

Alzheimer's Disease International World Conference, 2009

**Update from a former young-onset early-stage person
living with the diagnosis of Dementia,
Probably of the Alzheimer's Type**

Richard Taylor

Hello, my name is Richard, and I have Alzheimer's disease. I was diagnosed in Houston Texas, about six years ago. I am in the late stage of early stage dementia, probably of the Alzheimer's type. For six years, I have been living with the visible and invisible symptoms of failing cognitive abilities.

What you are seeing on the screen is me, my outside persona. You cannot see my symptoms, my progress, my fears, and my constant battle with forgetting and misunderstand. I live with my symptoms of dementia: trying with the support and enabling of my carers, and to the best of my diminishing abilities to avoid the symptoms and to pretend they are not here or there. And always I am attempting to stay just one-step behind them.

I have discovered I cannot anticipate what, when and where they will pop up. I have discovered I cannot be who I was. I have discovered I cannot be what I was. I have discovered I have to me. , I am still all me. I am not half-empty or half full. I am in fact not necessarily still Richard. But I am for sure Richard.

Some, in fact many around me still yearn for and seek out the "Old Richard." Well I am sort of old, but Richard is new everyday when he opens his eyes in the morning and engages today.

After I was diagnosed, after I couldn't drive, after friends started staying away, after sometimes heated discussions with family members concerning issues such as who was right and who was wrong, who remembered this or that and who forgot it, who was

confused and who wasn't; After I began to go to sleep earlier, stay asleep longer, take naps, watch TV, watch more and more and more TV - after all this happened over the course of a year I lost my way. I knew I was losing my old self, and my way, my purpose just sort of evaporated in ways I did not at first notice.

I think about thinking. As a psychologist, that is what people paid me to do. That is what I spent too long in school learning how to do. That, I might add is what I did, and I did a very good job of it. Now, I cannot find anyone to pay me to think about his or her thinking, but thinking about my own thinking is after-all free. I do not want to take away my own thunder and trust me; there will be thunder from my plenary presentation later on today. So if there are a few holes in this presentation, rest assured they will be filled in today in my late afternoon address.

Initially when I would tell folks about my symptoms many of their well-intended responses were to tell me that they too shared that symptom. "Oh yes," they would say, "I forget where my keys are. I used to do lists, and sometimes that was not enough." I smiled and said "Oh," and felt like I was being discounted. After thinking about it, I decided folks were not intentionally trying to diminish my symptoms. They were for their own benefit, trying to convince themselves that I had no symptoms. That I was okay. That led me to start asking people what came to their mind when they heard that a good friend like me had been diagnosed with dementia probably of the Alzheimer's type. Almost to a person somewhere within their rambling explanation were the words "The long goodbye." That is the stigma, I believe everyone with dementia wears, like a tattoo on our foreheads "I'm in the midst of "The Long Goodbye," and everyone who does not wear it, fears it, worries about themselves getting it, and sure as hell does not want anyone they know and care about getting it.

I would ask folks why they do not call as much as they used to. And they would respond that they did not know what to say. My routine and immediate response to this was, just say "Hello." And after thinking about that, I have decided "hello" is a response that people with dementia need every day, from everyone they meet. I have learned that every day is a new day for me and the others living with declining cognitive abilities. It is a new day in special ways that for folks who do not have the symptoms of declining cognitive abilities it is impossible for them to fully appreciate.

The sense that we will probably go through the entire day and still not figure out exactly what is new about today vs. yesterday, but we will know something is new. So now every e-mail I write, most conversations I begin by saying "hello." Try it with people who have dementia, and then wait to see what their response is. Listen for what seems to be new in their lives today or in the past week or perhaps in the past month. As a psychologist. I understand that every day is new to everyone. However, the diagnosis of dementia and the mental roadblocks, confusion, and black holes in our memory adds a new dimension to cause our today to be uniquely new from yours.

Several years ago I wrote that I had given up hope. Actually, I should have written I had given up hoping for a cure, in my lifetime or anyone's lifetime for that matter. I had given up hoping that for me tomorrow would be better than today. I had given up hope that I would ever be my old self again. Instead, I had decided to invest all my energy in today and not tomorrow. I had decided that today was as good as it was ever going to get for me, and that was good enough provided I was fully engaged in today and not sitting around hoping tomorrow would be better.

And so I am fully committed to living in today as best I can. I do not want to live in my past. I want to live in my present. I do not want to speculate about the future. I want to live in my present. To do so, I now need others to help me, to enable me to stay grounded in the moment, the moment that is shared by those around me.

Over the last six years, I have learned that my initial strategy and that of my family: to wait to cross this or that bridge when we come to it - this strategy creates more problems than it avoids. Do not wait to get lost to start talking about how to avoid it, brainstorm together how you can help yourself and others can help you. Do not wait for an auto accident to decide how and when to decide to stop driving. Do not wait until you discover that you feel you are your husband's nurse rather than his spouse, or you are your wife's caretaker rather than her lover. Talk openly and often about issues of intimacy and how you can remain best friends.

I realize everyone and every family have worked out rules concerning what they do and do not talk about it. When Dr. Alzheimer's walks in the door the rules of family openness and communication must change. What worked for 20 or 30 or 60 years will not work for the

next 10 or 20. Not to decide to talk about it is in reality to decide not to talk about it, even when "it" is my symptoms and me and I am

in the room with you, struggling with my symptoms. I am also frustrated and struggle with the professionals who try their best to meet my need.

The medical community strains to keep Alzheimer's disease within their "medical model." It gives physicians an excuse not to look outside the pharmaceutical industry for other forms of support for people living with cognitive decline. I think we are vulnerable to being led down garden paths by most times true believers (occasional deliberate misrepresentations) to eat this or drink that or act this way. There are individuals reporting amazing reversals of cognitive decline when they did this or that. Sometimes these occur overnight. Since governments do not investigate or verify research on the veracity of this or that, and the promoters promote individuals successes rather than accepted research protocols, the consumer is left to decide for her or his self. So what else is new?

As long as there is no evidence of hurting someone, I believe it is an individual's right and decision to eat more curry, or blueberries, or vitamin X, Y, or B. The potential harm comes from the hearts and unfounded hopes of folks who are living with some form of dementia. They want to be cured. They want the progress to slow down. In some cases, I believe they "will" it to happen and/or others "see" what they had hoped to "see" or a combination of both. In either case, the value is in and for the individual. If you think you are "better," if you act as if you are "better" - than for yourself, "you are better." I have little faith in the medical/pharmaceutical consortium. They will not come up with a "cure," certainly in my lifetime. They do not understand exactly how the brain works, so until they do so they will not understand how the brain does not work. They do not know how to deliver a cure to specific parts of the brain, short of saturating the body with the "cure," and that proved a failure with the original vaccine studies.

With a pound of caution and an ounce of this or that - it is worth the risk, especially since I get to define what, and how much of the "risk" The same holds true for caregivers. First, last and always, "do no harm" to yourself. There are risks in "overdoing" most anything, but risks can be identified and consider and an informed decision can be made. There is not an answer to the question "what's the best way to eat, act, think, and what's the best stuff to swallow if you have been diagnosed with dementia, probably of this or that type. We just do

"it." And "it" is what we decide "it" is. And how effective "it" is to some degree how effective we believe it is, and to some degree how effective it is regardless of our belief in it

What everyone directly and indirectly confronting dementia every day of their lives needs are not more pharmaceuticals. What we need is socialceuticals. We need to relearn how to communicate, how to love, how to get along, how to support and enable each other. We need social medicines, because dementia is for all practical purposes a social disease. The symptoms of the disease have social consequences. The impact of the disease, especially in the early and middle stages is social, not physical.

There is not much, if anything we can do about symptoms, progression, the end - what we can do much about is making sure we all live in today, in the moment. What we can do is join together and everyone identify and live in the midst of a purposeful and purpose-filled life. What we can do is learn to enable each other to be the most enabling caregiver, the most loving, open and supportive person with dementia, the most effective Alzheimer's Society we can be. We won't "beat" Alzheimer's and related and unrelated dementias, but we can all do a lot better at making the time we spend with each before the symptoms close in around us the best they can and should be. Filling out wills and forms is not the answer. Finding out more information is not the answer. Going to more and going more often to doctors is not the answer. And neither is taking two hands full of pills instead of one hand full. For me, for us, our lives will be changed and supported for the better in fact the best if we practice listening to each other. If we accept people for who they are today. If we enable and don't disable. If we reable when necessary. It's not how we solve problems that will mark out success as a person, as a couple, as a nation, and as a world. It is how we anticipate and avoid them. It is how we keep them from happening. It is in my sometimes-humble opinion no different with dealing with dementia. Hello and thank you . I am still Richard, and I still have dementia, probably of the Alzheimer's type.

Richard

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