

Jay Smith

is a former architect and an advocate for Alzheimer's disease research and programming.



I had no idea that I had been dealing with memory loss or anything related to Alzheimer's for several years. My diagnosis was a complete surprise. I had gone on disability from work a year and a half earlier because I was just too tired to work anymore.

After three months of seeing doctors, we had no answers except a false diagnosis of mild sleep apnea, and Alzheimer's had been ruled out by a neurologist. So I was at a dead end. When I finally got the diagnosis, my wife, Marilyn, and I kind of gulped. "My God, Alzheimer's. You know, I've heard of that. What do we do?" And so we went directly from the doctor's office to a Barnes & Noble.

We combed the shelves and came away with four or five books on Alzheimer's and began our reading, thinking, "We've got to find out about this. Now we know what the answer is to what I've been dealing with for the last two or three years, let's start dealing with it."

Let's start finding out what it is, what the choices are." We hit the road running. There was no period of denial. There was no emotional reaction. It was a relief to have an answer. And so what began was a new life of taking my life back.

Today I think of myself not as an Alzheimer's patient, but as a person living my life with Alzheimer's disease. I'm starting to get comfortable with it, and during the three years since diagnosis, I've become an advocate, committed to changing the face of Alzheimer's, eliminating stigma, increasing awareness, and influencing public policy.

I believe that exercise, good diet, stress reduction, support groups, socializing, and staying active are powerful tools we can use now to fight the disease while researchers continue their quest for better treatments. I don't put my energy into hoping for a cure in time for me. I turn my attention to living

Interview with Jay Smith

MoMA: Why don't you begin by telling us briefly about how you reached your diagnosis.

Jay Smith: When severe fatigue abruptly ended my professional career four years ago, I began to completely refocus my life. My career as an architect had been focused on planning and designing buildings for the justice system throughout California and the West.

My disability began an intensive search for the cause of my symptoms that quickly came to a dead end three months later with no answer. Over the next year I began to refocus my life as part of a holistic mind-body-spirit approach to taking care of myself. My return to doctors after that year-long hiatus came as a result of my fight with my disability insurer for my disability income benefits. In denying my appeal, the insurance company offered to keep my claim open for ninety days to allow me to submit neuropsychological test results in support of my assertion of cognitive impairment. I found a neuropsychologist and took the tests. The tests clearly indicated memory loss, and he recommended we see a doctor to find out the cause. We made an appointment to see my doctor. Upon reading the report, he told us I probably had early Alzheimer's. He started me on Aricept, ordered a PET scan, and gave me a referral to a neurologist to review its results. It's good for patients to know what's wrong with them and to be able to take charge of their lives.

MoMA: What we hear a lot is that people who have Alzheimer's disease or dementia can become apathetic and go into a shell. You, on the other hand, are very active and driven.

Jay Smith: Through my advocacy and media outreach, I am doing everything I can to put a new face on early Alzheimer's disease, learning and demonstrating that there is lots of living to do and much to contribute while living the hopefully many productive years available after diagnosis, and helping to change the conventional mindset about the disease, demystify it, and reduce the stigma.

As we confront the wave of aging baby boomers, who will be getting their diagnoses earlier, while having many years of living still ahead, the Alzheimer's community must now embrace the new, public face of early Alzheimer's and finally overcome and put an end to the widespread counterproductive, even crippling, belief that there is nothing we can do.

MoMA: What do you think are some of the prevalent myths associated with the disease that are contributing to the stigma that surrounds it?

Jay Smith: In the history of the disease, people have typically been diagnosed pretty far along. The prevalent myths about the disease are based on that, that people are already gone, sliding down the slippery slope of losing their minds. It's important for the patient to know what's wrong with them once they begin experiencing symptoms. In the future, we'll even be talking about how important it is for them to know way before they even have symptoms. The person in early diagnosis can take up the lifestyle changes that are known to improve brain plasticity. And if we don't diagnose people earlier, then how are we going to test promising drugs' effects on the very early stages?

MoMA: Have there been benefits — as strange as the question sounds — to knowing that you have Alzheimer's disease? Has your attitude or behavior changed since diagnosis?



this life. But medical science is starting to say that we can improve our health and possibly slow Alzheimer's progression with a vigorous program of good diet, exercise, and stress reduction, and that a healthy-heart lifestyle is the best strategy for a healthy brain. I take medications to treat my symptoms, attend three support-group meetings, and do volunteer advocacy work for the Alzheimer's Association in Los Angeles. But my best therapy is traveling with my wife, playing guitar and mandolin, attending music camps, singing in a choir, reading, and meditation.

My own personal mantra—and my advice to others who are just beginning the course that I began three years ago—has become “Live your life as if there's no tomorrow, and treat yourself so you will have as many tomorrows as possible.”



Jay Smith: Oh, yes, absolutely. It's refocused me on the importance of enjoying life, being present, and being connected with my family and my friends. I'm enjoying my music — mandolin lessons and my chorus — which started about a year or two before the disability. It's caused me to completely change my priorities. I just got in touch, through this process, with what my real underlying life's priorities were. As it became clear, it came down to four: commitment to family; commitment to self-expression, my own self-expression through music and singing and so forth; commitment to lifelong learning, which now looks like a bookshelf full of information on Alzheimer's, natural healing, mind-body-spirit meditation, and yoga; and then, finally — let's see, oh yeah, this has always been a footnote, and I've avoided it all my life — service to community, giving back. That one was kind of a surprise to me, because it's like I've always resisted that.

MoMA: Why had you resisted it, and why do you think it kicked in now?

Jay Smith: Well, it kicked in now because with my experience I have so much to share, and so much I can impact, improving the lives of thousands, if not hundreds of thousands of others like me.

MoMA: You spoke earlier about your own artistic endeavors. What do you think could be the benefits in general of engaging in forms of self-expression?

Jay Smith: There's a lot of science about this, creative expression itself, and it includes that whole orb — creativity, self-expression, living in the present. Art, self-discovery, and creativity are an important part of that. Talk about putting you in the moment — it really does it. I wish I could quantify the benefits for you. It just gives me a reason to get up in the morning.

MoMA: What do you think museum educators, or anyone else working with this population, should know or understand about people with Alzheimer's disease?

Jay Smith: In many ways, people living with early Alzheimer's are no different. We want to learn about and enjoy beautiful and inspirational objects and ideas. But we are different in some special ways. It can be very difficult for us to hold more than one idea at a time. It is nearly impossible to multitask. Reading a book takes more time, as we have to go more slowly and read paragraphs over and over. Following a plot line in a movie is getting tougher for me. Focusing on an abstract idea might be challenging for some. So concepts should be presented clearly and directly. Select and emphasize a main theme or idea, and describe it forcefully. Present one idea at a time.

MoMA: What do you think a museum program, specifically, can bring to people?

Jay Smith: Most people don't go to the art museum very often, and probably not as often as they should for their own good. Experience of art is important to self-discovery, so that brings us right to what we're talking about. Any program should be geared to opening people up to appreciate the beauty in the natural environment and in the man-made world — whether it be music, art, design, nature, animals, whatever it is, and extend the experience of art into everyday living. I think you've really come down to a question for me to continue to ponder. It sort of brings us back to the issue of self-discovery, finding your true self.

