

Is This as Good as It Gets? Is this all?

Richard Taylor, PhD

RICHARD TAYLOR, PhD, is a retired psychologist who lives with and writes about Alzheimer's disease (AD). Five years ago, at age 58, Richard was diagnosed with AD. He is the author of *Alzheimer's from the Inside Out*, Health Professions Press (see "Personal Reflections on Alzheimer's, Sing Along with Alzheimer's" in the May/June 2007 issue of *Assisted Living Consult* at www.assistedlivingconsult.com/issues/03-03/alz56-Alzheimers-518.pdf). Richard Taylor maintains a busy schedule of lecturing, writing, editing a newsletter, gardening, and playing with his 2 grandchildren. Richard has agreed to maintain frequent E-mail contact with *ALC* to provide us with a diary of his impressions, struggles, and conquests. Richard Taylor's reflections on AD follow.

May 7, 2007

May 7th note to self

There were times, no too long ago, when I thought about things. I thought about each of my children, my spouse, and the rest of my family. I worried about Darfur, the President, funding for the UN disaster committee. I do not think about these things much any more. They cross my mind from time to time. But usually I need some outside stimulation to fire up my memory and my thoughts.

It is not that I do not think as much anymore. I just do not remember what I thought about. Arguing with my spouse is a good



Richard Taylor, PhD, provides reflections on his battle with Dr. Alzheimer.

example. Yes, we sometimes argue over mostly stupid stuff. I can recall we argued. I have not let go of the feeling (one of my less healthy habits—but I do not smoke and no longer participate in recreational drugs). I feel sad, or happy, or bewildered or whatever, I just cannot recall any of the specifics, and now even the topic that motivated the feeling.

Formerly I revisited arguments between my ears until I was satisfied I was right or wrong, or we

were both a little right and a little wrong. I announced my findings (usually just to myself because I did not want to start another argument) and moved on, at least for me, and at least for a while. Now, Dr. Alzheimer seems to sweep away the details before I have a chance to attempt to understand them.

This phenomenon is not just reserved for arguments. I have pretty much lost the details of most conversations, unless I write

them down and most times, I can read or understand what I wrote down. I know I had them. I can usually associate a topic with a person; ie, she is talking about a DVD I am working on; he was talking about my trip to Idaho. But I am lost as to what exactly was said.

It's like reading the table of contents of a book or looking at the chapter titles one by one, but out of order, and then sitting down to contemplate the book and its meaning. It is all but impossible. It is frustrating, very confusing, and increasingly sad. There are more and more moments when I wish the curtain would come down quickly, and I could move to a place where I just cannot look back. The current situation is wearing me down!

Is this as good as it gets? Is this all? The End?

May 7th, 2 am

I am booked to speak in various towns, cities, and states from now until Christmas. I try to be on the road for 2 weeks, home for a week, and back on the road. I try to have someone pay my way to a state, and then I call around the rest of the state seeing if other groups would like me to speak for the cost of my local travel and a few bread crumbs every day. Oh yes, I also need a place to sleep, but I generally stay at someone's house.

Keeping track of the details is a monumental job for me. Even with everyone being cooperative and supportive, it is a constant source of frustration for me. I suppose it would be for anyone, but it is especially troubling for me. I try to bring a family member or friend with me on my trips, but they all work, so sometimes I depend on the generosity of spirit, time, and attention of my hosts. So far, it has worked out for me and for them. I have spoken at

universities, medical schools, private residential communities, nursing homes, schools, service clubs, police departments, public meetings, local Alzheimer's association chapters, and so on.

The question for me is: Is this it? Is there more I can do? Different things I can do? Or is this my final destiny? I have a couple of more books I could write. Currently about 100,000 + people have read my musings every month through publications for caregivers and professional journals. So what?

It is strange watching yourself misdial a phone number, time after time after time. Look for a name and then forget what I was looking for right in the middle of my search. Stand up from my chair to do something and not have a clue as to what it was.

Is this it? Should I feel complete? Why am I in such a hurry, such a need to do more, something different, other things? I'm also working on two DVDs, a television special, and, oh, did I mention I still have a fulfilling life as a husband, Dad, Grandfather, friend, bridge player, and gardener?

So why the rush? Why the need for more, for different? I am scared I am running out of usable time—usable in the sense that I am using it now. I know I am not at the same level of general competency this May as I was last May. I am more dependent on others for assistance in performing my daily

activities of living—other than the ones they are always putting people in homes for because they cannot perform two or more of them. I know I could not keep this pace of activities without my spouse cleaning up behind me, reminding me to do this or that, asking if I wanted to do this or that. Her patience is both generous and essential.

I have good days and bad. Good hours and bad. Good moments and bad. There is no predicting when or how the bad ones will come, except when I am very tired. Sometimes I am aware I am floundering and cannot seem to hold myself together. It is strange watching yourself misdial a phone number, time after time after time. Look for a name and then forget what I was looking for right in the middle of my search. Stand up from my chair to do something and not have a clue as to what it was. Most dangerous for me are the moments I don't understand, but think I do, or don't remember. I say things, I tell people things, I think I understand situations that are not true, a little true, or from out in left field, and the worse part of it is that I don't know when these moments are happening. Will I do something on this date? Sure. Except I wrote it on the wrong month in my calendar and didn't find out for 3 weeks. Can I do this? Of course! When I really didn't understand what was being asked of me, and I just said "yes" for reasons which only Dr. Alzheimer knows.

Tie these all together; multiple them by 25, and you have an insight into my days. There are, of course, lots of time between the events when I cruise along acting and sometimes thinking like there is nothing wrong, until SPLASH—another glass of ice water in my face, compliments of Dr. Alzheimer. I hate this disease!

AJC