When Dementia Comes Home

Perspective from a Daughter/Dementia Professional

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I leaned over and kissed mum goodbye, I tasted the salty tear that had made its way down her face, and my heart sank. Damn you brain, damn you! Why can you still create emotions and make mum feel pain, insecurity, and distress but you can't let her recognize my face and help her say my name? Damn you brain, damn you!

Everything about my mother is every bit my mother. She's still inside, she just can't decipher what's going on, she can't make sense of her world. She looks the same, wears the same clothes, smells the same, and her hand feels just as soft. She just grips a lot harder when we walk together. When I sit next to her I can still put my head on her shoulder and she still puts her cheek on my head. I close my eyes and can imagine it's just as it was, just for a few seconds. Then she tries to speak and nothing makes sense, and the reality of our real world comes flooding into the room. What I wouldn't give just for her to ask me how I am, just to tell me she loves me. I suppose most of all, I just want her to tell me she is ok and that the things I have chosen for her are what she wants. Living without any affirmation or confirmation that I'm doing things right for her has probably been one of the most difficult things.

Our journey with dementia started many, many years ago. Mum is 72 now and has had a formal diagnosis for over 6 years. I had studied and taught dementia care strategies to health and social care professionals for several years before mum's diagnosis. As a nurse and community care assessor, I had also cared for lots of people with dementia, but I was in no way prepared for the emotional journey on which I was about to go. *Expert to Novice in One Diagnosis*, I think that should be the title of my book!

In the early days, I battled with family and friends who were in total denial; they thought I just looked for symptoms because of what I did for a job. Those closest to mum did acknowledge the difficulties she had at the time, but found excuse after excuse for her behavior. She's tired, she doesn't eat properly, she's surrounded by old people, she's getting old, she's lonely, she's bored, etc. She refused to accept that the things she did were down to her brain not functioning. She would miss appointments, forget what she needed from the shops, and buy toilet rolls instead. She would get in a muddle with money and worry about not having any, so she would squirrel money away in pockets, shoes, boxes, and drawers. She couldn't work her TV, then the microwave, then the cooker, then anything with a button or a screen. She couldn't work things out and found it hard to make a decision.

Mum agreed to be assessed to see if there was anything that could help her with her memory, but refused to see her GP. She said she was so ashamed that her brain didn't work and she didn't want the doctor knowing. We wrote him a letter together telling about all the things that she found hard to do. He didn't see mum or even call her, but she got a letter from the memory clinic with an appointment for an assessment. The nurse who came out did the usual assessment. She had blood tests and scans which were all normal. When she found out that her CT scan was normal she was elated. I sat there frozen, knowing that everything else had been ruled out – so that meant Alzheimers disease.

We talked with the nurse about “memory problems” and to this day no health care professional has ever mentioned the *D* word. How are we ever to challenge the stigma when we can’t even say the *D* word?!

For many months I got up at 6, went to mum’s at 6:30 to help her up and get dressed. Then I would go home to sort the children out for school, then go to work at 8:30 – to continue talking about dementia all day. Then home to cook mum’s dinner and back home to cook for the children. Back to mum’s at 9pm to help her shower and into her night clothes, then back home to see the children before they went to bed. Just enough time to do a few emails before going to bed myself. Those were the easy days – then came the real work; the introduction of care partners and admission into residential care. They meant well but they constantly rang me asking me if I realized how bad mum was. “Why is she still living alone?” “She’s at risk, how could I leave her like that?” I told them that this is what she wanted, this is where she felt safe, but somehow they just couldn’t get it. We had cameras, tracking devices, and pendants that I could talk to her through. We had sensors on the doors that sent us texts when she left the house. Having cameras and sensors meant I had to constantly watch her from afar; I lived with a constant fear of missing her going through the door, choking, or worse. The technology increased my anxiety levels immensely. I became obsessed with logging on to the camera to check and see if she was okay.

By this time, my children were 25, 17, and 13. They all loved their nan and visited her most days. They would sit with her, hold her, and reassure her. They very quickly understood what worked, how to make her smile, and how to make her feel valued and loved. That’s all it took. I had always held it together and had been able to tell the children that everything that’s happening is normal for this disease. Somehow I could never bring myself to talk about what comes next. Then one day my son just held my hand and simply said, “You know mum, its fine, because I know one day nanny won’t know who I am. Her brain won’t know but her heart will, and no matter where she is in her world, I know she will always love me.” He was 13 at the time. Why couldn’t that be enough for me? Why did I need more? The children understood her and expected nothing from her.

Everyone around me (including all the health care professionals) expected me to know what to do, to know how to react, to know how to deal with the emotions because of what I do. I lost count of how many times someone said, “It’s okay for you, you’re the expert.” I just wanted to scream at them, knowing dementia doesn’t mean that I become immune to the devastation. I might know a lot about dementia, but my mum with dementia is a whole new world. Suddenly there is no detaching, no distance, no getting away from the pain this disease brings. Reading about dementia is fine until you begin to apply it to the most important person in your life, then it’s alive and real.

My mum is in a residential home now, one that has been an answer to prayer. Such amazing caring staff who understand the disease. They work hard to create an environment of acceptance and love. We were lucky enough to allow mum to stay at home for as long as possible, but residential care did not come soon enough. Mum's diseased brain was very advanced when she went into care and she has not been able to familiarize herself with her surroundings. She was too advanced to rationalize where she was and why. This has meant that she has been unable to tell me that she is ok and that she likes it. But that's okay, because on the good days she dances, she sings, and she hugs anyone walking past – that must mean she is happy. Well, that's what I tell myself each night before I close my eyes, wondering if she's asleep, too. No camera to check now though.