaning now. Woke Darcey so she could see Sue before she dies. Breathing is really shallow. Sue died this morning, having crawled onto the floor by the door. Sometime between 03:00 and 07:00. Difficult to get into the room. I swithered whether to leave Sue on the floor or to lift her onto the bed. I decided to lift her onto the bed and pull the duvet over her so Darcey would have a choice whether to see her. Having checked her pulse it still gave me a fright when she exhaled her last breath as I was lowering her onto the bed.

We had a police visit at around 20:15 on the Saturday night and they didn't leave until after 23:00. We both had to give statements and although they assured us there was nothing untoward, they made us feel like criminals. They asked what our preference would be with regards to a Post-Mortem. We didn't want one for obvious reasons. We knew that the cause of death was malnutrition and dehydration. The Procurator Fiscal went ahead with the PM anyway, with the process taking months.

As a side note, the PCN told us that they were there to provide support to Sue, Darcey and me. But we didn't hear from them again.

I phoned the local doctor's surgery to report her death…

The cause of death on the original Death Certificate was recorded as 'Unascertained' (Laboratory results awaited). Following further investigation, this cause of death has now been amended to 1a. Dehydration and malnutrition and 2. MND.

Sue was born 09 January 1961. I met her in Leeds University in 1979 where we were both members of the running club. Hopefully, some will remember her. We were together between January 1998 and July 2006. Darcey was the fruit of our relationship and they were both very close. Sue was Darcey's best friend. It's so sad that Darcey had to go through this. Sue died 18 July 2024 - a year today. It didn't seem right to say anything then. She saved my life once, but neither Darcey nor I could save hers. She was a very brave woman. RIP Sue XXX.

(Photo taken 11 July 2021)

*Postscript:*

I wrote this because the Scottish Parliament are voting amendments to the Assisted Dying Bill later this year. I wonder how many MSPs voting on this really have experienced this first-hand?

I wrote this because I wanted to point out that Sue was very, very brave. As many people will know she was very single minded and this trait in her will have helped her towards the end.

I wrote this because we see people every day and never know what people are going through in their lives.

As an aside, I just wanted to say a big thank you to everyone who has provided an ear or shoulder for me and Darcey over the past year. On a work front, with everything else that is (still) going on, my Clients have been really supportive with my work load.

And finally, some would say I was left with a poisoned chalice. I am the Executor of Sue's Will.