

Caring for Mum has made me love her even more

There are 50,000 family carers for people with dementia in Ireland. Here, one dedicated daughter shares her story



Special bond: Katie with her mum, Loretta

EVERY night it's the same routine. I coax her into her night-clothes, help her brush her teeth and tuck her in. I kiss her gently on the forehead and tell her I love her. She looks so small in her soft blue pyjamas.

Alzheimer's is a disease of loss that robbed my mother not just of her

By KATIE MORAN

memory, but of her personhood. Little by little she lost what made her unique — her intellect, her creativity, her voice. However, it is also very much a disease of loss for those who care for a loved one with the illness and are forced to watch as they vanish before their eyes. The

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hammering impact of it comes not at diagnosis, but as the disease progresses and the person comes crumbling down. It crashed into our lives when I was just 18 years old and my beautiful, artistic mother Loretta was 54. Now, five years on, almost everything is lost to her except for us.

The first time I noticed something was not right was six years ago during a family trip to Hong Kong. Each day, mum would get lost on her way from our room to the lift, despite the fact that it was just two doors down.

BACK home in Stillorgan, South Dublin, she began to frequently lose her way while driving, or we would open our school bags and realise she had forgotten to pack our lunches again. She would speak about her father as if he were still living, and muddle up names and situations.

It was clear her long-term memory was far sharper than her short-term one and that something was diminishing in her, but as Mum was only in her early 50s we didn't think about Alzheimer's and put it all down to anxiety.

I started college and was studying psychology when the spectre of this condition first raised its head. My stomach would sink as I read about the condition and its symptoms.

One afternoon at college I learnt that people with Alzheimer's had difficulty drawing shapes. I went home that evening determined to investigate and asked Mum if she would draw a star for me.

She was so artistic and creative that it seemed a ridiculously simplistic task, but I watched in bewilderment as she took the pen, and drew disconnected lines on different corners of the page. She just could not fathom how to join the lines up to create a shape. This is when I knew something was seriously wrong.

I brought her to the GP and this marked the beginning of several tortuous months of testing until we arrived at her diagnosis.

We were a young family and this came out of nowhere. I was just 18, my youngest sister was 14, my brother was 16 and Dad was 57. That summer changed our lives.

At the time I tried to deal with it by researching the condition and keeping my findings in special notebooks with

everything I could possibly learn about dementia. The task of keeping her alive and well for as long as possible was what I focused on to cope with the devastation of her diagnosis.

The real impact of the disease didn't hit me until further down the line and it continues to do so at every milestone moment in my life. It's the irrevocability of it, that's the hardest part.

As early-onset Alzheimer's tends to progress much faster than those who develop the condition in later life, in the five years since her diagnosis Mum has changed utterly. I was frightened for her when she was diagnosed, but also for myself and my siblings.

However, I have since learnt that the possibility of us also developing the condition is extremely remote and I have accepted that worrying about it won't change it.

Mum did her best to keep up with her treasured art and yoga classes for a while but soon had to stop. She also had to give up driving, which was very sad. But she still did everything she could to be there for us. Even after her

diagnosis, she surprised me on the day of my Debs by hanging a big photo collage of my milestone life moments on the wall and accompanying me to the event.

Most nights I bring Mum to the bathroom and change her clothes for bed, tuck her in, kiss her on her forehead and lay down beside her. She is wearied from a day spent traversing unfamiliar territory. Despite our role reversal, I still cuddle up to her like a child, her child.

With the break of day come new challenges. She needs to be bathed, clothed and fed. Her morning temperament often swings from bright and cheerful to frightened and anxious. To assuage her we play her favourite music, trying always to help her reminisce. We sing, whistle and dance, and in those moments she is happy. So we are happy.

I have so many fond memories of my mum when I was growing up and I make a conscious effort all the time to remember her the way she was. The first time she brought me to see the band Five in concert or the look of pride on her face watching me play tennis matches, just knowing that she was always there, always full of pride and love.

To this day, I know Mum still cares about us so much. Her love is innate. She lights up when we walk into the room, and she is so full of hugs and kisses.

My mum is my favourite person. And I think perhaps this has been the biggest impact of caring on me. My love and respect for her strength has expanded beyond comprehen-

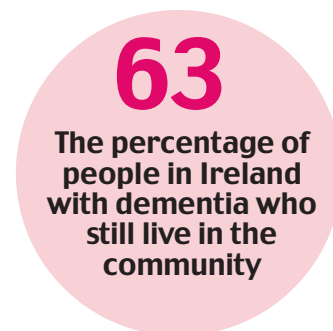


on. We have shared so many wonderful memories, and now my task is to remember them for both of us. I will become her memory and these special moments can live on in me. I can't think of anything good to say about Alzheimer's but there are endlessly good things to say about those who live with it every day. Caring for her is a challenge and at times it can be an inexorably lonely task. We are lucky to be a family of five — I live at home, along with Dad and my siblings — and we cope as best we can with the help of wonderful professional carers who assist during the day. At the beginning, when it was just us, it was extremely hard. I cannot begin to imagine what it must be like being a sole carer.

THERE are thousands of people out there caring for people with dementia on their own every day. They are often elderly people, isolated and without a support network. These people are invisible and need support from the Government and society in general. It pains me that people turn away from Alzheimer's, that there is still this stigma attached to the disease. It is because of this support network that we have been able to keep Mum at home for so long, despite her current advanced state. We plan to keep her here, where she is happiest and in a familiar environment, as long as we possibly can. But our lives are different now. We navigate our days according to schedules and "evenings off". We balance work, study and social lives with a care commitment. Mum can't be left alone for one minute and she can no longer do

anything for herself, from eating to washing. Her limited speech makes it difficult to anticipate her needs. She has occasional moments of realisation too, and nothing makes me sadder than seeing her tears and that look of momentary recognition of what's happening to her. In these moments, we hug her and return her words: 'I love you, you're beautiful. I love you.' This meditative mantra lulls her to sleep. I cherish these peaceful moments. Her words remind me of a mothering instinct not yet lost to Alzheimer's. There is nothing left unsaid between my mother and I and that is the boon that steadies us as we face the future together. Now I play the role of parent and she is the child but it's on those occasions when I see a look

of realisation on her face that I feel the most sadness, when I know she is scared. So I lay down next to her and comfort her as best I can and tell her I love her, and that everything will be all right. ■ *KATIE MORAN is taking part in the Alzheimer Society of Ireland's Impact of Caring campaign, which is running this month to raise awareness of the plight of the 50,000 family carers of people with dementia in this country. For more information or to get involved, see alzheimer.ie. If you have been affected by the content of this article please contact the ASI National Helpline on 1800 341 341, open Monday to Friday, 10am-5pm, and Saturday, 10am-4pm*



Distant
memories:
Loretta and
baby Katie
in 1992



Health



Mum can't be left by herself for one minute

