

A Personal Book of Hope

Throughout my husband's long and insidious illness, I have come to appreciate, firsthand, the motto of Hamilton's St. Joseph's Hospital.⁵ "It is an honour to serve the sick", it simply states.

Indeed, during the past five years, it has been my privilege to care for David throughout his relentless deterioration. Along with tremendous sorrow, David continues to fill my days with joy, my nights with thanksgiving, and my life with meaning.

Where is that written in all the depressing literature about Alzheimer's?⁶ I vow that one day I will write about those moments which crop up to delight and console at the most unexpected times, those moments which serve to ease a great hurt. Perhaps I will quote excerpts from Our Personal Book of Hope, a sort of journal which I began in 1990. The first page reads:

*Dedicated, dear David, to you and to our abiding love.
Yours, as ever, forever. M.*

Three such entries in my journal read:

June 30, 1990

Today, we began the experimental drug program. Very hard for both of us. But when the program researcher asked you to write down any sentence, you wrote, "I love my wife" ... That made a hard day easier. Remember that sentence, Margaret, in the hard days ahead.

April 18, 1991

You try so hard to help me, honey. Last night, you offered to get me a drink. With your fragmenting memory you returned, holding two ice cubes only.

June 14, 1991

Today I asked David how long he has loved me. He looked at me solemnly and replied, "Oh honey, for eggs and eggs and eggs ..." I have loved you for ages too, honey, and always will.

⁵ Located in Hamilton, Ontario

⁶ Today, it is my non-medical opinion that David's symptoms were more consistent with Lewy Body Dementia, a form of dementia similar to, but distinct from, Alzheimer disease. Parkinson-like symptoms and visual hallucinations are associated especially with Lewy Body Dementia. Happily, David's hallucinations always seemed pleasant. He often "saw" an infant and would warn me to be careful that I did not step on "the baby." David clearly appeared content and happy, even at these times.

In this journal, I also recorded encouraging excerpts from the literature on Alzheimer disease and many other sources. One passage that I found reassuring early in David's illness is from *The Loss of Self* by Donna Cohen and Carl Eisdorfer. It reads: *Alzheimer disease challenges the intimate bonds between human beings. For husbands and wives, though, the love may deepen. A special grace and beauty mark those who have learned to live with the disease and continue to find ways to enjoy each other.*

Postscript:

On Saturday January 15, 1994 at 11:20 p.m., time met eternity as David and I wrote the final chapter of this love story. Alzheimer and Parkinson diseases have fled, but our love remains.

This story is dedicated to other couples who are facing similar challenges and who are now writing their own love story.

—Margaret Pitkeathly

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