Annual Report 2025–2026

PART ELEVEN

10 Lessons Learned... a Family Caregiver Reflects

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Joan was a caregiver for her husband, both at home and in long-term care, until his death in 2025.

As a retired educator, I always knew that lifelong learning was in the books for me. I looked forward to choosing what I would learn, at my leisure. I had a list.

Being a full-time caregiver for my husband of almost 50 years was not on that list. A diagnosis of

Alzheimer’s disease drastically changed my learning trajectory. From the day of diagnosis–with insufficient information provided–until my husband’s death almost 10 years later, I found myself on a learning curve for which I was not prepared and over which I had no control.

A year has passed since my husband’s death. During these months, against the backdrop of profound, accumulated grief, I have had time to remember, reflect, and review. As I had done for every course I ever took, I kept copious notes. Over 10 years, I filled 31 journals. They recorded poignant personal details, medical data, and a wide range of emotions.

In addition, I wrote over 70 poems. They served as a creative outlet for processing grief. The lessons learned were among the most difficult and the most heart-wrenching in a lifetime of learning. Our story, although personal, is not unique. The growing number of persons being diagnosed with degenerative brain disease(s) attests to a collective experience from which we are all learning.

The foray into the unfamiliar territory of Alzheimer’s disease–which would eventually deprive my brilliant husband of the life he knew, deprive me of a partner in life and love, and change our family dynamic forever–unfolded in two chapters.

Chapter 1

Our plan and hope were that his illness would be managed at home, in surroundings that were familiar and comfortable, with added supports as needed. For the first five years, prior to and during COVID, the plan held. I was his 24/7 caregiver. As my own physical and emotional energy waned and behavioural symptoms of the disease escalated, there was no “Book of Instructions” provided. It felt like no one knew exactly what to do.

And so began a veritable “snatching at straws” that included medications with all their side effects. Risk/benefit, I was told. There was guidance from the LHIN (now Home and Community Care). In my journal, I wrote, “Caregiver without Portfolio” because I began to feel unqualified to provide adequate care. I had the loving support of our son, who worked miracles of care with his dad. When my personal safety was compromised, and the designated 911Emergency Plan failed me–by way of a criminal charge being laid against my husband–we moved very quickly to a crisis list for LTC.

Chapter 2

We entered the Long-Term Care system at a time when its “brokenness” was laid bare to the public, during the height of COVID. For the next 5 years, as designated “Essential Caregivers”, my son and I assumed our advocacy role as we dealt with numerous issues that impacted my husband’s care. It is important to acknowledge that there were good people–a compassionate physician, a caring Nurse Practitioner and some mature, experienced PSWs–but we most definitely encountered a system and staff stretched and stressed beyond capacity. Mistakes were made; hospitalization and overuse of antipsychotic medications robbed my husband of his mobility and the clarity that remained. What a disease trajectory would have done eventually was accomplished in 72 days. Family presence was essential to oversee, monitor, and advocate.

Long-term care can be a lonely place for a family member and for a caregiver. The role of family caregivers often felt undervalued. It was my good fortune to have connected with other caregivers who understood the reality firsthand and knew the sadness of watching a loved one slowly diminish. I found it appalling that there was no Geriatric Specialist to guide us. Throughout my husband’s illness, I had and still have the additional support of a personal counsellor.

The inevitable became the obvious, and my husband moved into a 10-day period of palliative care. Ironically, these last 10 days of his life and his peaceful death were one of the more positive LTC experiences we had. I had worked diligently to educate myself throughout his illness and specifically about the dying process. As prepared as I was, I was not ready.

This is what I learned:

1. Be present to your family member as much as possible
2. Educate yourself about your family member’s medical needs/ tests/results
3. Ask questions; push for accountability
4. Be your loved one’s voice; ask for what is needed
5. Document/record everything
6. Request/read copies of all medical records, periodically
7. Take initiative in the agenda for each care conference
8. Seek out support for yourself
9. Liaise regularly with interdisciplinary team–Physician, Dietary, Physiotherapist, Activation, etc.
10. Put in writing the “end of life” wishes for your family member

Should I ever need it, I now have a file entitled *Long-Term Care*