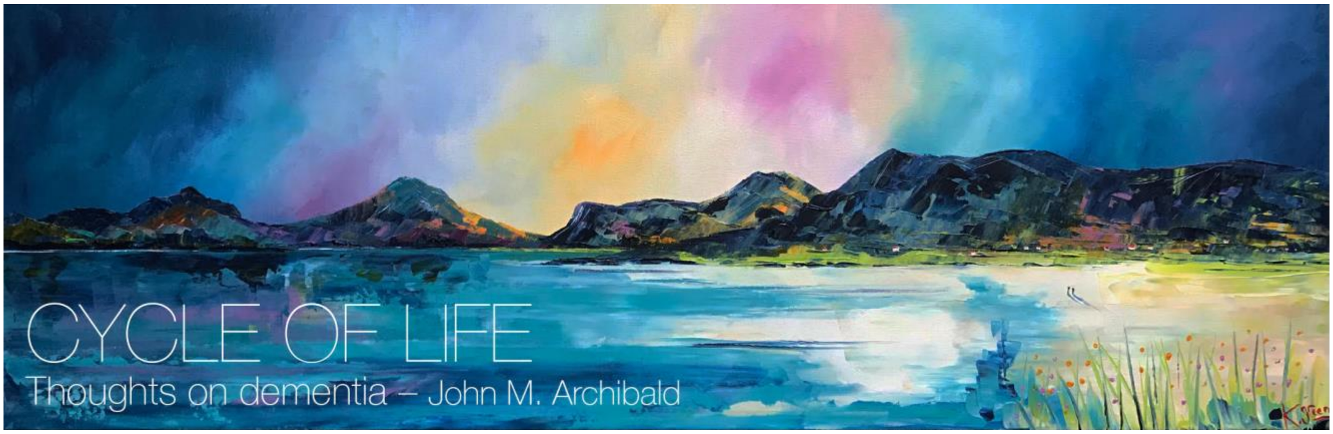

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GUEST POST 1 Reflections of a caregiver

By Clare Archibald

Introduction

I am happy to make a contribution in the form of a blog post to help draw more attention to Alzheimer's disease. I wish you success with the campaign and a good outcome for such a worthy cause.

I hope from my perspective as a carer for a number of years, there will be people who can take some comfort and encouragement from my personal journey caring for my husband Joel from 2014 until 2021 when he moved into long-term care. I noticed early stages of dementia in 2012 but he was officially diagnosed in 2014. I had a referral from our doctor for him to go to a specialist. The annual check-ups were helpful to monitor his progress and to have advice and encouragement. Joel has been taking medication and I think it has helped delay some of his memory loss.

Joel took early retirement from Michelin Tire in Bridgewater at the end of 1993. Just a few words about his interests. He was a keen sailor with a competitive spirit. He loved to read and spend time on the computer. Early in his career he had a chance to travel in Europe and had an adventurous spirit. He had selfconfidence and made new friends easily. He was keen to try new endeavours and was a willing volunteer. Many people remember his friendliness and easy-going manner. He was a solid family man and the two of us made a good team.

For those of you who are faced with a dementia diagnosis, I highly recommend taking the dementia course called "Shaping the Journey: Living with dementia", offered by the Alzheimer Society of Nova Scotia. I am a member of the society and receive information and publications. The course was informative and provided us with a framework for reference and it gave us an anchor and helped support us during the years we coped with Joel's dementia. After the course ended Joel attended a "Coffee Social" once a week held at the local library. For the dementia people the friendship could continue and it wass run by the Alzheimer Society. Although Joel could not contribute a lot, he still enjoyed going and seeing familiar faces. I had made a friend during the dementia course whose husband also went to the coffee social. So she and I would meet for coffee too which was supportive for both of us.

A few months on, I heard about a wonderful program run by the Victorian Order of Nurses in Lunenburg. It ran three sessions a week from 9:30 am to 3:30 pm with a hot lunch provided. I signed Joel up for the Monday session and he really enjoyed it. It gave us both such a lift and he looked forward to his day in Lunenburg. Eventually the program closed because of COVID-19 and by the time they reopened Joel had declined significantly and could not go back.

Benefits of a Diagnosis

It is so easy to put off this difficult moment. I personally believe it was a good thing to get Joel diagnosed because it gave him a little peace of mind and he decided he needed to know more. He took the news quite well and did not feel too despondent about it, although making the huge transition to real acceptance of the disease took time. Caregivers have to make many adjustments to cope with a lot of changes to their lifestyle. I knew that a few of my activities would have to go on the back burner for the time being to make space for the challenges ahead.

Joel felt it was a good idea to let one or two close friends know about his dementia. We had many Michelin friends and a large circle of contacts in the

Anglican church. Joel always attended church regularly and I was thankful for that because maintaining social interaction is so important. He felt some awkwardness at the coffee social following the service and the noise in the hall was a distraction to him. But it was beneficial for him to see the familiar crowd.

Keeping Healthy

The brain is affected by a person's general health. When you have dementia it is a good idea to make a healthy lifestyle a priority. Fortunately Joel did not have any major physical health issues and after taking early retirement he took regular exercise. Before his diagnosis he was an active volunteer for the Anglican church in many leadership roles. Being active and busy gave him a healthy attitude to life. After diagnosis it's good to try and continue activities as long as possible. Staying involved can be a nice distraction and a stabilizer. During the winter months he used an exercise bike down in the basement. He enjoyed it in part because it was something he could do by himself.

Being active should be balanced with time for relaxation. The challenge is controlling the stress and fear that is common with dementia sufferers. It's good to learn some coping skills that can help with the restlessness. Sometimes Joel needed me to suggest that he needed a quiet time to recharge. In the latter stages of the disease he began to take naps more often as his mind would tire from all the effort of thinking.

Life with Dementia

There are still many things that people with dementia can continue to do from day to day and I was able to make sure that we kept a routine and that each day had a purpose. During the first three years after diagnosis Joel was able to occupy himself. He enjoyed doing jigsaw puzzles, sudoku and watching sport on TV. All his life he had kept a day planner/diary where he recorded things. It was useful for a reminder and helped him feel in control. We learned that if he got too frustrated it was time to move on. We went on many drives in the countryside and he had his favorite places he liked to go.

Joel was able to help with chores around the house, like washing dishes, sweeping and helping in the yard. Simple tasks have their challenge because there is a process and going through the different steps can be muddling. This leads to frustration and impatience on the part of patient and caregiver. My intervention was not always helpful! But it was amazing to witness just how creative he could be in getting around a problem. I knew that his brain could still help him in some instances if you allow enough time and help him to avoid annoyance.

Feelings-Emotions-Change

People with dementia will experience similar feelings and emotions. What will differ is the fashion in which they are coped with depending on personality and temperament. It can be a massive change that comes with many painful and unwelcome feelings. It is so hard to comprehend why a simple task suddenly becomes a big deal!

With the disease emotions and different feelings can become magnified which can bring anxiety and sometimes fear and loss of control. With a lot of practice I think Joel found coping skills and was able to better understand that his reactions were part of the disease.

Some of the more common feelings and emotions are not trusting yourself, feeling trapped, loneliness, awareness of changes in relationships, anger, and coping with anxiety and uncertainty. I have not listed frustration because it was almost always present in most behaviour patterns.

As a carer I noticed a certain pattern emerge where Joel's behaviour would stabilize and I felt adjusted and on a more even keel. This could last a few weeks or months and then another change surfaced and we both readjusted to that level. This next level was often more difficult or just different. I think the "middle" stage of dementia was perhaps more chaotic because Joel was trying to keep too many balls in the air, but often he did not want suggestions from me and there was no stopping him!

Language and Speech

Being a quiet individual, Joel was not always wanting conversation. He always had excellent listening skills. He could be reflective and look for all the details and angles. But a decline in his speech was noticeable in the early stages of dementia. This broke my heart at first. How frustrating to have trouble finding words to enjoy a meaningful chat.

I spent a lot of time thinking of creative ways to help the situation. Some of that was useful but eventually the best way was to go with the flow and remember to speak slowly, and make sure I had his attention. I avoided using too many complex expressions because it seemed to muddy the waters. If we were with other people Joel often felt isolated from a group conversation because everyone was speaking too fast and he lost the thread.

I found it interesting that there were certain names or nouns that Joel had completely forgotten. In other instances it was pretty much hit or miss. Very occasionally he would speak a long sentence without any thought! Two months before he went to a nursing home I found that increasingly he could not understand the meaning of some words. I had to find another way and rephrase or just start again. This was a lot of effort and contributed to my exhaustion.

Joel was robbed of his love of reading and writing which he found very tough. The skill of writing letters or numbers was also gone. The losses were certainly stacking up. Joel had incredible determination and his patient nature took him a long way. He would acknowledge familiar faces around town; and getting him out of the house everyday was important.

We did have the occasional extraordinary moment when we could have a short good conversation. I treasured these times because they were rare and sweet. I’m curious to know what happened in his brain during those few seconds when he appeared so normal!

His lack of speech was definitely the biggest hurdle for both of us and our relationship inevitably had to change. There was no easy solution and it felt like a constant challenge that was always there. It was hard on family members to find effective ways to chat with Dad. As time went on they became more comfortable and speaking much more slowly was the key. It became second nature to keep topics very simple. I became accustomed to his quiet meditations.

Joel's Last Months at Home

In his seventh year living with dementia there was quite a decline in Joel's cognitive and physical abilities. He was much more out of touch and in his own zone. Much of his motivation had gone and napping was more regular. My children were now helping me lay out plans for long-term care. This was such a painful thing to have to go through. We found the process for entry into long-term care confusing. I hope that some improvements will evolve out of the COVID-19 pandemic because a variety of serious problems have been revealed and much work will be needed in the long-term care sector.

I was so grateful to have the support of our three grown up children. One of our daughters came from her home in Mexico and stayed with us during the first COVID-19 lockdown. The other two children are living in Halifax. As a carer it is impossible to manage all the responsibilities on your own. As this part of the journey was drawing to a close, I had to make sure I got more rest and try to stay calm during the high level of stress and uncertainty as to where a bed would be found for Joel. Even with the walker in the house he did not find using it easy, and I worried about his safety. I knew he needed much more care than I could give him.

There were now challenges during the night with Joel and this meant he was more upset and I was not getting enough rest. I was grateful that he had been a good sleeper until this point but his incontinence had become worse.

By this time I had eleven hours of day-time professional in-home care spread through the week. I was handling all of Joel's personal hygiene and he managed well physically. I was not keen to increase the amount of home care and felt that long-term care was a better solution. Due to COVID-19 Joel's reassessment by the care coordinator was long overdue. This situation weighed heavily on the family but the care providers knew that a nursing home had to be found for Joel as soon as possible.

Pat on the Back

It is so natural to think that you can carry on handling such a burden because one feels it's your job and no one else's. But even in my situation I did not want more home care. I was so grateful that Joel had coped with such courage through such a long haul. The journey he had taken showed such strength of character and his gentleness. Sometimes his sense of humour would come shining through. He was amazingly considerate of me. It is true that strength will come to you during adversity. I have not felt much guilt or regret at how we made it through such a difficult period. What would be the point? I think I have some good organizational skills which were useful to me. In such a demanding job as a carer, you will have moments that break your heart but there are many happy moments too. These moments will stay with you for a long time.

Conclusion

The future does not look good for those coping with dementia unless significant change is made. From my own observation, society in general needs to realize that people with dementia need more attention and to feel more included in public settings. How hard is it to ask one of them "How are you doing today?" They usually will have a reply and there needn't be any awkwardness. The carers and loved ones of these people carry heavy loads and it would be great if new ways could be found to support everyone on the dementia journey. I think about all those people who have the disease that are out there, doing the best they can to fit into a world that can feel strange and scary and sometimes unwelcoming. Having made this journey with Joel and knowing first-hand how devastating it can become, I am impatient to see meaningful and lasting changes to the lives of so many people with dementia.