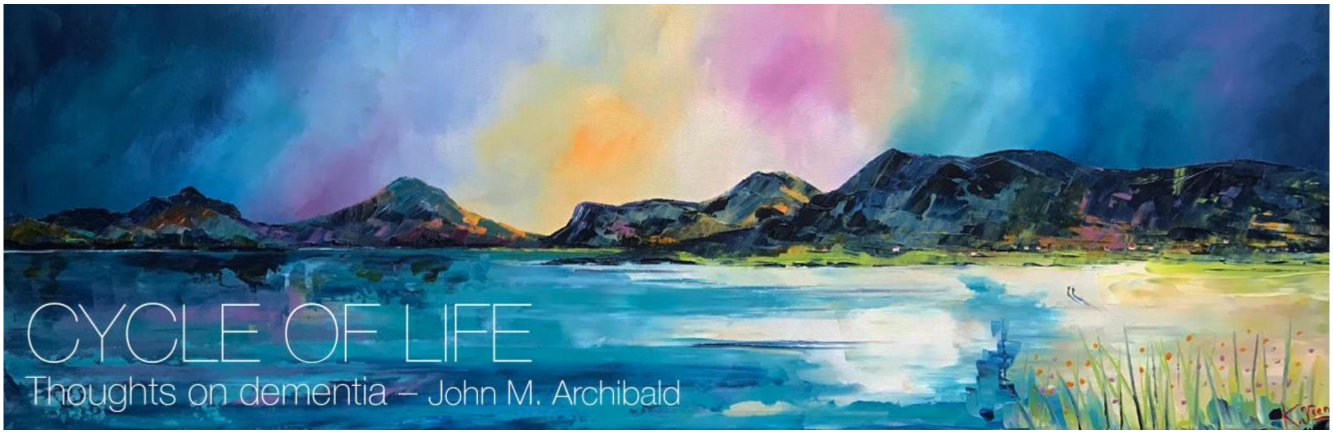


Artwork: www.facebook.com/kategreenartist

20 JULY 2021

POST 5 The dementia stigma

If you've visited the Cycle of Life blog before you will have seen the banner artwork from Scottish artist Kate Green. The colors are spectacular, aren't they?

Take a closer look. Did you notice the tiny figures on the beach? When I wrote to Kate in Spring 2021 to ask for permission to use her painting, I told her that I'd imagined them to be my parents. Dad has just been diagnosed with Alzheimer's disease and they are apprehensive about what the coming months and years will bring. But they are also trying to stay positive. They have accepted the reality of the situation and are committed to finding silver linings whenever and wherever they present themselves.

Kate said that the marriage of light and dark had been a recurring theme of her work during the COVID-19 pandemic: "*For me, it was the theme of lockdown*."

That's the beauty of art. Same painting, different symbolism. I see Mum and Dad in Kate's painting, but it could be anyone. The broad landscape of the dementia journey is predictable; its local terrain is made of shifting sand. My family's experiences with dementia will differ from yours. Coping strategies that worked for my parents may not be helpful to your hairdresser's mother or your friend from high school. The things they found most difficult about living with dementia may not even register with that quiet couple across the street. But while there are many different ways to paint a bright life with dementia, they share common colors: kindness, compassion, dignity, respect, open-mindedness, and a willingness to engage in difficult conversations. We all have a role to play.

Dementia – glass half empty or half full?

This post is about the stigma of dementia. My views on the subject have been shaped largely by my own experiences and feedback I received from friends and colleagues who kindly responded to an informal questionnaire in early 2021. I've also found several books to be particularly enlightening, none more so than Tia Powell's Dementia Reimagined.

Let's start there. Let's start from the beginning, or rather, the end.

Why is a diagnosis of dementia so terrifying? According to Powell, when people think about the disease and what it means to be 'demented', they see themselves as *"…bed-bound, incontinent, drooling. They don't want their family to ever see them that way.*"

There is no denying that this disturbing vision is based on the realities of mid- to late-stage dementia. But for most people there is a lot of living to be done between diagnosis and the onset of significant cognitive decline. "*Most people with the disease are walking about, joining the family at birthdays and summer picnics… some activities are no longer possible, but many remain not only feasible but enjoyable*."

Powell's metaphor is that we can choose to see the onset of dementia as a glass half empty or a glass half full. Most of us are hard-wired to dwell on the former – we focus on what is being lost rather than what still exists. She believes that "…*the fear of the ending prevents us from taking steps to improve life earlier on*." I believe this to be true.

Culturing a glass half-full view of dementia is easier said than done. There are many aspects of the disease and its progression that people find deeply unsettling. We fear the loss of autonomy, the loss of respect from family and friends. Incontinence, difficulties with speech, and issues with short-term memory often appear sooner rather than later, while the person with dementia is still very much aware of their place in the world. This leads to anxiety, shame, and a perceived loss of dignity. People often go to great lengths to protect themselves and others from the emerging realities of the disease. Some choose to never seek an official diagnosis.

At the same time, spouses and family members can struggle to reconcile their commitment to respecting the wishes of their loved one with the obvious desire to keep them (and those around them) out of harm's way. When it is no longer safe for a person with dementia to drive a car? Should they still be living at home alone? Should they be allowed to cook for themselves? Is long-term care the most appropriate course of action? These issues are by no means limited to people with dementia, although cognitive decline adds another element to factor in when trying to balance safety and independence.

It's not you, it's me

What does the person with dementia want and to what extent does it jive with reality? When this is called into question, conversations become difficult. Family tensions can emerge (or re-emerge), and financial considerations often take centre stage. The 'right' solution to a given problem can depend on one's perspective.

Research shows that simply being around someone with dementia can lead to negative emotions. In a recent survey by the Alzheimer Society aimed at better understanding how Canadians perceive dementia, one in five caregivers admitted to sometimes feeling embarrassed about being seen in public with the person they care for. 41% of caregivers thought that their life would 'be better' if they weren't caring for someone with dementia. More than 50% of survey respondents admitted to using stigmatizing language such as referring to someone with dementia as being senile or crazy. People with dementia can be taken advantage of, verbally or

physically abused, and socially rejected far more than people with physical health conditions. Remarkably, one in five Canadians said that if they thought they had dementia they would avoid seeking help for as long as possible. Given these sobering statistics, it is no wonder that many people would rather die of cancer than live with dementia and everything it entails.

It needn't be this way. My feeling is that we spend too much time focussed on what makes us feel less anxious, awkward, and embarrassed, and not enough on what is good for the person with dementia.

I recently read a fascinating – and unsettling – article by Han Yu entitled "The radical impact of seeing Alzheimer's as a second childhood". Among other things, Yu discusses the so-called 'retrogenesis' model of dementia. At the level of the brain, "…*the deterioration of a patient with Alzheimer's disease follows, in reverse order, a child's normal development."* Consequently, *"…what a child learns first in this world, a patient loses last; what a child learns last, the patient loses first. The beginning is the end; the end is the beginning*."

The jury is apparently still out on the retrogenesis model. But as a scientist, I find it intriguing in that it attempts to provide a biological explanation for some of the behavioural and cognitive changes that accompany the onset of dementia – changes that we might label 'childlike'. For example, people with dementia can experience difficulties with speech and a reduced vocabulary. Their awareness of social norms can change in ways that are out of keeping with their 'old self'. And as the disease progresses, their basic emotions can come closer and closer to the surface when dealing with frustration.

By no means all of these symptoms apply to all people, but they feature prominently on the list of things that can make us uncomfortable about someone with dementia. As difficult as it can be, understanding and accepting these symptoms is the key to helping your loved one through difficult moments.

In encouraging you to read Yu's article, I recognize that it might be hard to even get past the title – it seems disrespectful and demeaning to use 'Alzheimer's' and 'childhood' in the same sentence. Click on the link and you might also be taken aback by the image that accompanies it: a picture of an elderly woman holding a doll. I myself was surprised to learn that doll therapy can be an effective, drug-free way to provide comfort to people in mid- to late-stage dementia. Studies report reduced levels of stress and increased levels of engagement and communication.

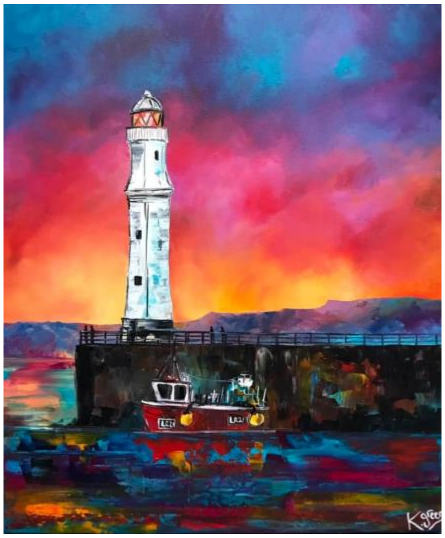
If the idea of giving dolls to people with dementia makes you uncomfortable, you are not alone. Bioethicists have argued that it is harmful to perpetuate the notion that "…*dementia is essentially a return to childhood and those affected must somehow be similar to children*." Infantilization can promote "…*inadequate understandings of dementia and hence also influence our attitudes and behaviour towards those affected in several problematic ways*."

These are important points to consider. But I confess I find Powell's no-nonsense, person-centred take on the matter refreshing: "*If a thing* [playing with a doll] *makes my demented self happy and hurts no one else, I should do that thing.*"

There are no easy answers here. The terrain we are being asked to navigate is complex. It demands that we get comfortable with our parents, spouses and friends cuddling dolls, while at the same time resisting the temptation to speak to them like they are children. They are not children. And the dementia journey is not for babies.

Nothing about us without us

The stigma of dementia can act as a barrier to diagnosis. Decisions on critical matters related to dementia care can be delayed or moved permanently to the side because the conversations they involve are difficult. Psychosocial and environmental factors, as well as family dynamics can play disproportionately large roles. Differences in the way that people from different cultures treat their elderly are often ignored or downplayed by healthcare professionals. Simply put, the dementia stigma acts at different levels and in different directions to prevent people from getting help.

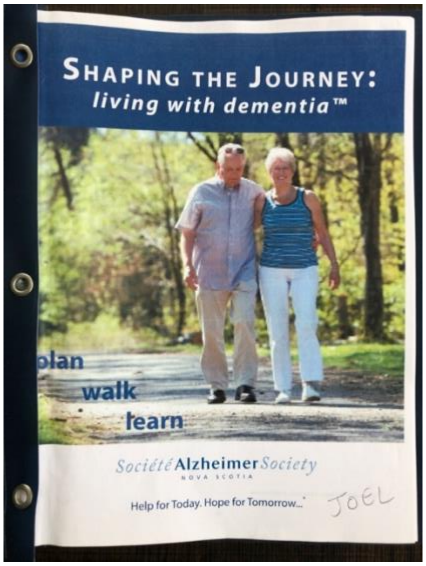


The Alzheimer Society of Canada provides a wide range of supports to people with dementia and those who care from them. In doing so, they strive to take into account the lived experiences of people who have the disease. You can read some of their inspiring stories in their I Live With Dementia series, and you can share your own story here. The By Us For Us guides are similar in spirit: "…*they are created BY people living with dementia and care partners, FOR people living with dementia and care partners*." These are fantastic initiatives but there is still much work to be done. We need to double down on our efforts to educate people about dementia and the stigma that surrounds it. We need more person-centered care. We need to focus squarely on the needs of the person with dementia, not on what makes us feel better.

It takes a village

Shortly after my father was diagnosed with Alzheimer's disease in 2014, my parents took the Alzheimer Society's Shaping the journey: Living with dementia course. I cherish possession of Dad's copy of the workbook. It's full of his hand-written responses to the questions that he and my mum worked through separately as the course progressed. It's a window into his thoughts and feelings at the time.

Dad was not experiencing fear or sadness and grief to any great extent – if he was, he wrote nothing about it and did not tell my mother. What is clear is that he was frustrated by the disease ("*it's here, and won't go away!*") and what it was taking from him, namely his ability to communicate ("*I can't get the words out in a clear way. Words don't come out*").



But Dad still enjoyed exercising at the YMCA, driving to Halifax (to see family), visiting friends, and working at Church dinners. In response to the question "Who am I?", his exact words were these:

Father, Grandfather, Churchgoer & Support.

Friend to a dozen people.

Husband.

Engineer mechanical.

I'm proud of my parents for the glass half-full approach they took to shaping their dementia journey. I believe that the Alzheimer Society of Nova Scotia had a lot to do with it. My sincere hope is that the Cycle of Life - Ride for dementia project helped trigger conversations that might not have otherwise happened – conversations that will lead others to seek help and work towards a life with dementia in which darkness is balanced by light. It is possible. My parents are living proof.

Resources

Stigma against dementia

Alzheimer Society of Canada 2017 Awareness Survey

The radical impact of seeing Alzheimer's as a second childhood

Pros and cons of doll therapy in dementia

Return to childhood? Against the infantilization of people with dementia.

By Us For Us guides to living with dementia