

# Richard Taylor

Ph.D., is the author of *Alzheimer's from the Inside Out*.

My name is Richard Taylor. I live in Houston, Texas, and for the past few years I have been living with the symptoms and diagnosis of dementia, probably of the Alzheimer's type.

For as long as I can remember, I have feared snakes. I have at one time or another in my life feared polio, shots, tall women, death by suffocation, failing a spelling test, asking a girl to go out with me, the atomic bomb, going to weddings where aunts would kiss me, and did I mention women who were taller than I?

I am older now, we have all but eliminated polio as a disease in the world, shots don't bother me, frankly I seldom run into women who are taller than I, I still become anxious at the thought of drowning, I don't have to take spelling tests (thank heavens for spell check), I've learned to live with the bomb(s), I can now outrun most of my kissing aunts,



and most all of my family is through getting married (or at least I hope so as far as my own children are concerned).

So what's left for me to fear? I'm not concerned with being stalked by lions or dinosaurs. I'm large enough that street criminals don't present much of a threat to me. However, most unfortunately for me, I now am living with the disease of dementia, probably of the Alzheimer's type. I AM PROBABLY MORE FEAR-FILLED NOW THAN I HAVE EVER BEEN IN MY LIFE.

I am fearful of tomorrow, and tomorrow, and tomorrow. I am beginning to be fearful of my todays. I am fearful of myself and my ability to know what is going on within and around me. I am fearful that I am now leading a purposeless life; I'm just waiting around for the disease to take its toll on me. I am fearful of others because I sometimes know, and sometimes suspect, that those



# Interview with Richard Taylor

**MoMA:** Richard, how do you think art and, more specifically, engagement with art can be beneficial for people with dementia?

**Richard Taylor:** First let me talk about self-expression and dementia. The idea that you're losing your cognitive abilities is very destructive to your self-esteem and your self-image, that you're losing control of the most fundamental of all processes: how your brain works. And both directly and indirectly that lesson — both the opportunities and your willingness to be self-expressive — causes people to pull into themselves. They do this because other people tell them they're saying good-bye to them, and so when you're saying good-bye, it's not the time to get into a long conversation. And because they can see it in other people's eyes, people don't have a value for themselves. So over time I think they just stop thinking about themselves, and pull into themselves.

Concurrent with that and the disease process is losing some of your inhibitions, that is, the things that kept you from being as self-expressive as you might have been earlier in life. That's just a fact of what's happening in your brain. So, the very time you can be more self-expressive is the very time when you're less self-confident to be self-expressive, but the self-confidence has nothing to do with your ability to draw, or write, or read, or sing; it's a much deeper level of loss of confidence. All these programs that are beginning to blossom in the arts are all addressing and creating opportunities for people with dementia to be self-expressive in ways that they've never been before, and it's easier for them to be that way as they're not inhibited with their form of expression.

**MoMA:** I would even add that when one loses some inhibitions, when one doesn't have certain controls, let's say, one can really do very interesting work.

**Richard Taylor:** Yes. But then there's a parallel force — a kind of an anti-self-expression force going on at the same time.

**MoMA:** Do you mean within the person?

**Richard Taylor:** Yes. As the person is feeling insecure about themselves — about their future — they're full of fears.

**MoMA:** In the past you've said that being diagnosed with dementia is quite different than being diagnosed with other illnesses. What do you mean by that?

**Richard Taylor:** When you're diagnosed with dementia of whatever kind, everybody goes home and cries. Everybody is just worried about how bad it's going to be. And that really makes it very difficult to deal with it, and makes it fundamentally different in how people respond to it. There's a hopelessness about it. Nobody thinks that there is a way to compensate for what's happening.

**MoMA:** When describing your own diagnosis, you often say that you've been diagnosed with dementia, probably of the Alzheimer's type. How do you characterize what is called "Alzheimer's disease"?

**Richard Taylor:** It's not a discrete process in human beings. It's not a foreign process. It's not like it's introduced where you have a virus or a bacteria. We don't know what causes it. We don't know its progression. We don't know how to differentiate it from the other fifty forms of dementia, right? It may just be the natural response of aging brains, because no two brains are exactly the same in terms of how they work.

around me are not being truthful with me. In fact it would be easier to list what I am not fearful of: my family, my granddaughters, my dog, my garden, the Dalai Lama, and a few other people and things.

I have many fears about what is going on inside of me. I fear I am losing control of what rightly or wrongly I have long thought I was in control of: me, who I am, how I am, how I think, what I think about. It all seems up for grabs now. What happens when I lose confidence in my ability to think... when I begin to suspect and then confirm that what I thought was true was in fact not true—at least in the eyes of most others—when I know my thoughts are confusing rather than clarifying to me?

I'm fearful of my own self. I'm fearful of not knowing who I am. What's going on around me, my sense of a lack of control, lack of knowledge of myself and my world.

We get these variances in how people grow old. Just because one person is ninety-one and has all their faculties doesn't mean that that's the gold standard, and that's how everybody should be, and everybody who is not is diseased. They may not be diseased at all. It's the wrong way to look at them.

**MoMA:** Coming back to the idea of art and expression, do you think that social institutions and society at large might also be discouraging people with dementia from exploring their expressive sides?

**Richard Taylor:** Well, yes, they're not encouraged to do it, even by their caregivers, because there's this sense that they're fading away, that they're damaged, that they're losing themselves, and you don't want to embarrass people by pointing out their deficits. You just don't engage them. People will say to me, "I didn't call you because I didn't know what to say on the phone." They don't want to embarrass me, but actually they don't want to embarrass themselves by asking me a question that I can't answer because I can't remember or I don't understand it.

**MoMA:** You are an advocate for creating meaningful programs. What should people creating these programs take into account?

**Richard Taylor:** They should be thinking about their belief in the possibilities within people who have dementia for original thought, for a metaperspective on themselves, for personal growth. People who have dementia are not perceived as having the capacity to learn anything new. They're just hanging on to what they had, and everybody's job is to hang on for them or with them. The idea that you can be failing cognitively and still learn something new is foreign to most people, and I see it as potentially very satisfying to people who know that they're failing, that they can also realize they still have the capacity and the desire to learn

something new, feel something new, to have an insight that is original and that other people honor.

**MoMA:** How do you see that translating to museum programs, specifically?

**Richard Taylor:** People in museums should be sensitive to how people with dementia need to be — I call it re-abled. People who come in might be beaten down because nobody's had a conversation with them in a year or two years or five years about anything other than what they want to eat for dinner — that's probably true of half the people who come to the museum. They need a more tolerant audience than the general population.

**MoMA:** You mentioned that it is often thought that people with Alzheimer's disease cannot function at an abstract level, that they cannot learn. Which common assumptions related to Alzheimer's disease do you believe are myths and which are really legitimate?

**Richard Taylor:** There are two dynamics going on with dementia. One is that people can't recall things, they forget things; and the other is that the process that recalls things is not functioning properly. The things are there to be recalled; they either can't access them — they learn something, but now they can't remember it — or they learn something but when they access it, it comes back in a different form, so they actually unlearned it as they're reprocessing. It's a myth that people in an IQ sense get dumber as they get Alzheimer's. It's a myth that they can't understand, but it's a reality that they forget quickly. It's a reality that they recall things in different ways than they have actually learned them because they may not recall them accurately. That's not justification for not teaching them something initially. Unfortunately though, that's what happens — people just give up.





I'm fearful of my own shadow because I don't know who that is who sometimes follows me around morphing from a giant to a dwarf as I change directions when walking.

So how can you empathize with my situation? You who are still scared of snakes, losing your job, that your hair is falling out, that you have bad breath? I don't mean to diminish the importance of your fears; I just want you to ponder the ultimate fear, fear of watching yourself, as you know yourself and as others know you, die, morph into someone no one knows and perhaps no one including you may particularly like or love.

I just want you to ponder how it feels to be out of control of your thought process (and sometimes be aware of it, and sometimes not be aware of it, and never know what state you are in), to not trust what you see, hear, smell. This is my world. This is what is going on between my ears some of the time.



**MoMA:** You've worked a lot with different associations, institutions, etc. What can be done to change thinking about Alzheimer's disease at an institutional level? How do you think cultural organizations can assist in helping people work through the disease differently?

**Richard Taylor:** Frankly, I think there's a very paternalistic attitude with a lot of institutions; you know, "Isn't it amazing that somebody with Alzheimer's can paint? Oh, there's still something left, isn't it amazing," as opposed to it was always there and has never left. Most organizations are caregiver-driven, caregiver-focused, caregiver-peopled. I think museum programs can help caregivers get a better perspective on their loved one as a whole person because you're giving them the opportunity to actually watch their loved ones talk to other people and act like a whole person. You're also presenting the opportunity for individuals with dementia and their caregivers to become socially networked with others.

**MoMA:** For assisted-living facilities, nursing homes, etc., making trips to a local museum or gallery can be incredibly challenging. How do you think we might convince the staff at these facilities that these trips are worthwhile?

**Richard Taylor:** I think you have to sit down and try to find a kindred spirit there who understands — who appreciates that this isn't a field trip, this just isn't an exposure to the market or a show. This is really an exercise in self-expression. That's how you have to say it. This isn't a "go look at the art"; this is a "go look at yourself," and the art is just a stimulus for that. You've got to break the mind-set that this is a field trip, just going to observe something. You have to distinguish for them the difference between purposeful activities like going to a museum and other activities like going to a show or festival. This is an opportunity for self-expression. People participate in this; they help define

it rather than just observe it; they are not just a part of it, they are "it." They are what's happening in it. It just happens in front of a piece of art.

**MoMA:** Richard, one last thing before we go. How are you feeling these days? How is this disease transforming or affecting you?

**Richard Taylor:** I'm much more scattered than I was when you last saw me, but I can sit down and still have a conversation like this. I loved this. It's reaffirming to me, but I won't be able to recall most of what I said now, because I used to be able to do that. These insights just sort of come and spill out, and then they're gone for me.