

Ann Dellar's story

As told to her sons by her husband, Owen.

It was 2005. Ann and I were in Scotland celebrating our Golden Wedding Anniversary. It should have been a much happier occasion, but something wasn't quite right. I couldn't put my finger on it, but Ann seemed somehow *different*.

The initial changes would only have been apparent to someone very close. Ann seemed happy enough but in some strange way not really "with me". This initial pattern of slight changes progressed for another year and by late 2006 it was obvious to most people that Ann was not herself.

We were spending Christmas with one of our sons and his wife and at this point, I thought Ann was heading for a full nervous breakdown. I was familiar with the signs as there had been other major depressive episodes in Ann's life. However, this time things were different. She kept discussing the details of her tragic family history, which decades previously had involved several suicides. An uncharacteristic and inappropriate directness had also crept into Ann's conversation, making for some embarrassing conversation-stoppers with friends and even strangers.

Naturally, the grandchildren were very upset and kept asking, "What's the matter with Nanny?" but there was no answer for them, because we didn't know. Ann seemed to have many of the classic signs of depression but there was also a resurgence of an addictive behaviour pattern relating to the use of sleeping pills, unseen since her first breakdown some forty years prior.

From about the age of 30, Ann had been a committed Christian and had clung very strongly to all the values normally associated with her faith. How strange then, that she should suddenly become blunt to the point of rudeness and, even more distressingly, quite dishonest regarding her compliance with antidepressants and use of sleeping pills.

All these signs continued to become more acute, resulting in some uncharacteristic and occasionally quite hurtful manifestations of selfishness. As Ann's husband, I had a terrible foreboding that something was seriously the matter.

On an emotional level, nothing seemed quite good enough for Ann but now, some physical signs also began to appear. Ann was complaining of trouble with her eyesight, but after two new prescriptions her vision was still not adequately corrected. She also began to find her dentures uncomfortable and would frequently leave them out – something she would never previously have done.

Ann had always been highly creative, but from this point on she simply gave up reading, writing, sewing, embroidery and all her other creative hobbies. All she seemed to want to do was lie on the settee. This once very smart, well-dressed and beautiful woman now seemed to have stopped caring about herself.

Ann's balance became poor, resulting in numerous rather nasty falls. She would usually tumble forwards and on five occasions these falls caused head wounds that needed suturing at A&E. At other times, Ann would fall off the settee from a lying position, having tried to reach something only a few inches away on the coffee table.

The medical diagnoses on these A&E visits would have been laughable had the situation not been quite so serious. The attending physicians suggested everything from mini-strokes via concussion to a minor heart attack. By now, the whole family was beginning to feel that Ann's condition must have a name, but that something had been overlooked.

As things progressed, Ann began to socially isolate herself; first from normal acquaintances, then from friends we had known for decades and ultimately from close family members. I was unaware of this until I started running into old friends around town. I would comment that we hadn't seen them in ages, only to be informed that Ann had told them not to call any more. Consistent with her dishonesty over medications, this had been done out of my earshot. Without realising it, Ann was starting to isolate both of us. In late 2008, our youngest son revealed he had not heard his mother on the telephone in over 18 months. Our eldest son was among those quietly asked not to call round.

At some point when discussing Ann with the boys, the suggestion of a neurologist had been raised. Sensing Ann's condition might need urgent attention, I arranged for her to see a private consultant. On her first visit to this neurologist, Ann was diagnosed with Parkinson's disease. This came as something of a shock, although it was a relief to finally have a name for Ann's condition. Or so we thought.

Following the Parkinson's diagnosis, Ann and I got into the habit of taking regular exercise. We would usually walk about a mile or so but, as time wore on, Ann would make excuses to go shorter and shorter distances. Our walks diminished to 200-300 yards at a time and then stopped altogether. Throughout this time, Ann's balance was deteriorating and in the end I had to support her all the way.

As time progressed, Ann seemed to lose all her energy and drive and her appetite became very poor. By 2009, her estimated daily intake was barely 500-600 calories. Breakfast would be a half-slice of toast with no crusts and maybe a very small bowl of porridge. Lunch might comprise half a potato, a dessertspoonful of meat and a further dessertspoonful of vegetables followed by a *single* grape. Her evening meal might include half a very small tin of baked beans and a cup of tea.

On this meagre diet, Ann's weight loss accelerated and she quickly dropped from what had been a healthy weight of about 10 stone to around seven stone (44.5 kg). This became yet more acute when she also began having chewing and swallowing difficulties.

Despite ongoing prescriptions for sleeping pills, Ann's sleep pattern deteriorated. She also became worried about incontinence and would wake me six or more

times in the middle of the night. This rose to 12 times as the condition worsened, or once every 40 minutes! Although the feared incontinence did not become a reality until some while later, this stage was totally exhausting. Already in my late 70s, the resulting sleep deprivation became a major problem for me. I would trail around like a living ghost, going out for things from the supermarket and hoping Ann would not have another fall whilst I was gone. Frustratingly, through all this, Ann seemed completely unaware and continued to make great demands on me with no apparent realisation that I was on the point of collapse.

Ann was probably more bothered by her incontinence than I was. I have never been squeamish about such things and we had been utterly devoted to each other all our lives, so I was happy to take care of her in this way. Nevertheless, having now cared for Ann alone for four years, I finally reached the point where my legs quite literally buckled underneath me. I just could not go on, so there was no option but to call social services.

One might be forgiven for thinking that this is where things immediately began to improve. Regrettably, there were to be many more months of professional vacillation and box-ticking before permanent care was put in place. Ann was finally admitted to a care home on 16th March 2009. This place was fifteen miles from our home and initially seemed alright. However, it soon became evident that its standard of care was, in the words of its official inspection report, merely “adequate”.

Ann’s muscles were now extremely rigid and, given the state of her incapacity, it was glaringly obvious that the nursing care which should have been provided from the outset was now imperative. Even so, there was to be one further battle with a particularly stubborn social worker. This lady cited every excuse in the book to try and preserve Cornwall’s social security budget. Perhaps her most worrying suggestion was that Ann’s condition was “behavioural”; in other words, psychosomatic. I was appalled at how this unqualified “diagnosis” was allowed to slow things down. Thankfully, events overtook us.

In late November of 2009, following a most uncharacteristic and rather violent outburst against one of the care home staff by Ann, she was admitted to Treiske Hospital. Her bed was at the furthest reaches of the building in a room right at the end of the ward. The care here was not good and staff seemed to spend most of their time wandering aimlessly about or gathering in huddles for meetings. When somebody was available to speak to, there was little or no information about Ann’s condition to be had. A further string of hopeless misdiagnoses followed, nibbling at the edges of Parkinson’s disease and resulting in a continuation of ineffective medication against that.

Ann’s voice started to become very weak so that people could barely discern what she was saying. I tried using a microphone amplifier, but in the end this too became useless.

On Christmas Eve 2009, Ann was moved to Camborne-Redruth Community Hospital, where she remained until late March 2010. After a couple of months on a ward, she was diagnosed with PSP by the Parkinson’s specialist there. For some

reason, we were not informed of this change in diagnosis until much later. Still, for about a week at the very end, we finally had a name, and thus a reason, for Ann's condition.

One unintentional benefit of all the moving between hospitals was that Ann was finally allocated a different social worker. This lady was wonderful and quickly appreciated that Ann had to have the proper, full-time nursing care for which her family had been pleading all along.

This second social worker obviously understood the limitations of her own field in regard to medical diagnoses and was wise enough to arrange a proper nursing home place for Ann. The difference in Ann's care from this point on was incredible. Suddenly, she was surrounded by trained and qualified nurses who knew exactly what they were dealing with. She was checked every twenty minutes and made as comfortable as possible.

Three or four weeks from the end, Ann's joints became very rigid and painful. Her hands, mostly on the left side, became clenched and it was painful to try and unfold them. Her legs (mostly right side) were twisted into a foetal position.

Ann passed away quietly in her nursing home on 2nd May 2010 surrounded by her husband and two sons. She weighed barely five stone (31.7 kg) when she died. It is perhaps worth noting that, despite all her other symptoms, she never lost her mental acuity.

Perhaps this is the place to sum up Ann's medical care over the years where her condition was really a problem:

- GP – treated Ann for depression and doled out sleeping pills. No suggestion of a brain scan or referral.
- Consultant neurologist – this expert in his field diagnosed Ann with “a mild form of Parkinson's”(!)
- Psychiatrist – treated Ann as though for depression and commented that, “Medication can only do so much. The rest must come from Ann”
- GPSI (GP with Special Interest) – placed Ann on hormone replacement therapy.

Ann was also seen by:

- Community Psychiatric Nurse
- Community Nurse
- Falls Expert
- Occupational Therapist
- Physiotherapist
- Carer Support Officer
- Community Care Officer

- Two social workers (as mentioned above)

In the majority of instances, the input of these people seemed to consist of a great deal of “box-ticking” and expansive talk, but very little action. **Despite a six-year battle with this ghastly disease, Ann’s final correct diagnosis of PSP was set only weeks before she died.** For reasons unknown, her family only got to hear of it in her final few days and then only from the nursing home staff. No doctor or specialist ever spoke to us directly about what was the matter.

Signs as noted by Ann's family

- Sleeping problems even with sleeping pills
- Frequent night-time visits to the toilet (6-12 times)
- Uncharacteristic lack of tact in the most inappropriate circumstances
- Never satisfied
- Noticeable selfishness
- Visual disturbances
- Social isolation
- Loss of interests, hobbies etc.
- Loss of energy
- Loss of appetite
- Frequent falling
- Feeble voice
- Mental acuity unimpaired