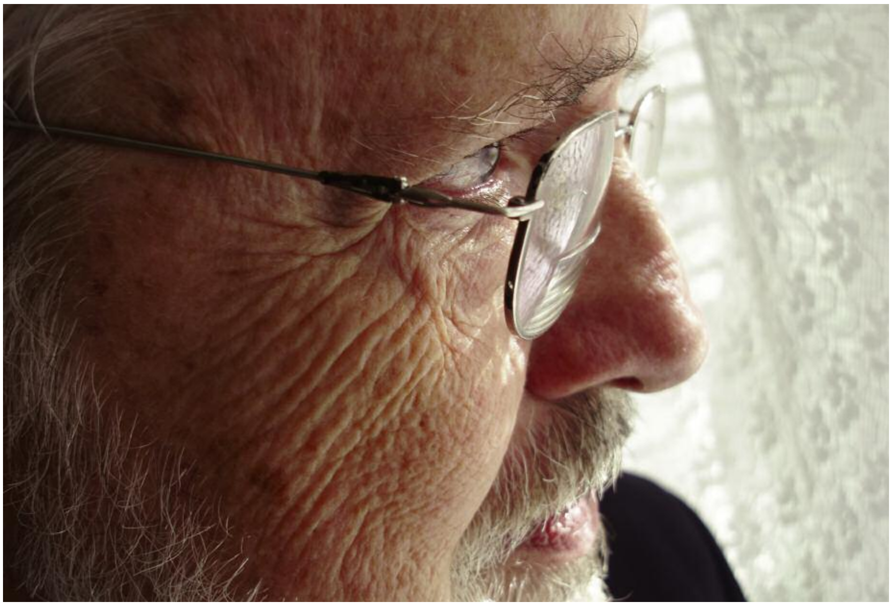
I Forgot Some Real Good Stuff

Richard Taylor, PhD

"Everything has been thought of before, but the difficulty is to think of it again."

—*Johann Wolfgang von Goethe (1749-1832)*

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 *ALC* at www.assistedlivingconsult.com/issues/03-03/alc56-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 *Assisted Living Consult* to provide us with a diary of his impressions, struggles, and conquests. Richard Taylor's reflections on Alzheimer's follow.



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

March 6, 2007

A glass of whine every day prevents ulcers but causes other problems.

I finally decided to stop whining about how overwhelmed I was and try to do something different rather than just trying harder. I'm reorganized! The system has backups, alarms, redundancy, color codes, different scents, and it thus far seems to make sense to me.

No promise that I will be more timely with my responses, but know that I am trying instead of just complaining. I had become dependent on others to store information for me and resend it when I finally got around to acting on it. No more, I hope. Thank you for sticking with me. Have I mentioned lately how much I dislike this disease? Well I do!

March 22, 2007

Is longer and more of it, by definition, necessarily better?

The Advocacy day is over, looks like the Democrats already decided to double the NIH's research budget before we showed up. Of course they are waiting until an election year to do it.

Everyone wants more money for research to slow the pace of the disease. A great solution? Except for people who have it and their caregivers! They will then need support and services for longer periods of time.

And where is the ramping up for that? Isn't any, focus is mostly on finding a cure! Then only those who have the disease will have to be concerned about Alzheimer's disease.

The chances of finding a cure for something that is being caused by something(s) we don't know seems at best long-long range. Let's just drag out (people who don't have the disease like to call it "extending") the length of time people have to live in and with the disease. What a great solution for everyone except caregivers and people who must live with the disease. Great?! A stage one twice as long. Great? Maybe! A stage two twice as long. Great? A stage 3 twice as long? Oh?

Sounds like a guaranteed improvement for some at the relative expense of others. Living a month or a year more with a debilitating cognitive disease, which inevitably ends in a horrible death, may seem like a giant step forward to some, but certainly not to all who now have the disease. If there is not an equal effort to expand the quality of life for those living with the disease, longer and more of it doesn't sound the same to me as it sounds to others. Who leads the charge for quality of life?

May 4, 2007

May 1st note to self

Honest, I have tried to consistently write in the first person (I). It is not my intention to write about you (people with dementia and/or their caregivers). It is certainly not my intention to refer to myself as "we." W.C. Fields once said only Popes and people who have tape worms could legitimately speak of themselves as "we." Now here comes the big BUT, so to speak. But people, especially caregivers, are increasingly responding to my observations as if I were speaking for their loved one or directly to them (the caregiver) and worse yet, at them.

Honest, I am not trying to shame or reason or push others, especially caregivers, into changing how they act. Only they can change their minds and their actions. I just want them to know what their actions sometimes look and feel like to me. I just want to paint the picture with my brush before they bring out their rollers to paint me. I just want them to look before they leap.

I just want them to spend more time listening than they do talking. I just want them to remember that people with dementia are still people—are still whole human beings. Individuals who are struggling even more than they are to make sense of what is being said to them.

I wish there were more people in the earliest early-stage Alzheimer's disease who wrote what they were thinking, and how they felt about themselves and their caregivers. I think there are many personal advantages to writing things down. First, it slows us down. Feelings frequently rush on past my ability to record them, to type, and I am a very fast typist. I can slow down my thoughts to match my typing speed, but I cannot seem to slow down my feelings as easily. The challenge to write about how I feel seems to keep my feelings from running away from me and taking them with me.

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Writing allows me to return to the thoughts and feelings erased by Dr. Alzheimer. Writing allows me to compare the "myself" of today to the "myself" of yesterday, to last month's "myself."

Unfortunately for me as I lie down each evening to go to sleep, a rush of ideas seem to come racing through my brain. Each one is more interesting than the previous one. When I open my eyes in the morning, I daily discover Dr. Alzheimer's has pulled up the sheet from my Etch-a-Sketch—otherwise referred to as my short-term memory—and the only real recollections I have are that I forgot some real good stuff.

I'm considering wearing a very small tape recorder around my neck hanging by one of those trendy lanyards people now accessorize with. I have been thinking about doing this for about a year now, and I have not done it. For some reason I feel uncomfortable with the thought of carrying around my thoughts around my neck. It seems ostentatious to me. What can I ever say that was worth preserving and carrying around with me? Of course it also invites people to ask me what's that thing hanging around my neck, and then I feel obliged to go into a long explanation of what's it like to have Alzheimer's disease when all they have asked is, "What is that hanging around your neck?"

I have started to sometimes feel sorry for myself. Everyday somebody calls me and wants me to go speak somewhere. Currently I am just overwhelmed with trying to stay organized with all the speaking engagements I have accepted. It seems as if people believe I became infinitely more interesting to listen to the day after my book came out than I was the day before it came out. The farther I live away from audiences, the more they seem to know I know what I am talking about, even before I begin to talk! But I digress. Just at a point in my life where I have access to larger and larger groups of listeners, I seem to be in a position where I have less and less abilities to make that happen.

Do people come to hear me speak? Do people come to hear what I have to say? Do people come because they have never seen anyone who has Alzheimer's speaking to a public forum? I would settle for two out of three true. ALC