

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 "Validation," Roberta emphasizes the value and importance of a person as a human being—in sickness or in health. We have also included "Cranky vs. Dusty"—Roberta's endearing description of an event that leads her to soul-search and consequently adjust her priorities.

CHAPTER 3

by Roberta Bedard

Validation

Ray tells me today that when he is lying in bed, all alone, he gets depressed, his thoughts go in circles. He says he needs to feel that he has a purpose, that there is work for him to do, that he can help the "organization," that he needs a niche. When I tell him that he has a niche with me, "does that count?," he is comforted.

This set me to thinking about what I have been told about helping persons with AD by validating the things they have done in their past lives. By going over who they were, the value of their contributions—in

short, what good things they have done.

And I wonder.

When we are reminding them of how valuable they were, are we not, to some degree, confirming that they are not valuable now? When I tell my husband that he is essential to my well being now, as he is at this moment, I sense the depth of comfort this affords him. His face relaxes, his eyes glint, he smiles and says, "I'm glad I talked to you." He can still express himself, but I plan to remember these moments for the future when he can't tell me how he feels.

I plan, in language he will understand, to continue to let him know how important he is, at that very moment. Not how important he has been in the past, but how valuable a human being he is in the present.

If we can love a "useless" child, just because he or she exists and is ours, and if we can love a cat, for heaven's sake, who does nothing but accept our feeding and our cleaning of its litter pan, then we should be able to convince persons with AD that they matter in the present. That they do not need to feel only dependence, but can know that

they are, and will be, valued as they are now.

I believe this process of validation must start early, before feelings of worthlessness become entrenched. It behooves us, when considering the whole person, to give the present person equal importance.

Cranky vs. Dusty

I've finally found a solution to my embarrassment and guilt over my inability to maintain my housekeeping standards while being a loving wife, mother, companion, nurse, chef, physiotherapist and all-around caregiver to my husband. While staying relatively sane and maintaining some kind of life for myself.

I've given up. Trying to maintain my standards, that is. What a relief!

I came to my decision when I heard myself snapping at Ray, "I've just cleaned that!!!" when he put a dirty spoon down *right on the counter*. The poor man stood there, looking ashamed of himself, thinking he had just committed a terrible deed. He shuffled dejectedly out of the kitchen, sat down on the couch, stared ahead and stayed out of trouble.

And my heart broke.

This is not what I want for us. Neither for him nor for me. "But I can't do it all!" I told myself, and proceeded to have a severe attack of the "poor-me" syndrome. I wept in guilt and frustration. "I can't do this."

Luckily, I am a practical person, even when I'm feeling terrible. What was it I couldn't do, exactly? I was happy and content doing everything that needed to be done to be a good wife to Ray. I enjoyed my volunteer work, and the occasional Rotary meeting. I loved having lunch and giggling with a girlfriend. I could manage all these things as well as napping every day. The only thing that got in the way was the housework.

"So," I asked myself, "why can't I give up most of the housework?" Other than what the neighbours would think, did it really matter if my windows sparkled? All I really needed to do was lower my standards to just above what was needed to keep the Board of Health away; which only means sanitary and safe; which doesn't even attempt perfect; which doesn't even care, really, about neat. The clutter only needs to be kept within reasonable bounds. I don't need always to be "ready for company."

This decision came hard. I had the sort of mother who could spot a thread on the carpet at 20 paces, who insisted that not only must work be done well, it must be seen to be done well. I'm the type of person who schedules housekeeping chores into my Microsoft Outlook® computer program, with reminders for daily, weekly, monthly and yearly duties. If these chores are done regularly and well, keeping a small condominium "up to snuff" is relatively easy.

But ... I don't like housework. I like a shiny house, but I was born to have maids (notice the plural—it would take at least two) who would do the work for me. Housework makes me snappy and cranky, which is not a good thing to be when your beloved has AD. Hence, my decision.

Now we hold hands and watch television while a pile of unsorted, unironed clothes are piled on a chair. Now my carpet keeps its spots. Forget writing my name in the dust—I could build little forts. But I now have time to cook great dinners, searching through my cookbooks for variety. I don't rush through eyecare and footcare duties. I have the time to just sit and listen to and appreciate the terrific guy I'm married to—Alzheimer's or no Alzheimer's. My husband is smiling more, as am I. I even have time for a belly laugh.

The ghost of my mother looks disapprovingly over my shoulder. I still cringe internally when the doorbell rings unexpectedly. I am not able to get over my upbringing enough not to be embarrassed, or feel occasionally like a failure at wifehood because I can't do everything. But I've made my choice.

Cranky? Dusty? If that's the choice—and for me it is—then it makes itself. Life is too short to keep chasing dirt as my main mission.

Please look for *Chapter 4: You and Me and Spook* in the next issue of the *Canadian Alzheimer Disease Review*.