

# Personal Revelations, Experiences and Reflections of an AD Caregiver

Roberta Bedard is a caregiver for her husband who has Alzheimer's disease (AD). She has written many humorous and touching vignettes about her personal experiences in dealing with the development of the disease, and has graciously agreed to feature these vignettes as a series in this and upcoming issues of the *Canadian Alzheimer Disease Review*. Roberta's writings enable readers to share in her journey with AD caregiving, provide valuable insight on the human aspect of disease and stimulate contemplation on the deeper meanings of life and love. In this feature, Roberta discusses the ways in which she and her husband dealt with his diagnosis and came to terms with the impact it would have on their future.

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## CHAPTER 1

### *The Beginning*

by Roberta Bedard

I cried. For three days. Straight. I cried when I woke up. I cried as I was driving to work. I cried as I sat in front of my computer. I cried when I tried to eat lunch. I cried on my husband's chest. I splashed tears into the pan as I cooked dinner. I cried when I was getting ready for bed. I weep now as I am writing.

Even though writing this article brings back the overwhelming emotions that assailed me when my husband and I began this journey into the black unknown that is Alzheimer's disease (AD), it must be done. And it is important for the reader to know that I am not a "Pollyanna." I am not one of those

sunny people who seem to go through life facing devastating circumstances with unthinking optimism.

My husband and I view ourselves as survivors. The habits of a lifetime took over and we thought, "We will get through this." But how? This terrible disease would rob each of us of our best friend. Because, make no mistake, AD is a joint disease. Just as we have ownership of our condominium, so we have joint ownership of AD.

We decided to take advantage of the knowledge we already had. My husband, a retired social worker, had worked with AD patients in an auxiliary hospital setting. I had re-

cently studied the sociology of aging, which included studying dementias from the sociological perspective. We then plunged into the depths of information provided by the Alzheimer Society of Canada. We read. We talked to each other and to anyone else we could find who could give us information.

We soon found that there is no shortage of available material about AD. And there is support for "caregivers" (my new label).

But as I learned more, my sense of panic grew. There were warnings about patient wandering, patients hiding things and about the constant anxiety and fear patients feel. And it seemed to me

that caregivers had to be one step removed from angels. We are to be understanding, to take abuse from our previously gentle loved ones, to live in chaotic households... to have no lives of our own.

I am not a saint! I have never considered myself a “caregiver.” My approach to someone else’s headache is to make sure they know where the aspirin are.

My beloved husband would become dependent on *me*? My heart ached for him. He would be in my hands, and those hands felt much too weak for the task.

Through all this initial turmoil, my husband was a bastion of strength. He kept reassuring me that I could cope. The knowledge he had gained while working with AD patients and their families in the auxiliary hospital setting comforted him—enough to be able to comfort me. We drew strength from each other, but in the beginning, I was the one making the heavy withdrawals.

As practical people, we knew the beginning period was the time to take action to protect us both from the future consequences of the disease. We drew up Enduring Powers of Attorney so that I would have the legal authority to conduct our financial affairs when my husband became incapable. I told his children and mine. We started organizing our household and making lists. We had taken to heart the “three months or ten years.” If three months was all we might have, a lot had to be done.

And still, occasionally, I cried.

One day, in our local paper, there appeared a small article describing a medication that was

newly available in Canada. Though not a cure, this medication could possibly slow down the progression of AD symptoms. Clutching my two-inch newsprint square of miracle, I talked to our doctor.

“It’s not worth trying,” he said. “It will only buy you six months. It doesn’t work for everybody. It’s expensive,” he said.

Through the AD Society, we found a different doctor: one who had a different approach and who, at least, supported us in our desire to try.

And we learned again that part of our survivorship skills was stubbornness. Because we were among the lucky ones. The medication worked. It has already bought us an extra year. More than that, it has given us hope.

Matters were in good shape when I came across an article by Barry Reisberg on retrogenesis. As I read about the Retrogenesis Theory, my sense of competence grew. Vastly simplified, the theory is that stages of AD can be correlated to specific developmental stages in children. This correlation can help caregivers understand what can realistically be expected from our loved ones. For example, a patient at Stage 5 can be expected to function at the level of a five- to seven-year-old child.

My heart pounded as I read this information—for two reasons:

- 1) I, along with a great number of caregivers, have been a parent. I may have no experience with AD, but I do have experience with children;
- 2) what the article *didn’t* say.

What the article didn’t say is that five- to seven-year-olds are fun

to be around. They are nice people. And I thought, “If I can get my mind past grieving for the 70-year-old husband I have lost, and find ways to enjoy the seven-year-old I may have in the future, maybe—just maybe—I can find joy.”

I began to visualize going for walks, stopping to admire an anthill. I thought about bath time, with games and laughter. And I imagined myself laughing at the antics of Teletubbies—just as John Bayley did when he watched television with his wife, philosopher and novelist Iris Murdoch, after she developed AD.

Nowhere in the literature available to me was such a point of view expressed. As I talked to various professionals to see if my feelings made any sense, I found they agreed. Although *everyone* stated they had not thought about the disease that way. Therefore, I decided that something (a book or booklet) needed to be written.

Dr. Bernard Groulx, chief psychiatrist at Ste-Anne-de-Bellevue Hospital and an associate professor at McGill University in Montreal, Quebec, also thought I made sense. He graciously agreed to take time from his busy schedule to look over what I wrote, so that I would not inadvertently mislead anyone. So, while these writings are very personal, the facts about AD will be correct, and my interpretation of the research will be realistic (though colored by my feelings).

**Please look for Chapter 2: *The Retrogenesis Theory in the next issue of the Canadian Alzheimer Disease Review.***