Carol and Malcolm Ferry at home in Portstewart.

Surgery has 'given me my life back'

At the age of 36, with three children under 10, Carol Ferry was diagnosed with Parkinson's Disease. Over the next 20 years, her condition deteriorated until, in May 2022, she underwent Deep Brain Stimulation, a surgery that would literally give her her life back. Carol and her husband, the Rev Malcolm Ferry, rector of Agherton, share their inspirational story.

The first symptom of her illness, Carol recalls, was a finger which kept moving involuntarily. Other early symptoms included walking with a shuffle and dropping things. At this stage, Malcolm was rector of All Saints', Craigyhill, and the family was living in Larne. Initially this was thought to be an 'essential tremor,' a condition which causes the sufferer to shake. The family had moved to Castlerock when Carol got her Parkinson's diagnosis.

"It was the last day of school when we were called to Belfast City Hospital," Malcolm recalls. "I had picked the kids up and we all travelled to Belfast, where they confirmed that Carol had Parkinson's. After the news, we had to drive home with the children in the back seat not knowing their mum had just received devastating news."

As a family they tried to continue life as normal and went to Summer Madness with a group of teenagers from Castlerock. They went on holiday. "We knew there would be no fix," Malcolm says. Carol experienced a slow decline. "It is chronic and degenerative, but at what rate we didn't know," Malcolm adds.

"We kept living life so the children would think it was all normal, even after telling them of the diagnosis of Parkinson's. Carol continued to work as a pharmacist for a number of years. She participated fully in all their big days through our careful planning and managing the situation as best we could."

Carol nods. "We tried not to let Parkinson's get in the way." Malcolm agrees: "If Parkinson's was going to take one of us, it could not take all of us. We saw it as a guest that was present in our home - sometimes very amenable sitting in the corner of the room, and at other times right in the middle of the sofa, or at the kitchen table."

Carol experienced stiffness, rigidity and dystonia (muscle spasms). Things were becoming more difficult. She could not do long journeys easily or be out late in the evenings. Many of the symptoms were due to her medication. "She was on a cocktail of drugs that were working to maintain her, but it was a constant struggle. At the same time, our lives were going on at 150 miles per hour," Malcolm recalls.

He remembers plaiting the girls' hair because Carol had lost her motor skills. "A mother has her role, but when a mother is taken out because of illness, what can you do but fill in as best you can."

The family set about resolving this by making a point of ensuring there was always a role for Carol. "We did our best to find the things that she could do and find alternative way of parenting three young children," Malcolm recalls.

Their children are now grown up. James, 29, is a talent acquisition manager in Manchester having completed a Degree at Chester University. Sarah, 27, has a First Class Degree in Natural Science from Cambridge - her Dissertation was on stem cell research into Parkinson's. She now lives in London. Twenty four-year-old Rebekah, after doing a Degree in Loughborough, is completing her professional examinations as an actuary, also in London. Malcolm and Carol are very proud of their children.

"We sit back and, like the Stephen Hawkins' character in the movie of his life when he is watching his children play, we say 'Look what we made,'" says Malcolm.

Carol was aware many years ago that Deep Brain Stimulation was an option, having seen the difference it had made to a friend who had Parkinson's.

"I would not have considered it when the children were still at home," she says. Malcolm adds: "We were not taking a drill to Carol's head when the kids were still young in case anything went wrong."

Carol was struggling with different medical cocktails when her consultant in Belfast suggested she might be a candidate for Deep Brain Stimulation. She completed all the tests, including physical and psychological tests, and had to stop all her current medication - effectively going cold turkey for the tests. These were completed in 2019. But then Covid hit.

By the time the pandemic restrictions had lifted, Carol had to go through all the tests a second time before she could go to the London National Hospital for Neurology and Neurosurgery for the operation. Carried out in May 2022, it took nine hours.

"After the operation I struggled with the simplest of tasks, but after a couple of days my brain started to recover," Carol recalls.

She has two rods inserted permanently in her brain. A wire runs from these under the skin, behind her ear to a small box, again under her skin. This box sends electronic signals to her brain.

Carol Ferry demonstrates the remote control she uses to stimulate the brain when needed.

"That box replaced the big bag of meds," Malcolm says. "If Parkinson's symptoms change, we can sort it with the remote control which is connected to the brain stimulator."

The handheld remote shows the amount of stimulation being applied to each side Carol's brain. Carol and Malcolm can use this to alter the stimulation levels. "The big benefit is that before this, if Carol had a trailing leg, we would have to go to the doctor to alter the medication which could take weeks. Now, we can alter it immediately at home," Malcolm explains.

"If we turned off the stimulator, we would not do any harm, but Carol would go back into full Parkinson's."

Every Saturday, Carol uses a portable charger to recharge the box on her chest through her skin and this takes about 40 minutes.

Carol and Malcolm outside the National Hospital for Neurology and Neurosurgery, London, just before she was admitted for the Deep Brain Stimulation surgery in May 2022.

"Everybody who knows Carol prior to the operation and has seen her since cannot believe it," Malcolm says. "Before, we didn't make plans because we didn't know how Carol would be on any given day. Now we will accept any social invitation!"

Carol adds: "I see so many more hours in the day. Before, it took me so long do simple things."

Parkinson's meant Carol had to give up driving. Since surgery, she is now driving again, giving her back her independence. Malcolm smiles: "We are living again. We can go for a walk on the promenade, meet friends and be out for coffee until 10pm!"

In terms of the surgery, it wasn't all smooth sailing. "We did have some serious setbacks, recovery took a lot longer. We had to go back to London and into surgery three times," Malcolm explains. These setbacks included infections, and a very real chance the rods - which were already making such a huge difference to Carol's life - might have to be taken out. Now, she just has to return for an annual check-up.

After the initial surgery, there was a period of adjusting the stimulation to get the rods to work effectively. Carol admits it was a year and a half before she felt confident. Now, she says: "It has given me my life back."

Over the years, the family has been fully supported by their parishes, who all ensured rectories had disabled access and facilities suitable for Carol to live as normally as possible.

Prayer played a big part, Malcolm says. "Carol is a scientist so we didn't pray for healing. We could not deny the science of Parkinson's Disease. We prayed for the courage to keep going. At no point did we ever feel helpless - every time there was another hurdle, we focused on clearing it.

"We got a sense that we were carried in prayer. Everybody did whatever they could to help us. We felt very much a part of the parish family and very supported by our own family and friends."

Carol says the treatment is not a cure for Parkinson's, but is an alternative treatment for some of the symptoms of the disease. "No two people have the same symptoms and for me it was the side effects of the drugs that was the main problem causing dyskinesia [involuntary movements]," she explains. "It has made such a difference to me after 20 years of gradual decline. I am back to driving, using my exercise bicycle, doing yoga and going out with friends. I have a renewed quality of life."

On May 5, Malcolm and Carol's family took part in the Belfast Marathon, raising over £9,000 (including gift aid) for Parkinson's UK. Their niece Vicky ran the full marathon, while their daughters Sarah and Rebekah, along with El, fiancé of their son James, Sarah's fiancé Max and Vicky's boyfriend Ed did the marathon relay.

"I am so proud of my children, niece and their partners wanting to do the Belfast Marathon to raise money for research into Parkinson's," Carol says. "I want to thank everyone for their support and generosity. Together, we will find a cure."

Archdeacon Stephen McBride and the Very Rev Sean Emerson.

Archdeacon speaks at Novena in Antrim

On May 22, the Ven Dr Stephen McBride, vicar of Antrim and Archdeacon of Connor, was the first speaker at St Comgall's and St Joseph's Novena in Antrim.

He first preached in St Comgall's in 2004 and said he was delighted to be invited to take part in the parish's latest Novena.

Archdeacon McBride and the Very Rev Sean Emerson, parish administrator, first worked together in 1990 when Stephen was rector of St Peter's Parish in Belfast and Sean was parish priest in the Holy Family group of parishes.

In his address to this year's Novena, Archdeacon McBride gave a resume of all progress that has been made in Antrim over the past 20 years through the input and encouragement of the local churches.

He said that he was delighted with the warmth of the welcome he received from the parishioners at the Novena.

Congratulations to 'Trudy and her tea ladies' from Christ Church Parish, Derriaghy, who were the winners in the community caterer category of the inaugural Funeral Awards NI held in the Crown Plaza Hotel on May 24. Attending the awards on behalf of the parish funeral team were, from left: Penny Jarvis, Mildred Leathem, Trudy Hull, Barbara Morrison and Margaret McCullough.