

Like a Snowflake in Texas

Richard Taylor, PhD

RICHARD TAYLOR, PhD, is a retired psychologist who lives with and writes about Alzheimer's disease (AD). 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.

Yes, it's that haunting feeling. It has haunted me for the past 7 years. The tight knot in my stomach, the lump in my throat, the uncontrolled crying, and the sense of falling into an abyss. This is not a bad dream for me. This is how I feel right now.

I feel as if I am reliving my own response 7 years ago on hearing my neurologist's words, "Richard you have dementia probably of the Alzheimer's type, and certainly with Alzheimer's features." Seven years ago! And now the same identical feeling, the same intense crying is all suddenly back. Feeling as if it will never stop. Feeling as if I have no control over it. Feeling helpless, unable to avoid something awful.

Previously I felt as if I have always been walking 1 step behind Dr. Alzheimer's. Every morning I would wake up and see what old and new symptoms he had placed in my IV, as he made his rounds while I was sleeping. My focus was on how to overcome, avoid, or at least deal with each of these symptoms for the rest of the day in ways that would not appreciably impact what I wanted to do that day.

My goal has always been to stay only 1 step behind the good doctor. My fear was I would fall 2 steps be-



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

hind, and then 3, and then 4, and then I would begin to consider just giving up trying to catch up.

I have recently returned from being on the road, meeting, speaking, and listening to people with dementia, their caregivers, and engaged professionals. I try to become engaged with about 500 people a week (people with dementia; caregivers; physicians; nurses and nursing assistants; occupation, physical, and recreational therapists; nursing and social work students; medical students and residents; home health care workers; direct care workers and managers; politicians; professionals; leaders; managers and staff of various organizations committed to supporting people with

dementia; volunteers, etc.)

Over the course of the last year and a half, I have tried to maintain a schedule of being on the road for 2 weeks, home for 1 week, and then on the road again for 2 more weeks. Occasionally I was on the road for 3 weeks and then home for 1 week: but always when I came home I reorganized, recentered, repacked, refocused, and took care of the details as I headed out on the road again.

For the past 3 months I have on occasion asked family members or friends to accompany me on the road. It is a lot to ask someone to take a week off from work. After all, I am always surrounded by loving, supportive people. But when I

miss airline connections, when everyone is busy just after the program is over, when I become restless at night, when I can't remember when someone is picking me up, or sometimes even if or why someone is picking me up—it assures everyone at home and me that I am safe, if sometimes unsound, if a family member or friend accompanies me.

To no one's surprise I diverge and digress from my point. After spending a week and a half at home—I haven't reorganized, recentered, repacked, refocused, and taken care of the details for the next 2 weeks. In fact, I am more behind now than when I came home a week and a half ago. I've made additional problems for myself as I attempted to deal with my original "to do" list. Help, I realize I'm falling behind—across the board! Not just with 1 symptom here or there. I'm not keeping up, much less getting ahead of myself with the details of

my life. I have a spouse who is an angel, a fulltime care assistant, dozens and dozens of people around me here in Houston, and literally hundreds of people around me in the US, and even a couple of dozen in foreign countries—all dedicated to enabling me, all helping to keep me safe and organized. And now I have observed I am my own worst enemy and an additional force for them to deal with as they attempt to support me.

Why don't/can't I stop this madness—this counterproductive behavior? Ah, now I am back to thinking like a psychologist. But, alas I am not. I no longer think enough like one for the label to mean anything useful to me. I still think about my own thinking, but honestly I almost never can recall what I was thinking about more than a couple of hours after I thought of it. Great ideas and insights come and go like snowflakes in Houston, Texas. First, they are pretty rare. Second, they exist

only in the moment. Third, they leave no trace of their existence.

Oh, I still have access to crystallized memories. I still recall what I did yesterday, at least some of it. I know what you just said, and I might recall it in conversation yesterday. But figuring out today what to do about tomorrow—that has become a real challenge for me. Sticking to a plan is almost impossible, if the plan is longer than a couple of minutes.

Writing about me is still a clarifying and reassuring experience for me. I don't understand myself "on the fly" as I did, or at least thought I did, in the past. And, those times when I am confident I know what's going on are not only fewer and shorter, I am less sure of them when they do show up between my ears.

A local merchant recently told my spouse he thought I was such a kind person, and sometimes I acted a little oddly. Me odd?!

That's why I'm crying!

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Legal Corner

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careful to disclose information only to those who have legal access to it.

Summary

The purpose of the HIPAA Privacy Rule was not to restrict information at the expense of providing appropriate care for residents. Instead, it was created to prevent unlimited sharing of information to anyone who requests it. To ensure that this rule is implemented properly, covered entities should weigh all the factors in a given circumstance and determine whether the release of the information is necessary to promote the best care and treatment for the resident. By keeping this in mind, the facility's staff can ensure compliance with the rules and the best care possible for its residents.

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