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Struggling with Dementia

The worst day of Mary Donovan's life was when her mother didn't recognise her. Mary, the only daughter of Doreen and Tom Howe, was close to her mother and saw her almost every day. They sang in the choir together, went out for coffee regularly and enjoyed time with Mary's children and grandchildren. The day Doreen didn't know her, Mary cried.

But Doreen had dementia, a disease that destroys the brain. Doreen was the matriarch of the Howe's and being a close-knit family the children took the journey with her through the different stages of the debilitating disease. It was a journey of family, faith and music.

Doreen Bennett was born in 1924 in rural Cygnet, Tasmania, and was taught by the nuns at the local convent. While she was working in an office in Launceston she met soldier Tom Howe. Their love for one another blossomed and the young couple married in 1947. Doreen and Tom moved to the Hobart suburb of New Town and over the next few years, Doreen became the loving mother of Michael, Bernard, Tony, Mary, Vincent (Vin), Francis and Chris. Another girl, Catherine, was born but died after only one day.

After he left the army, Tom worked in a variety of jobs to support his growing family. His day jobs included clerical and store work, while at night he supplemented the family income by playing the piano and piano accordion in local dance bands. It was a musical family. Doreen also played the piano and their children sang and played musical instruments.

On Sundays, Tom played the organ at St Mary's

Cathedral and Doreen was involved at the local Sacred Heart parish. "The church was at the very core of her being," says son Vin. It became a shared activity of the whole clan, with Doreen helping to prepare the liturgy, singing in and organising the choir, and her sons either serving on the altar or playing guitars and singing in the choir. The entire family was always busy with various church activities.

Tom's brother was a priest and two of his sisters were nuns, so the family home in New Town often hosted visiting clergy. Meals were prepared, beds provided and clothes were mended. In Tony's eyes, his mother treated the priests almost 'as gods', so well did she look after them!

Vin remembers fondly the close interactions with his mother around the kitchen and the dining table. His mother seemed to be constantly cooking with a magic pot that could cater for the nutritional needs of everyone who came through the front door. It was a door that was never locked. Even the archbishop was a regular visitor.

Doreen worked outside the home too. She was secretary to the Director of Catholic Mission in the diocese for more than 20 years, until she retired at the ripe old age of 77.

A few years before Tom died, and with his health declining, Doreen was worried about how she would manage, so Vin, his wife Ingrid, and their children decided to return to the family home. After Tom died, Doreen continued to live there in a self-contained section of the home. It was an arrangement that worked well for one and all. Doreen had company and support, but retained

her independence. She had her church, her friends, the Orpheus choir, her art classes and she was still the strong matriarch who liked to know what the extended family was doing.

It was also beneficial for Vin's three children who had nan living under the same roof. They could sneak in to see her and snuggle up in her bed, as she handed out treats and told stories from long past.

A few years before her death in 2013, her children noticed things were changing. When Doreen turned 80, Ingrid, realised some of her mother-in-law's 'sparkle' had disappeared. The symptoms came and went, so those who saw Doreen less often didn't realise how bad things were, but the decline was slow and steady.

When her sister-in-law Josie died suddenly, Doreen said to Mary, "I'm depressed. I'm mad at Josie because she shouldn't have left me like this." Yet this was a person who had never known depression. When Mary picked Doreen up for their weekly choir practice, she'd sometimes say, "I don't think I'll bother tonight." Yet this was a person who had always been a regular attendee at choir practice.

Also, Doreen began to recite poems from her childhood out of the blue. She would forget things and was confused about time: she couldn't operate appliances and was fearful of electricity. She would wrap up presents, then undo them and wrap them again. She couldn't remember making arrangements and sometimes asked three different people to take her to Mass. Ingrid recalls Doreen dressing for Mass in the middle of the night.

The family had discussions with Doreen to talk about her possible future needs. Doreen helped make the necessary practical decisions and then in 2009 came the diagnosis. She had dementia with Lewy Body disease which causes the degeneration and death of nerve cells in the brain. "Don't let me wander the street in my nightie," she begged. At this stage the family rallied round to implement what had been pre-planned.

At first, overnight care fell largely to her daughter-in-law, Ingrid, who found in some ways it was harder than looking after a child. "I was trying to

balance dignity and respect for my mother-in-law with having to do quite intimate things for her and help organise her life, but she was always kind and grateful. It's very hard to watch someone so lively and independent declining," she says.

As the disease progressed, Doreen spent some time during the day in respite care. But later, and for her own safety, it was decided that she should be admitted to a nursing home full time. There were times when Doreen had hallucinations, bushes on fire or people in her bed, possibly as a result of the medications she was on and her illness. She sometimes confused the nursing home for her own home and wasn't always sure who people were. And she complained that for much of the time she didn't like being in the home, especially the secure unit.

Doreen's social skills, however, never abandoned her. According to Vincent, she greeted visitors, especially her great grandchildren, with looks of sheer delight and could "engage with her eyes even when she couldn't speak".

The family used their musical skills to bring some joy to their mother. When Vincent took his guitar in, he says she 'came alive'. Music and faith remained with her until the end. Her family arranged for one of her favourite priests to provide the last rites. At the concelebrated Mass of Christian Burial her beloved Orpheus Choir, including her daughter, Mary, sang her out of the church with *The Blessing Song* by Rutter while at the graveside, one of her sons, Francis, played the bagpipes.

Each of the Howe siblings did their best to care for the special, gentle person for whom they all had a special love and deep affection. With her passing they lost their 'central focus', the woman who had united them throughout their lives, with meals, celebrations and family get togethers. Mary felt really lost when Christmas couldn't be celebrated the 'familiar way', with Doreen presiding over the festive table. Although the extended family still meets on the weekend after Christmas each year, Mary laments, "We still are lost (without mum)."

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