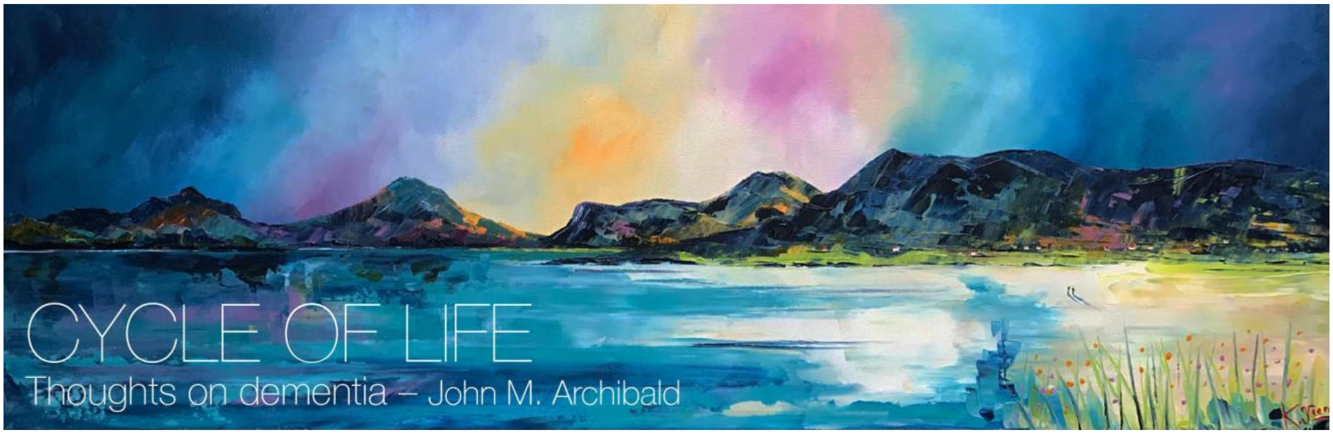

Artwork: www.facebook.com/kategreenartist

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POST 2 Confessions of an amateur caregiver

Friday, February 26th, 2021. I will never forget it. It was the day my father moved into long-term care.

At 10:00 AM my mother and I got Dad into the car and drove the short distance to the facility. 20 minutes later, we 'handed him off' to the staff at the front door. They were kind and understanding and prepared to receive him. We weren't allowed in the building. All we could do was say our goodbyes and assure Dad that he was in good hands, that we'd see him again soon.

Dad didn't know what was happening. As we backed away, he looked at us with confusion; he was wondering where we were going.

Back in the car Mum and I had a good cathartic cry, the kind that only happens when one feels that a huge weight has been lifted off one's shoulders. We recovered, took a brave-face selfie, and drove slowly to the next town over. We got some take-away coffees and sat in the sun looking out at the ocean. It was a sunny, brisk winter day — perfect for reflection. We had some laughs, cried some more and talked about the mysteries of dementia.

The previous two weeks had been a whirlwind of anxiety and emotion. My father was diagnosed with Alzheimer's disease in 2014, and while his cognitive and physical decline was for some years quite gradual, by mid-2020 it had begun to accelerate. Things came to a head in mid-February 2021 and I made the hour-long drive to stay with my parents and help out 24-7.

‘Unprepared’ doesn’t even begin to describe how I felt.

My sisters and I had each spent time caring for Dad over the years – afternoon visits, weekends, and occasional week- or month-long stints that gave Mum some respite. And my parents were themselves well-prepared. After Dad’s diagnosis they’d taken advantage of services provided by the Alzheimer Society of Canada, in particular, their Shaping the Journey: Living with dementia program. It taught them about the psychosocial and physical challenges they would soon be facing and helped them make sound choices. They had done their homework. We three sibs watched, learned and helped to the extent that our busy lives allowed.

But until I moved in, I hadn’t appreciated just how far Dad’s health had slipped and how much pressure my mother had been under. The demands of the job had ratcheted up over the years, slowly, almost imperceptibly at first but with a quickening pace that had begun to take a toll on Mum’s mental health. Dad now needed help in almost every way, not just during the day but several times a night as well. With the benefit of hindsight, she was clearly suffering from caregiver burnout. I felt guilty for not recognizing it sooner.

Mum was exhausted and I felt like an incompetent substitute. What does Dad need in this situation, in that? It was difficult for him to tell me. Speech and vocabulary had been an issue for years and it had only gotten worse. What can I do to ease Dad’s frustration and anxiety? How can I ease Mum’s?

I learned on the job, as one does when there is no choice.

Mum taught me Dad’s daily routine, such as it now was. He was no longer able to do most of the things he had previously enjoyed. He’d long since given up reading – which had been a passion for as long as I could remember – and the puzzles that had more recently occupied his mind were now also shelved. He liked watching TV, pedaling gently on his recumbent exercise bike and, for short periods of time, looking at photo albums. That was pretty much it.

And naps. Dad took lots of naps (I come by it honestly). But just because his eyes were closed didn't mean he was asleep. On one occasion Mum and I were having a hushed conversation in the kitchen when Dad suddenly spoke up from the next room:

"What about me?"

Our jaws dropped; my heart sank. Dad was tired of being talked about like he wasn't there. I knew this was a no-no and kicked myself for not doing better. As the dementia journey progresses, it becomes increasingly difficult to avoid having to speak for – and about – your loved one in their presence. But anything that can be done to include them in conversations and social interactions, even passively with regular eye contact, is worth the effort. For them and for you.

As Dad's situation continued to evolve, routines and practices that had worked well even a few weeks back became problematic. Sometimes they failed spectacularly (why on Earth did I leave Dad's walker in the trunk of the car?! He needs it now!). Mum and I learned about 'sundowning' (or 'late-day confusion') and took steps to minimize its effects.

Probably the most important caregiving lesson learned was this: be prepared to tear up the script at a moment's notice. As time goes on, the need for a flexible, adaptable care plan becomes more and more important. This can be difficult for people who, like my parents, were encouraged by dementia specialists to build their journey around healthy routines. It's great advice but it is possible to follow it too strictly.

In our spare time, and with regular input from our extended family, Mum and I navigated the complexities of the long-term care placement system. This was of course something that Dad had consented to ages ago, and by this time he'd been on a wait list for over a year. Despite the pandemic, we were lucky to be offered a place for him nearby. It all happened so fast – too fast, actually, but I doubt there is an easier way.

There was a mountain of paperwork to be completed (the Continuing Care and facility staff were amazing) and we needed to arrange for a COVID-19 test before Dad could move in. We did our best to explain to him what was going to happen in the coming days. We printed out a simple map to show him how close to home his new home would be. We showed him pictures of inside the building posted on the facility website. We even did a drive-by the day before so that the outside would look familiar to him.

In the end none of this mattered. There were times when Dad seemed to appreciate where all this was heading, but most of what we told him didn't stick – the inability to lay down short-term memories is one of the most challenging aspects of Alzheimer's disease and other dementias. Occasionally we saw this as a blessing rather than a curse. Moments of intense frustration were quickly forgotten. His early morning COVID-19 swab had been bothersome, but by lunchtime he had no recollection of it.

Dad's last 24 hours at home were full of 'lasts', some more difficult than others.

The last supper (Mum made salmon, Dad's favourite).

The last night in front of the TV (Dad laughed at slapstick Kramer in a *Seinfeld* re-run, as he always did).

The last time through the bedtime routine.

The last breakfast. As we finished up Dad innocently asked: '*what are we doing today?*' Mum and I struggled to keep it together.

The last car ride and the doorway hand-off.

My feelings immediately afterward were an intense mixture of sadness, guilt and relief. Sadness, obviously; guilt over my role in shifting the arc of Dad's life in such an impossibly strange way; relief that he was now in the hands of professionals and I was no longer directly responsible for his safety and wellbeing.

For me, the transition from spending two weeks straight with my father to suddenly not having him there at all could not have been more jarring. For my mother, it felt like her 50-plus-year marriage had ended. It hadn't, of course, but there was no denying that at 10:20 AM on that late-February day, their relationship changed forever.

We'd been warned that the transition to long-term care would probably be more difficult for Mum than for Dad. They were right. Four months on, however, Mum has found her feet again, relieved that Dad has adapted to his new environment and new routines. My parents have moved on to the next stage of the dementia journey.

We are proud of them both.

Resources

Alzheimer Society of Nova Scotia

Alzheimer Society of Canada

Victorian Order of Nurses