

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 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...

In "You and Me and Spook," Roberta explains how her husband's psychologic and functional status is being affected by AD and how she creatively manages the situations which present to her. We have also included "Laughing"—an uplifting account of how important it is to cherish life and our loved ones, one day at a time.

CHAPTER 4

by Roberta Bedard

You and Me and Spook

For a while now, we have been dealing with "sundowning" which, combined with Ray's REM sleep-wake cycle disorder, leads to some pretty exciting night-time adventures. For instance: Ray imagines that there are enemies hiding in the walk-in closet, ready to attack. So he removes the books from the bookshelf, barricades the closet door with it and piles the books around the floor to trip the bad guys. Or he becomes extremely concerned over whether the puppies have been bathed (we don't have puppies). Only when I reassure him that the puppies are all fluffed up and asleep in their kennel does he go back to sleep. Another time, it is the "circus folk" who have surrounded the house, installing large searchlights. Then they break one of the lights, which

necessitates going out to check for broken glass so I won't cut my feet if I should go outside.

But I'm used to this and, other than not getting enough sleep, it is not upsetting, except for the fact that winter is coming, and we need to find a way to get Ray to sleep through the night so he won't go outside in -40°C weather. Our psychogeriatrician has found a medication that seems to work and doesn't over-sedate Ray. Night-times are better now.

Spook is something new. Ray tells me he senses a third person in the house. This explains why he keeps setting the table for three—now I understand. I also understand why he asks me now and again whether we are alone in the house. He is convinced that he will find this person but every time he thinks he has found him or her,

it turns out to be me. I reassure him that there is no one here but us, but he is not entirely convinced.

Then I remember. Children have imaginary friends. How would I deal with a child who has an imaginary friend? I would accept the friend and go along with it. So it is with Spook. We have given it a name and a gender (male), and include him in our conversations. Spook is our buddy. We invite him to join us at lunch, but he never shows up. We don't mind; more for us. And we laugh at Spook for missing a meal. Funnily enough, since we started doing that, Ray is no longer concerned with finding Spook and hardly even mentions him. I think that when I denied Ray's reality (of having a third person around somewhere) it made him uncomfortable. How would I feel if the person I loved

most consistently denied what I felt to be true?

According to the Functional Assessment Staging (FAST) scale, Ray is functioning at around stage 5, which corresponds to a child between the ages of 5 and 7 years. Just knowing that makes it so easy to deal with the changes which are beginning to appear. It helps me to understand when he needs help putting on or taking off a sweater. He has trouble getting sweaters over his head, so I'll have to buy a cardigan or two, with big buttons, anticipating the time when small buttons are difficult.

What is interesting is that these changes are sporadic. In between episodes, Ray is himself, he continues to understand concepts and his insights are well worth considering. He sees facets to situations and people that I miss. He continues to be the loving, gentle caregiver, and his wacky sense of humour is still operating. He takes over the crossword puzzle when I quit, and finds esoteric terms that I have never even heard. He is going to an Alzheimer Day Program twice a week now and wows everybody with his personality.

He has told me that, though he may act bashful, he likes it when I kiss him goodbye in front of everybody. I only know this because I asked him if he minded. It is important for me not to make assumptions, but to ask him how he feels and to use all my senses to understand fully his answers.

None of this is hard to do.

Laughing

I've just finished laughing. Big belly laughs that left me gasping. Something that doesn't happen very often. Though I am, in general, satisfied with my life at this time, I have to admit that I have periods of weeping, in the midst of mainly benign periods of quiet enjoyment. But I don't really laugh very often.

Let me explain. My husband and I watch television in the back bedroom, snuggled under the quilt. He more snuggled than I, since I like the room cool-to-cold and he likes it much warmer (he's bald and his head gets cold). My philosophy is if you're cold, put on a sweater—I'll even help. Today he turned up to watch one of our favourite programs in a getup that brought back memories of the sort of thing my children used to do. He was wearing his warm dressing gown over his clothes, ski socks on his feet and, to top it all off, his postman's hat. You know the ones. They have furry earflaps. He looked so pleased with himself. He was making a statement.

I took one look at him and choked. And laughed. And ran out of breath. Tears of laughter came. My sides ached. I gasped and choked, finding myself helplessly banging my heels on the bed. I kept trying to sneak looks at him without laughing and I couldn't pull it off. I would slide a sidelong look at him and be off into gales of uncontrolled laughter.

Ray laughed with me. "I'm a practical Albertan," he said. We had hysterics together.

Then I realized. There are some things about AD that I actually like. It is disinhibiting. When we think of AD patients losing inhibitions, we (or at least I) have tended to think of it negatively. We believe the result is socially unacceptable behaviour, of lashing out.

But if the AD patient is treated with love, with acceptance, with an honesty that recognizes that accommodations can be made with objective truth, then the greater truth of the AD patient's acceptability as a human being is maintained. My husband's self-esteem is intact. We both accept that he has AD, we both talk about it. We both laugh at Spook. We laugh when he forgets that dinner is formal—that is, he has to wear pants. There are times that he tells me that

AD is hell, that he forgets what his hand was aiming for when he stretched it out. But these moments are rare. On the whole, he knows that he is still perfect in my eyes.

So he is liberated from inhibitions. This allows his truly wacky sense of humour to flourish. The social unacceptability of wearing a postman's hat to watch TV is pretty benign. When it is done as a humorous statement, it is unalloyed joy. Before Ray developed AD, I had no idea that he could be so funny! Which reinforces for me the benefit of understanding and incorporating the Reisberg Theory into my daily life as a caregiver. We delight in our small children. We appreciate their humour. We look with fondness on their eccentricities. There is no reason to take a different approach with a loved one who has AD.

I am not a fool. I know that, as AD progresses, things will get more difficult. I know that, unless Ray dies of something else first, AD will kill him. We both agree that our goal is to keep him happy and functioning as long as possible, with the sad hope that something else will kill him first. We have said our goodbyes more than once.

Having said that, there is no reason to live under a cloud every day. For now, I take the joy and fun that each day offers. September 11th, 2001 taught a whole continent that our daily lives with our loved ones are what count most when the chips are down.

AD has taught me the same lesson. And I am glad to learn it. Were there an easier way to become fully aware of this, I would take it. But the lesson is still a valuable one and a great gift.

And I can still feel the ache in my ribs from laughing.

Please look for Chapter 5: New Stage in the next issue of the *Canadian Alzheimer Disease Review*.