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 “New Stage,” Roberta talks about how the Reisberg theory is a source of comfort and confidence as she and her husband must accept that, as she puts it, “he is slipping.”

CHAPTER 5
by Roberta Bedard

New Stage
“Looking at you right now, I’m not quite sure who you are.”

This addressed to me by the quiet, gentle man who is my husband, as he sits up in bed.

He has just explained to me seriously that, “... we have to make sure that the windows are open, because Roberta needs her fresh air.”

“I’m Roberta. I’m your wife and I love you more than anything.”

“Oh, good.”

This confirms what I have been suspecting for a few months now. The Alzheimer’s symptoms are becoming worse. This after four years of a moratorium on symptoms imposed by donepezil.

Lately, even an overnight stay at a hotel has left him disoriented for about a week afterward. I have awakened to find him packing because, “It’s really too bad that we have to move every month. There should be a way that we can stay in the same place for longer than that. Oh, we have purchased this home? We can stay? That’s good,” he says as he snuggles under the covers and drifts off. He’s also been asking me where Juliette, his long-dead sister, is. I have to accept the reality. He is slipping.

Oddly, I am not terribly upset by this. I have had four years to
prepare for this time, and the knowledge I have gained, especially understanding the Reisberg theory, has given me the confidence that I will know what to do.

My biggest fear when I undertook this journey was that I would not be able to cope; that Ray would not have good care from me.

But now I have a road map. What I must establish is where Ray is now in terms of AD and then correlate this to a developmental stage in a child. I am already, without much thought, relating to him at a different level.

I was right that joy can still be found. We are having many hilarious moments. This is because I am also free to express my inner childishness. Ray is the one person with whom I can be as silly and childish as I want, and it’s alright with him. So we share stupid jokes at which no one but us would laugh. I can dance around making monkey noises and the fact that I am in my mid-sixties, and a large woman, does not appear to him to be incongruous. He just thinks it’s funny and we laugh together.

At this point, his moments of disorientation are few. Most of the time, he is himself. He can still think and has invaluable insights that I am not willing to overlook just because he doesn’t always know exactly what’s going on at any particular moment.

The man I married still lives. Because we have been honest and clear with each other from the start of this illness, we can discuss what is going on and the changes we need to make.

He doesn’t have to pretend he does not get confused. He can acknowledge that I have to hide the medications. If I don’t hide them, he does, which leads to panic on my part when I can’t find them. He accepts that driving is not a good idea and that he should not have the ignition key to the car. This wonderful man looked me straight in the eye and said, “We have to do what we have to do. My ego’s not involved here.”

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Please look for Chapter 6: I am Loved in the next issue of the Canadian Alzheimer Disease Review.