

**Regional Geriatric Program of Eastern Ontario, Annual Meeting - Panel, October 23, 2015 – Hellenic Centre, Ottawa**

Thank you for the opportunity to talk about my husband's journey with Dementia. Bob, in his 81<sup>st</sup> Year, passed away in Long Term Care in March.

He was my beloved partner of 25 years, a loved father and grandfather; a valued friend and colleague. We shared a wonderful, perfectly ordinary life, where we spent time with family and friends, worked, traveled, lived.

Although recent years have been all about living with and coping with dementia, previously, Bob had a long and distinguished career.

He joined the Canadian Air Force after high school, achieved a Chemical Engineering Degree from Queen's University and served for 35 years in various roles in the Canadian Air Force, across Canada, on Canada-U.S. projects and in Germany for three years. In his early forces career, during the Cold War, he worked as a Navigator in the Voodoo fighter jets. After retirement, he began a second career with the Federal Public Service, working in Emergency Preparedness.

When he finally retired, there were beginning signs of memory problems. That was 2004.

I tell you about his career because that life is in such stark contrast with what becomes of a Person With Dementia and how society views and acts toward them.

As Bob's memory issues continued, he was trying valiantly to live normally; he was struggling. We worked to find answers about what was wrong. His young, male, family doctor was in a group Family practice and initially did the requisite testing for cognitive decline. He was wonderfully understanding and supportive and referred Bob to the Geriatric Day Program at the Civic Hospital for further assessment. He also scheduled a series of monthly follow-up appointments to monitor Bob's condition. These served as an ongoing and needed support. Bob's G.P was very helpful to me as well, encouraging me to call the Alzheimer Society, early, for information and assistance. I should have thought of this myself, but was as shell shocked as my husband by the changes being identified.

At the Civic Geriatric Day Program, Bob was diagnosed with Fronto-Temporal lobe dementia, after undergoing all the required assessments and scans. Over time, we had some follow-up appointments, which further confirmed the cognitive and functional decline. Bob could not tolerate any of the popular dementia medications and there were none available for this particular type of dementia. Eventually, the Program said goodbye and ever so nicely indicated there was nothing to be done. It felt as if we were baby birds being pushed out of the nest, not knowing what to do, where to go or how to view the future. It was a time of confusion and upheaval and sadness for both of us. Our future retirement plans changed forever.

In the early years of the diagnosis, Bob was at home alone as I was working. I began to see he was having trouble with basic tasks of daily living. There were things forgotten. He exhibited unusual emotional responses, and lapses of judgment such as trying to retrieve, with a metal fork, toast from the plugged in toaster. He lost his ability to read, write, speak and understand and, he had problems with memory, judgment and inhibitions.

Initially, I arranged time off my work at Health Canada to accompany him to his medical appointments. But, I was soon compelled to take early retirement to be home, available. I was initially resistant to getting outside help for him as I fancied myself perfectly capable of doing whatever was needed for him. Bob was fortunate and not typical -- as a person with Dementia-- in that he did not have, at that point, any other chronic disease or condition along with his dementia. Although he had previously experienced and been successfully treated for two auto-immune diseases, ITP (Low blood Platelets) and Temporal Arteritis (inflammation of the arteries leading to the brain), I was assured that neither had anything to do with the dementia.

Looking back now, that time was a bit of a blur. He was shocked and trying to function as normally as possible. I was shocked and was trying to handle everything in our lives alone, including assuming all financial responsibilities and decision making. This was tough as we both had previously functioned so independently. Bob's ability to drive was eroded by his reaction time, memory lapses and judgment. The decision was reached for me to do all the driving one day after Bob had gone out for an errand and did not return home for 4 hours. He had been driving back and forth on the Queensway, unable to find his way home.

My eventual call to the Alzheimer Society, was the best thing I did. We were immediately connected with the next series of dementia information sessions for couples. Those helped in understanding the disease and helped us not feel so alone. From there, we linked to monthly couples' lunches and support groups. It was reassuring to share our experience with others, going through the same difficult journey with dementia. Through this process, I learned of other resources and soon I was able to enroll Bob in two wonderful day-away programs each week. These programs saved us for a long time.

We also received help from unexpected sources. Bob was passionate about music and we loved to attend concerts at The National Arts Centre. But with the dementia, he became less inhibited -- inclining him to enthusiastically express his joy with the performance when no-one else was doing so. The NAC accommodated our special needs by making a box available which provided necessary privacy and an easy exit if needed.

Day to day, as he increasingly could not be left alone, I was afraid for his safety. I engaged some private caregivers for a few hours each week and we had a Personal Support Worker through the Community Care Access Centre as well, though Bob's requirements did not quite fit into the criteria for that service. We, nevertheless, struck an

implicit bargain for two hours service a week. I accepted anything I could get to add to his comfort, safety and personal well being.

The outside assistance gave me some time to shop for groceries and supplies and occasionally have a quiet moment alone. Despite all the services, it was still a 24-hour, 7-day a week challenge for Bob and me.

Fatigue, exasperation, sadness, loneliness and loss – all haunted me during my care-giving experience.

I developed Rheumatoid Arthritis, probably not helped by the stress we were under.

It is so sad and difficult to see the person you love melting away before your eyes. Our world became smaller and smaller. Bob's care needs became more pressing as incontinence became a critical care issue and his behavior became less predictable.

I was really concerned that I could not continue to care for him and I started the process for long-term care admission. Fortunately, before too long, Bob was admitted to a lovely facility out of the city and was well cared for there during his stay and through his death.

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How did we get through all that?

In the Fall of 2013, I was fortunate to be part of the creation of a grass-roots group that we call **MIND THE GAP**. The five (now six) of us, women, who met at an Alzheimer's Society Wives Support Group, have been active since in trying to highlight gaps in services for Persons with Dementia and their caregivers. By listening to others and comparing notes in our support groups who were coping with similar situations, we became increasingly aware that we were getting conflicting or inadequate information from health and community support services and we needed clarification.

We noted the need for: more suitable respite beds; more or varied hours in day-away programs; more dementia-responsive and consistent Community Care Access services; easier processes to get home help; and better transition to long term care.

We advocate for caregivers who want to keep their loved ones with dementia, at home as long as possible, and have tried to put a human face on the issues facing persons with dementia and their caregivers when we meet with policy and decision makers, educators, health care or community service providers.

To this end, we met Members of the Provincial Parliament, Federal Members of Parliament, representatives from The Perley Rideau Health Centre, The Bruyere Centre, Carefor Health and Community Services, The Community Care Access Centre, The Champlain LHIN. We have spoken to the media and been speakers at various meetings, presented at Grand Rounds at the TOH, presented to Medical Students and sat on committees related to Dementia.

For those of us who still had our husbands at home, it was a major challenge to find the time and substitute home help in order to do this advocacy work. But, it was worth the effort as we have found the work, and some results, enormously rewarding. We have seen some improvements in some services and policies, (though progress seems glacial), and are hopeful that there are more changes on the horizon. We are well aware that changes might not come in time to help us but could benefit others in future.

For us as Caregivers, our advocacy work has been empowering. We have benefited enormously from mutual support and a sense that we were doing something positive and constructive.

Dementia can color one's world extremely negatively. Many caregivers suffer from depression or develop significant health issues – making two patients, instead of one for the available health or community service providers. We advocate that it is essential for the formal health care and community services systems to treat the Person With Dementia and their Caregiver as a unit.

We firmly believe that to ease the suffering of the Person With Dementia and support their Caregiver, and, to provide the right care at the right time, in the right place, -- the silos of services (Hospitals, physicians, Memory Clinics and Community organizations) to name a few, need to melt their boundaries to better serve the Person With Dementia and Caregiver as a unit. This, as we all know, would not only save the health system financially but would enable the Person With Dementia to truly **“live well with dementia”**; and, with no cure on the horizon, that is all we can do.

Thank you for your attention.