

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 explains how she has come to understand the Retrogenesis Theory and reveals the joys and sorrows this understanding brings.

CHAPTER 2

The Retrogenesis Theory

by Roberta Bedard

It's taken a long time to settle down to write this chapter. Months. Not because I didn't understand the idea behind the Retrogenesis Theory. But I was determined to write these articles in the spirit of hope and joy. And before we can find the joy we have to come to terms with the sadness.

As I stated previously in Chapter 1, vastly simplified, the retrogenesis theory correlates the stages of AD to specific developmental stages in children. For example, a Stage 3 AD patient can be expected to function at the level of a teenager, whereas a Stage 5 AD patient can be expected to function at the level of a five- to seven-year-old child. In effect, retrogenesis is child development—only backwards.

In the "backwards" lies the sadness, although the Retrogen-

esis Theory can help caregivers understand what can realistically be expected from our loved ones. Because in our human understanding and socialization, from the time we are in the crib through to our adult lives, and then the lives of our children, the emphasis is on learning, developing, and moving forward.

When we strive to manage and love our way through the various stages of children's development, we are doing it with the idea of teaching and preparing for the next step forward—helping our children to become adults who will make and live in a better world.

In fully accepting the Retrogenesis Theory and in using the knowledge to help our loved one, we must first accept that we are not promoting growth. We are not moving forward, but backward.

To find the joy inherent in our loved one's current stage of awareness, we must let go of anticipation of the next higher level of accomplishment.

We are not teaching. But we are loving, interacting, managing.

We are not preparing for future depths of awareness. But we are constantly assessing where we are at the moment.

We are not holding on to the idea that tomorrow there will be a step into a greater future. But we are open to the pleasures to be found this day.

We must set aside mourning the adult we have lost and take pleasure in the child we have found.

Please look for Chapter 3: Validation in the next issue of the *Canadian Alzheimer Disease Review*.