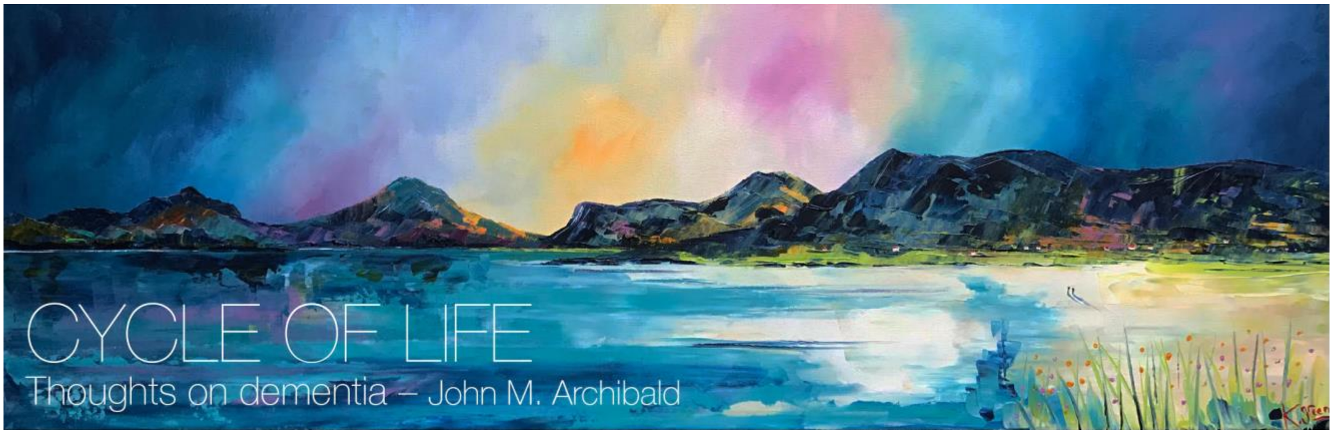

Artwork: www.facebook.com/kategreenartist

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POST 1 The dementia journey

About ten years ago I received an unexpected phone call from my brother-in-law in Mexico. My parents were visiting my sister and her family, and he had a question.

"Have you noticed anything different about your father?"

"Umm, no, why?"

"Well, he's been asking the same questions over and over again. Your sister and I are a bit concerned".

Perhaps because they had not seen my father in some time, my sister and brother-in-law noticed changes in his behavior that those of us in Nova Scotia had overlooked.

Or ignored.

The truth is that my father *had* in fact been complaining about his memory for some time, but always in a funny, self-deprecating way that made us smile instead of worry. Until that phone call I hadn't given Dad's memory a second thought. I'd certainly never considered the 'D-word'.

In 2014 my father was officially diagnosed with Alzheimer’s disease – and so began my family’s journey with dementia. Fast-forward to February 2021 and Dad’s cognitive and physical decline was such that he needed to move into a long-term care facility.

During the intervening years Dad was cared for by my rock-star of a mother, who three years ago lost her older brother to dementia. It’s been a challenging road. My siblings and I have supported our parents as best we can, learning along with them about the difficulties faced by persons with dementia and their caregivers at different stages of the journey.

Here is what I have learned so far.

I’ve learned that more than 17,000 Nova Scotians and roughly half a million Canadians over the age of 65 currently live with dementia (the number is 47.5 million worldwide). With our aging population, these numbers are expected to double in the coming years. If you don’t already know someone with dementia, you likely soon will.

I’ve learned that the societal burden of dementia is tremendous. Twenty years ago, the annual health care costs for Canadians with dementia was $8.3 billion. By 2031 it is projected to be almost $17 billion.

I have learned that dementia comes in many forms. Alzheimer’s disease is the most common, but there is also vascular dementia, frontotemporal dementia, and Lewy body dementia. They can be difficult to tell apart. In addition to memory loss, symptoms of dementia can include changes in behavior and mood as well as issues with communication and reasoning.

I’ve learned that there are both modifiable and non-modifiable risks associated with dementia. One’s age, sex and genetics play a role, but so too does diet, physical activity, and cardiovascular health.

I have learned that there is currently no cure for Alzheimer’s disease and most other forms of dementia. Research scientists are working hard to figure out what causes the different dementias so that they can be better diagnosed and treated. The ultimate goal is to be able to prevent people from getting dementia in the first place, but the brain is our most complex organ, and dementia has proven to be a tough nut to crack.

I've learned that there are many resources available to people with dementia and their families, including those provided by the Alzheimer Society of Canada (which has a branch in each province) and the Victorian Order of Nurses. These organizations do incredible things with limited resources.

But I've also learned that there is a stigma associated with dementia – a stigma that can make it difficult for people to confront the realities of the disease and prevent them from seeking the help they need, when they need it.

And I have learned that everyone's dementia journey is different. The path it takes is influenced by many different factors, only some of which are directly related to how the disease manifests itself.

The stress of a dementia diagnosis can exact a heavy toll, not just on the person with the disease but on their primary caregiver(s), family and friends. What's important is that people with dementia are treated with dignity and that we continue to engage with them. My dad is still Dad, despite how dementia has changed him.

With input from family, friends and colleagues, I'll be unpacking some of these difficult topics in future Cycle of Life posts. But for now, let me say this:

I am learning that with dementia – as with most things in life – the journey is more important than the destination. There are things we can do to help point the journey in a positive direction from the outset. It starts with talking openly about it.

Resources

Alzheimer Society of Nova Scotia

Alzheimer Society of Canada

Dementia in Canada, including Alzheimer's disease – Highlights from the Canadian chronic disease surveillance system