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ESSAYS/PERSONAL REFLECTIONS

Supporting a loved one living with motor neurone disease

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In the present, I could only anticipate what was going to happen in the future. My mother had been my world, and I had to imagine a lifeworld without her being there for my family and I. She accepted the "givens" of being diagnosed with motor neurone disease (MND), and she was relieved to finally know what had caused her speech loss. I just want to emphasize what this loss of speech meant to her and us all at that time. That once-familiar voice was gone, communication replaced by a pen and paper in the early months and then by use of a lightwriter. We listened to Professor Stephen Hawking responding to us through the lightwriter. I missed the phone calls giving me those words of wisdom, sometimes well received, and sometimes not. She still looked the same, though she seemed to have lost those taken-for-granted facial muscles that enable us to smile, laugh, frown, gasp. Her emotions were difficult to control; sometimes she laughed inappropriately. All her life she had tried to lose weight; without effort, the weight now dropped off her because she was not able to swallow many foods. Food was pureed: though it may have tasted the same, it was unrecognizable. Within months, she had gone from a size 16 to a size 10, never more apparent than the day she opened the door to me, finding it difficult to hold her balance while holding up her oversized trousers.

Walking the walk of diagnostic reasoning. At the consultation, my mother did not ask any questions or read the information provided about MND. I was grateful that the consultant neurologist and the MND nurse did not elaborate on her prognosis. Only grateful because I wanted to keep hope alive. That discussion might have included information on how she would soon experience loss of muscles impacting on her whole body. My mother, brother, and I traveled home from the hospital in silence. I believe we were experiencing what Brown (2003) defines as "existential shock." I continually questioned why the consultant had not elaborated on how the illness would progress. I considered how he might discuss the impact of MND on the person at the next consultation. Only there would not be a next consultation. She had chosen not to be a patient at the MNDA clinic—but to receive support from the community palliative care team. I understood why she made this choice. She had sat in the waiting room at the MNDA care center observing people further on in their illness and in wheelchairs. She did not want to experience that again.

The consultant had asked that she consider having a PEG tube inserted. This was sold to her as a technique to provide quality of life. I sat in silence, thinking, "What quality of life, when she will soon be unable to move?" "How will she cope with not being able to move or communicate?" We were living on borrowed time. The day following diagnosis, my mother asked me to contact her solicitor and arrange an appointment. There was an urgency to get things sorted—for example, to complete a living will, get papers in order, and make her wishes known. When the solicitor asked about her wishes for her funeral, my mother shrugged her shoulders and pointed to me, which indicated that this decision was mine. How would I know whether I was getting that one right? I decided to have this conversation again. The solicitor spent time alone with my mother while she crafted her final will and power of attorney. She made her needs, priorities, and preferences known through the use of the lightwriter. The solicitor was so understanding of her needs; perhaps she had done this all before. We made the return journey from the solicitor in silence. Discussions about life and death with your loved one are so difficult, especially when about finiteness. Who really wants to go there? I asked the palliative care team to provide support for these

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discussions, because she needed someone outside the family to talk with. In the days that followed, as we all attempted to come to terms with the thought of a future without her, she asked me whether I would have the PEG tube inserted. I replied that I would not.

Life as before, but not as before. My mother continued to prepare family meals and to drive, but only locally. Her spatial world was shrinking. Because she could only communicate through her lightwriter, being with others was embarrassing, and so she chose not to go to the Women's Institute meetings and to only take visits from her closest friends. Her sister would visit, and together they would go to the garden center for lunch.

The PEG tube was inserted two months after the initial consultation, by which time my mother was losing the ability to communicate through her lightwriter. Her hands were so weak she could no longer type, and she could no longer mobilize. She acquired a hospital virus, was finding it difficult to hold up her head, and was having difficulty breathing. She was now in need of "continuing" healthcare. Continuing healthcare involved 24/7 nursing care. The choice was to be discharged to a nursing home or to her own home.

Our being together would never be the same again. The home we once shared for so many family gatherings had been turned into a nursing home. The bedroom had a hospital bed with an airwave mattress, a gantry hoist, and a PEG feeder. The dining table where we shared so many family meals was now a nursing station, where notes were written and handovers done. The conservatory was a storeroom for the PEG feeder, syringes, medication, and incontinence pads. The home had lost its homely smells, replaced by medical odors. End-of-life drugs were on hand, although locked away. The human rights of freedom and choice were compromised, as extended family members had to seek permission to visit. Power of attorney ensured that my brother and I could be there 24/7 if needed, and that we were consulted for all medical and financial decisions. There were times when I wanted to run as far away from this lifeworld as I could, but I still had a mother, who was trapped in her body and in her own world.

Every hour of every day, I thought about how being trapped in her body and in her own world must have felt, and so I found ways of helping others understand her needs. Not being able to move those heavy edematous limbs: hands, arms, feet, legs, body, and head, I requested that physiotherapy prescribe a passive range of movements for the nurses to do daily, to relieve those heavy limbs. People living with MND retain their senses, which are possibly even more intense than before. My mother was hypersensitive to light, and so the curtains remained closed, the room dimly lit. Her sense of smell became more acute during an early stage of her illness trajectory. She could no longer tolerate wearing perfume, or to go to the hairdresser. It was unbearable for her to experience the smell of food cooking, when she could neither eat nor drink, and to have an itch she could not scratch. The loss of dignity: not being able to toilet herself anymore or raise awareness that her pad needed changing, lying still in one position, observing others come and go, listening to them tell their stories of life outside the four walls of what was now her lifeworld: the bedroom. I introduced a communication board with all her different needs and senses. Though communicating her needs was difficult, the nurses gave her the best possible care they could. My mother's needs could be understood by searching through the sensory board, and her blinking her eyes for yes and moving her head slightly for no.

Observing existential suffering. During the final months, my mother cried continually, though her physical and psychological pain were under control. What I thought I was observing was existential suffering. She did not want the lifeworld with MND anymore. Dignity and respect were paramount in this context. The whole family, nurses, carers, and palliative care team achieved so much together. I woke early on the morning of her death and rang for the nurse on duty. She told me to get there as quickly as I could, but to be careful. The nurse who helped our mother out of this world said, "You must keep talking to her; she can still hear you." I will never forget being there at her end of life with my brother, husband, and sister-in-law, as we watched a single tear fall down her face. The sun was shining and the birds singing. Our mother had made her end-of-life journey her own. Just as midwives usher babies into the world, the nurse in charge ushered our mother out of her lifeworld, and we were by her side.

The demands of getting it right. I continually reflect on whether we got our mother's needs, priorities, and preferences right. I take comfort in the fact that she was cared for at home and died with those who loved and respected her. I wish that I had been brave enough to have had those end-of-life discussions—when she could still communicate.

REFERENCE

Brown, J. (2003). User, carer and professional experiences of care in motor neurone disease. *Primary Health Care Research & Development*, *4*, 207–217.