



In support of Dying Matters Week 2020 'Dying to be heard', Mary shared her experience on having those tender conversations with her loved ones as they prepared for their final journey.

Mary's Story – 'It starts by listening'.

Mary has had the 'death conversation' three times. First with her father after his stage 4 cancer diagnosis. A second time with her late husband, James, following his Motor Neurone diagnosis in 2016. A third time with her siblings about her own death. It was having the conversation on the first two occasions that convinced her it was the right thing to do for her family.

Shortly after her mother's death her father was diagnosed with lung cancer, it was stage 4 and terminal. She describes how her father took the news, *'He took it really bad in the beginning. And then after a while he asked me to listen to how he wanted things done. He didn't want treatment and wanted the same as my mother when he was gone. The one thing he did say was that he didn't want to be alone. After that he didn't want it mentioned again.'*

Understanding his choices Mary told the rest of the family. From that point onwards they organised a rota to ensure that their Dad was never on his own. Mary's father died and his family carried out his wishes taking comfort in knowing it was the last thing they could do for him.

Unfortunately for Mary this experience was to prepare her for having the same conversation with her beloved James after he was diagnosed with Motor Neurone Disease. Having no children, it was Mary and James for 52 years, 47 of which they were married. James was a quiet man who spoke wisely and always from the heart. Describing them as 'two peas in a pod' Mary remembers how they could sit for hours, James in his chair and her in hers, without a word being said. So connected to each other they didn't need words to communicate.

Recounting how and when they were told James had MND she remembers how it was their faith in God that helped them through those first few days. Acknowledging it was in God's hands now James asked Mary to help him make plans for the time he had left. Completing the MND forms and information for Altnagelvin they discussed how he wanted to be cared for and what his wishes were around resuscitation. Mary remembers how she struggled with this part of the conversation and how James was resolute in his decision not to be resuscitated if the situation arose.

Together they planned that his funeral would take place in Ballymac and not the Long Tower because *'it had a bigger carpark'*, James was so practical. Between conversations with family James was able to choose his gravesite in the cemetery. In the older part of the City Cemetery overlooking the Brandywell Stadium beside Mary's parents and where Mary will come to rest beside him in time. He instructed Mary what personal items he wanted to go to who. James,



COMPASSIONATE COMMUNITIES

in keeping with his reserved nature wanted no fuss at his funeral, no hotel just 'back to the house'.

The 18 months that were follow were precious time for Mary and James. His primary caregiver Mary undertook her role to preserve James' dignity and ensured she carried out his every wish. As his condition accelerated and the stairs to their bedroom became impossible a hospital bed was moved into the spare room downstairs. Their gradual separation had begun, it was very difficult. Mary remembers how neither of them slept that night. The next day James said he didn't want to die in bed and from that point onwards they both slept in the living room, James in the recliner and Mary on the sofa.

Mary, with the help of their neighbour cared for James at home up until his admission to hospital. His stay here was to be brief, Mary knew he would never return to their home. She maintained a vigil by his bedside for 5 days. Mary remembers when she briefly left his room, when she returned, she looked into his eyes and answered the question he asked without saying a word. Mary reassured him 'Don't you worry about me I'll be alright'. With that James closed his eyes and died, he had needed to know that Mary would be ok when he was gone.

The next year was difficult for Mary as she adjusted to life without James. She remembers how family support got her th

rough the dark days. She spent the year living in her sister's house, the spare room is still referred to as 'Mary's Room'. Her sister's house in Creggan is close to the cementary where she visited James's grave three times daily initially. Mary was referred to Cruse for bereavement counselling which she found immensely useful. It helped her deal with her feelings of loss. As time went on and in her own time Mary acknowledged that she had to move on and she moved back into her home

Back at home Mary put her own plans for death in place with the help of her brother who was assigned as her power of attorney. With her 'house in order' she is confident that her final wishes will be honoured and that her death will be less stressful for her family.

Mary acknowledges that she is still grieving the loss of James but takes comfort in talking to him daily and holding his memory in her heart.

*We sincerely thank Mary for her courage in sharing her personal story with us. As Mary told us,
'If I can help someone by telling my story then that's a good thing'.*