

perspectives

This section features conversations with leading authorities in the fields of Alzheimer's disease and creativity and aging. It begins with an etching by Grayson Perry in which the artist attempts to map the landscape of his mind.

Two national advocates describe their experiences of living with Alzheimer's disease and provide insight into the disease's effects on daily life and cognitive functioning and the inherent need for self-expression of those affected by dementia.

Interviews with professionals in the fields of art, aging, and Alzheimer's disease give a sense of the importance of and potential for personal growth for older adults in general and individuals with Alzheimer's disease in particular. The conversations focus on the benefits of meaningful programs for individuals, families, professionals, and institutions, as well as society in general.



Conversation with Jed Levine and Peter Reed of the Alzheimer's Association

Jed Levine is Executive Vice President and Director of Programs and Services at the Alzheimer's Association, New York City Chapter.

Peter Reed, Ph.D., is former Senior Director of Programs at the Alzheimer's Association National Office.

MoMA: In your experience, what are some of the programs or services that people with Alzheimer's disease are asking for?

Peter Reed: I think one of the things that came out loud and clear when we conducted our town hall meetings and heard directly from people with dementia was that people are looking for ways to remain involved in the community and to participate in activities that they enjoy in their daily life. It gets fairly complicated, though, because there's the stigma that's associated with the disease, and there's almost resistance on the part of everyone else to allow them to continue to maintain their relationships, to maintain their friendships and their connections with other people, to remain a part of community organizations that they've been a part of. They are looking for new opportunities and different things that they can do that are specific to them as people with Alzheimer's disease.

MoMA: How would you characterize a successful activity or program?

Peter Reed: There is a need for programs that are not necessarily therapeutic but that engage people socially and give them an outlet, programs that give them an opportunity to express themselves, to connect with others who are going through a similar experience, and to maintain meaning and dignity in their lives. It is really very important, and it's something that people with early-stage Alzheimer's disease are telling us they really need and want, and there aren't a whole lot of programs around the country that enable them to remain active in that way. It's certainly something that needs to be developed, and where there are ideas and models, such as the one MoMA has developed, they need to be disseminated more widely.

Jed Levine: We are not solely cognitive beings but have social, creative, and emotional sides that can be nurtured through programs. No one is claiming that museum programs delay progression of the disease, but they do improve quality of life and may have a secondary impact on depression and isolation.

MoMA: You have both mentioned a need for programming with a social component. How important is community building when it comes to this population?

Jed Levine: Part of our goal at the N.Y.C. Alzheimer's Association is to create a sense of community to combat isolation. MoMA creates that sense of community, too. Part of it is the nature of the educators — caring, compassionate, and smart. People with dementia are accepted for who they are, and everybody can relax and enjoy the moment together. All people need meaning in their life.

Peter Reed: Art museums are natural gathering places where people can come together, share their experiences and ideas, and get beyond the disease, which I think is really nice. It's not a support group, you're not talking about Alzheimer's disease. You're just expressing



yourself and enjoying a discussion about a great work of art — something that is very creative and inspiring to others — so it allows people to continue to flex their creative muscle.

MoMA: What should museum educators know or understand about people with early-onset or young-onset Alzheimer’s disease? Is there anything about this sector of the population that is different than those who are diagnosed later in life?

Peter Reed: The experiences of younger people with the disease really relate to where they are in their life course, now that they are experiencing cognitive challenges. So, for example, many of them probably were working, many of them probably have young children, and so there really is a different experience. Also, they’re unable to access a lot of the federal funds that are available for medical care. I think that the most important thing in terms of programming is recognizing that if there are younger people that want to participate, that’s great, but they also need to acknowledge and embrace the fact that there are older people there as well. The dynamic between an older person and younger people with different needs can sometimes be a challenge. The museum educators need to make sure that people are being mutually respectful and patient with each other.

MoMA: What do you think that all participants, regardless of age or cognitive ability, take away with them after the program?

Jed Levine: I believe that there is an emotional carry-over from a museum program. It’s an enormous gift to give people, especially for lifelong patrons of the arts: an important part of who they are and an opportunity to normalize their lives again, to share the museum’s wonderful richness, to regain that relationship when there’s no Alzheimer’s in the room.



Conversation with Mary Sano and Margaret Sewell of Mount Sinai School of Medicine

Mary Sano, Ph.D., is Director of the Alzheimer's Disease Research Center and Professor of Psychiatry at Mount Sinai School of Medicine, and Director of Research and Development at James J. Peters Veterans Administration Medical Center in New York.

Margaret (Meg) Sewell, Ph.D., is Assistant Clinical Professor of Psychiatry at Mount Sinai School of Medicine and Director of Education Core at the Alzheimer's Disease Research Center in New York.

MoMA: Based on your research, do you think that there is value for individuals with dementia in engaging with art?

Mary Sano: I've observed MoMA's program, and the thing I am most impressed by is the positive engagement between the person with Alzheimer's disease and the educator and their caregiver. You can see them become more verbal, more engaged.

Meg Sewell: Interestingly, memories that are visually encoded are very vivid and can be easily stimulated, so you look at a painting and you may suddenly remember a house you had on Cape Cod when you were fourteen years old. Research has shown that memories that get encoded visually versus just aurally are very powerful, both in normal aging and in patients who have cognitive impairment. Consequently, visual stimulation is very powerful. It may also trigger visual memories that a person may not be able to expand upon verbally.

MoMA: What research has been done that validates this notion?

Meg Sewell: There's been some research on patients with dementia — again, not just regularly aging people — and music therapy and art therapy, very broadly defined, that has shown interesting changes in cognition, sustained attention, behavioral symptoms, self-esteem, increased socialization, and sense of well being, which is important, but a lot remains to be understood. The point I want to make is that I think it's good that the outcomes are more quality-of-life or person oriented, rather than focusing on improving performance on memory tests. I don't think we need to say, "Ugh, well, there's no scientific proof that this works, because you didn't remember words on my memory test after you participated in one of these programs." I think it's much more reasonable and important in the long run to focus on quality-of-life outcomes. They're more meaningful, they're more practical, and they're more realistic for this group of people.

MoMA: In terms of Alzheimer's disease and other dementias, do you know of other non-pharmacological treatments that are being explored?

Mary Sano: There is a lot of interest in keeping individuals engaged in socializing activities. The thing I've been particularly impressed by in MoMA's program is the training of the educators who understand that the individuals may have some perceptual difficulties. So they help them find their way through the picture by pointing out objects and drawing their attention to certain things.

MoMA: Both of you have observed the Meet Me at MoMA program. What advice would you give to museum staff who plan to work with this audience?

Mary Sano: I was really struck by the fact that the program didn't depend on a person's specific history with art. I thought it was very mature and respected the individual. The educators acknowledged that people had lives and histories before they came to have a disease, and they called upon that. I thought the program was highly structured and planned. There was enough staff, spaces, and resources so that the people who were there had the full attention that they needed. It's done on a day when the Museum is closed, and everybody can sit. It's physically manageable, and the groups aren't large. You can't take those things for granted. I think that those are the features that make people more likely to attend. Keeping it at that level is really, really important to make it successful.

Meg Sewell: A successful experience involves interaction with a sense of humor, along with redirection and validation of the patient. Tangentiality, getting off topic, is a big issue in this population, so you may be talking about the use of color in a painting, and someone will say, "I wanted to paint my room red, and they wouldn't let me." It's okay. That's their own association. Help guide them back, or feel free to go off on their tangent—sometimes their tangents are more interesting than what you were talking about anyway! Most importantly, be sure to validate whatever it is that they're able to bring to the program in any way that you can.

MoMA: What should educators know about the early versus the later stages of the disease?

Mary Sano: When I saw MoMA's program, there were both early and more impaired individuals there, and I was impressed with what appeared to be real positive experiences even in the more impaired individuals. I think it's so obvious when you see the faces of the people participating in that program that it has great value. You don't have to make people's memories

better. You just have to give them a chance to have a nice time with someone that they're spending time with.

MoMA: Why is early diagnosis so important?

Meg Sewell: You want to offer patients and their families an opportunity while the patient still has autonomy to make choices about their life: to talk about end-of-life care, advanced directives, finances, family issues, living arrangements, for them to be able to participate with dignity as a person in their future and engage in the world around them, in programs like this, while they still have the ability to do that.

Mary Sano: We know that one of the toughest parts of this disease is keeping family members and partners engaged with the patient. These programs offer an activity that they can share and enjoy and allow them to keep their bond strong so that the caregiver is then able to keep caring for the patient, maybe in another moment in time when they're more difficult, when they are having more problems or when they feel fatigued themselves. I think that's really where the strength lies.

MoMA: Do you see a role for the medical community in supporting, promoting, and expanding these types of programs?

Mary Sano: I'm not exactly sure what role they can play, except to encourage people to participate. I think that in some ways some of the advantages to such programs is that they de-medicalize individuals with a disease and allow them to go back to being the person they once were.



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?

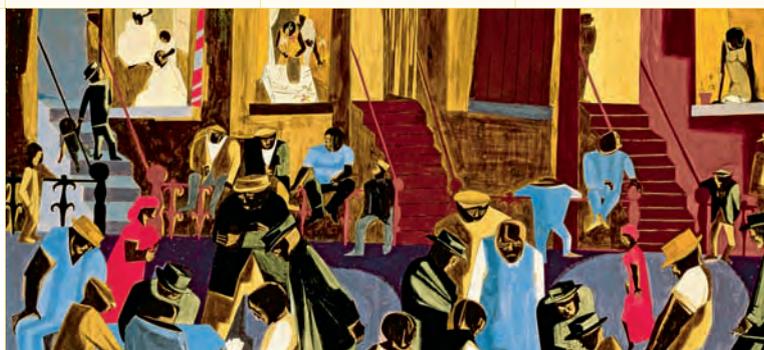
Richard Taylor: There are two dynamics going on with dementia. One is that people can't recall things, they forget things; and the other is that the process that recalls things is not functioning properly. The things are there to be recalled; they either can't access them — they learn something, but 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.



Conversation with Gene Cohen of the Center on Aging, Health & Humanities and Gay Hanna of the National Center for Creative Aging

Gene Cohen, M.D., Ph.D., is Director of the Center on Aging, Health & Humanities at The George Washington University, Washington, D.C.

Gay Hanna, Ph.D., M.F.A., is Executive Director of the National Center for Creative Aging, Washington, D.C.

MoMA: Dr. Cohen, why don't you begin by talking a bit about your research into memory and the imagination.

Gene Cohen: We're born with no memories, but we're immediately responding to things that are stirring our imagination. Similarly, when memory is going, the capacity for imagination is still there, so even in the absence of understanding something from the perspective of specific memories — concrete facts — the imagination helps people enjoy what they're looking at. When we enter middle age the two hemispheres of our brain begin to work more closely together. Prior to that, we used them both, but depending on the task, we would use left-brain more for some activities, and right for others. It's not the same as what people sort of narrowly saw as right-brain versus left-brain people. It's not at all that simple. Everybody uses both sides, but in middle age they begin to use both sides of the brain together. I've described it as moving to all-wheel drive. I've also suggested that any activity that uses

both sides of the brain optimally is, in effect, savored by the brain. It's like chocolate to the brain. It's like you have a new capacity or skill. One of the things that people don't realize that's also going on here is that with the dementia people still have their imagination. Especially if they're beyond mid-stage or early dementia there's still a lot of capacity; in mid-stage, where there's a lot of impairment, the imagination is stronger than the memory.

MoMA: What can arts programs offer people with dementia and their caregivers?

Gay Hanna: The power of art to engage is clinically so very strong, in terms of serving people with Alzheimer's and memory loss. The energy coming from the visual art itself engages in ways that are so unexpected, and actually they're quite mystical, so I don't think anyone really knows why this happens. The ability of the museum educators to break through and engage, always with the highest expectations, I think that is what we are finding is so important in our work.

Gene Cohen: There's been such a shortage of quality-of-life experiences for individuals with Alzheimer's — still you hear that there's no treatment for Alzheimer's disease and it's such a narrow use of the term. It means that right now we don't know how to prevent it; we don't know how to cure it; we don't know how to stop it. But there are all kinds of treatments that affect your quality of life and, in that broad spirit, what museums like MoMA are doing is a major contribution. They're getting people out; they're mobilizing the caregivers as well as the patients.

MoMA: If you were trying to convince a museum to begin a program like Meet Me at MoMA, what would you say?

Gay Hanna: That it's highly replicable and can be adapted to any museum of any size. It serves an untapped demographic that's huge and that's growing, and it will build new partnerships and awareness for the museum and what it can do. I think it's a very easy sell. I think the challenge, which is being met beautifully by MoMA, is coming forward with that clear, replicable model. Programs such as Meet Me at MoMA are really changing the whole paradigm of aging — from aging as a time of loss to aging as a time of gain and growth.

Gene Cohen: People want to tell their story. This is a period of life where you see a growing interest in writing autobiography, memoirs, genealogy, so this storytelling about one's life is normalizing, and also, in general, a lot of people who attend theater, opera, concerts, and museums are older persons, so it's normalizing in that sense to do so. I think museum programs are a terrific thing to do and help both the patients and the caregivers. These are the types of things that people remember; they eclipse the many ugly and depressing and distressing experiences. Having an upbeat experience, that's what most people tend to remember. It displaces a lot of the garbage in the memory.

MoMA: How do you see these types of programs affecting society at large?

Gay Hanna: There's a growing field in education called geragogy, which focuses on learning and teaching in later life. This is all emerging because our demographics are changing so dramatically, and will be for decades. We are interested in people living longer and healthier lives, and even if they aren't so healthy they need to have a way to be engaged and to find meaning and purpose. We as a society need to change our expectations.



Interview with Anne Basting of the Center on Age & Community

Anne Basting, Ph.D., is Director of the Center on Age & Community at the University of Wisconsin-Milwaukee.

MoMA: Let's start, if you would, by talking about why it's important to bring art — in its broadest context — into the lives of people with Alzheimer's disease.

Anne Basting: It's important for the reason that art is important in anyone's life. It's a way of thinking and a way of experiencing the world, and a way of expressing yourself for anyone, so in some ways you go back to the inherent value of art, in general. I think the shocking thing really is that people have assumed that this wasn't possible for people with dementia.

MoMA: And why do you think art can be so effective when working with this audience?

Anne Basting: I think one of the reasons it's particularly effective for people with cognitive disabilities is that rational language and communication is exactly what it covers. Art offers emotional communication and the opportunity to train not only the people with dementia how to communicate emotionally, or how to use their remaining capacity to do so, but also to train the staff and caregivers who do the same thing. So, you're basically creating a mode of communication or a way for people on both sides of the care partnership to communicate through the arts, which is essentially emotional communication.

MoMA: How do you define success in a program?

Anne Basting: I think it is improved well being and quality of life for both sides of the care partnership. When you're able to increase the sense of well being and the quality of life, you're enabling people to make choices longer.

MoMA: What aspects of quality of life could these programs address?

Anne Basting: The vast majority of people are cared for at home, and the vast majority of them don't have any services at all. They're off the radar; we don't even know about them in aging services. These are the people who, if they heard that a cultural institution had a program, could be in a potentially life-changing situation. Over and over again we hear, "My friends never come around anymore; our family lives too far away." There's no socialization, which is so crucial, and there's no inspiration. That's one of the things about art; it can inspire you to think beyond your situation. So I think making cultural institutions, including art museums, part of the solution and part of the support network can have a dramatic difference on the experience of caregiving.

MoMA: What effect has your work with individuals with memory loss had on you on a personal level?

Anne Basting: In this kind of work, it's really crucial to recognize a couple of points. One is that people with dementia are capable of growth and skill building, really, truthfully, at any point. If you begin where they are, they can build skills, grow, and understand themselves more through their own self-expression. The second is that it's a reciprocal process, not you doing charity work. There's an incredible opportunity for the facilitator to grow as well. If you look at it as one dimensional, you're going to miss out on a rich, rewarding experience. I do think that people with memory loss and dementia, and people who are in

situations of struggling with loss, offer a unique view on life. They bring you into the present moment in a way that you otherwise might not be in the world of Black-Berries, calendars, instant communication with other people, and forward-driving productivity. It's almost as if because you're trying to be in the world of the person that you're interacting with, they're giving you the gift of that real-time moment. They remind you of the importance and the essence of human connection and communication, and that's a really powerful place to be. They also see the artwork through that same lens, and it's a really valuable way to see the world.

MoMA: How does this audience differ from other groups you've worked with?

Anne Basting: They are vibrant members of my community, and this is really no different than all the other work I've done with other groups. We had to change communication techniques a little bit, but it's not a huge shift. As with any different type of group, you're exposing yourself to a different view of the world.

MoMA: I'm thinking about the feedback that we have received from caregivers who take part in Meet Me at MoMA, and one thing that they seem particularly thankful for is that when they come to the Museum, the condition of their loved one, their memory loss, is a nonissue. I think what programs should strive for is this idea of normalcy.

Anne Basting: I think that's exactly right, and there's actually some research on that. One of the things that happens is that, as a family caregiver, it's as though nothing exists other than that disease, it completely consumes your life. To get out and get into a place where the disease doesn't even feel present, where you don't have to think about it for that time, where you're being honored and inspired instead, and invited to express yourself—that is a huge relief.

MoMA: How could cultural institutions contribute to this process of reducing the stigma surrounding the disease?

Anne Basting: Why should we set up this parallel universe for people with dementia and their families? Why should they go to adult day centers when they—living at home—can actually use their own cultural institutions for support? In some ways the role of institutions is to serve their community, and this is in many ways just another group within the community.

MoMA: This is really a societal issue. How can we bring about this cultural transformation?

Anne Basting: I think the whole key is in mainstreaming, because imagine if—and this actually happens, because enough people are experiencing this in their lives—the waitress at the corner diner actually knows exactly what you're going through, because her grandmother has it. So when you go down to the corner diner to have your ritual mid-morning cup of coffee and a doughnut with your husband, it's fine. You are in a safe place, where you don't have to worry about editing him, or that people are going to give you the hairy eyeball. It could be the same thing at cultural institutions. There may be a time when this kind of training is just normal for staff, so you just can go and not worry, you know? That's the whole thing—and it feels like it's happening pretty swiftly, and it can make all the difference in the world.



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.

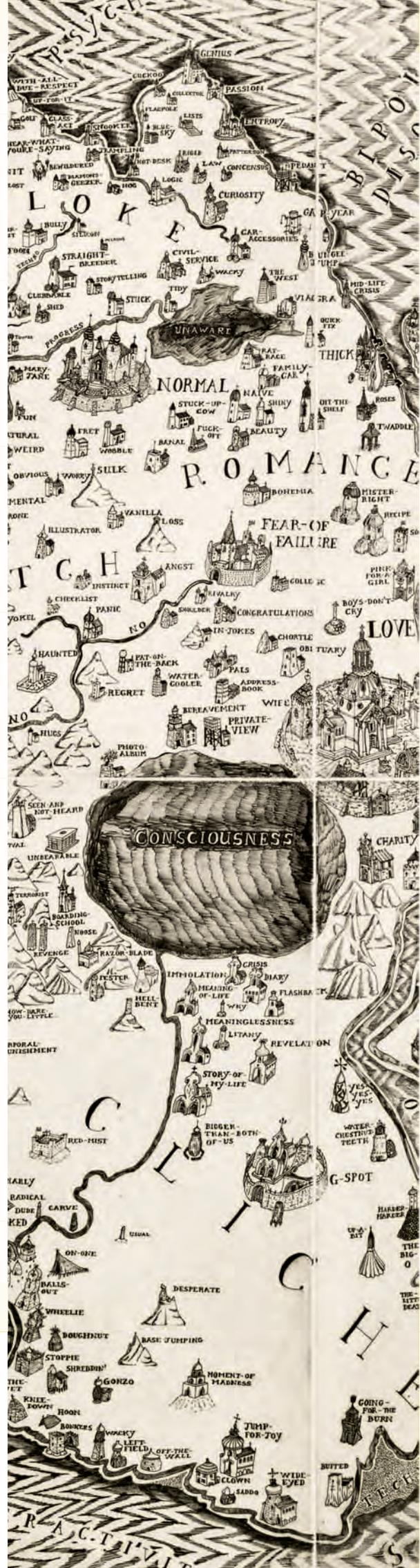
MoMA: What do you think museum educators, or anyone else working with this population, should know or understand about people with Alzheimer's disease?

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.





Roundtable with MoMA Educators

*Wendy Woon is The Edward John Noble Foundation
Deputy Director for Education.*

*Francesca Rosenberg is Director of Community
and Access Programs.*

*Amir Parsa is Manager of The MoMA Alzheimer's
Project.*

*Laurel Humble is Assistant for The MoMA
Alzheimer's Project.*

*Carrie McGee is Assistant Educator for Community
and Access Programs.*

Wendy Woon: Why do you think Meet Me at MoMA is an effective program?

Carrie McGee: At a basic level, engaging with art is fitting for people with memory loss because it does not require the use of short-term memory. Works of art — for the most part — are stationary objects. They don't move or change over time. Beyond that, engagement with art triggers both intellectual and emotional stimulation, and individuals with dementia are perfectly capable of responding to both types.

Francesca Rosenberg: Art also engages because it enables people to tap into the imagination. Even though memory may be affected by the progression of Alzheimer's disease, the imagination is still alive and rich. Art can serve as a tool for allowing the mind to roam. Whatever the medium — painting, sculpture, photography, and so on — and whatever the genre,

representational, abstract, expressionistic, etc., the works can serve to stir the imagination.

Amir Parsa: People talk about art as if it is clearly definable, as if it's all the same thing. It's in fact sometimes difficult to point out what these objects we refer to as "art objects" have in common. But I think the fact that we cannot clearly define art, that there is a wide range of possible definitions, makes this — and really a lot of our educational programs — successful. It allows for a certain type of engagement where opinions can truly be validated, where inquiries and digressions and insights lead to a wide range of legitimate interpretations, which in turn really allows people to understand and appreciate that they are contributors, part of a community of interpreters. The process becomes very exploratory and thus social and interactive and stimulating.

Laurel Humble: I think that, on top of that, we try to encourage people to determine their own narrative. We're not trying to convince them that one particular interpretation is the only correct one. We're not there to make people follow what has been established as the storyline of art history and theory. We definitely provide some of that information but the program is really about using that information as well as the interpretations of other participants to determine your own story for the work and reach your own conclusions.

Amir Parsa: That's why you have to emphasize the importance of the educators: they should not just lecture, but facilitate this type of exploration and discussion while giving information in relevant ways that allow participants to make connections.

Carrie McGee: It's important to point out that this program is not simply about looking at art; it's interactive. We use works of art to provoke dialogue. For individuals with Alzheimer's disease, this is especially

important. The way the disease can affect your ability to communicate as well as the stigma attached to it can make many individuals feel isolated. In this program we bring people together and encourage conversation and interpersonal connections.

Wendy Woon: Do most participants have prior experience with art?

Carrie McGee: Yes and no. We see participants who were never interested in art before coming to Meet Me at MoMA become incredibly engaged. They return to the Museum again and again, contributing valuable insights to the group discussion. I think it is because we are highlighting their strengths. We're asking them to think critically and to engage with art — and they rise to the occasion. Works of art are challenging to decipher and interpret for all audiences, so the program offers participants a chance to strengthen their sense of self and be empowered intellectually. An entire new world of interest can open up in this later chapter in life.

Laurel Humble: And it is precisely at the time when you're hearing that you won't be able to learn anything new. I think that along with highlighting people's strengths we are also simply expanding their worlds. I don't mean by just exposing them to the Museum and its collection, though I think that is very important for some, but more importantly we afford participants an opportunity to think beyond their current state. That brings us back to what Francesca was saying about the imagination, but the program moves beyond imagining to actually learning about developments in the practice of particular artists and art history, in general. Furthermore, you can connect the works to current and historical events.



Wendy Woon: How is this program different from other educational programs offered at museums?

Carrie McGee: People ask that a lot. I think one answer is that it's not that different; we're utilizing and experimenting with various strategies from the fields of museum and art education. We're just adapting them for this audience based on what we've learned about Alzheimer's disease and its effects on cognitive function. Another answer is that we emphasize the social component of this program much more than we do with other programs. Socialization is a fundamental part of the program.

Amir Parsa: I agree. It's not that different from a regular museum visit. In reality, the educator is engaged in the design of a certain type of interaction. I teach and conduct programs with that same frame of mind for all audiences. Educational programs are ways of creating connections to the world and to yourself. It's a way of knowing the world, relating to and understanding the world. That is still very true with this audience. In fact, the life experiences of participants, along with the changes relating to their cognitive abilities lead to great interactions, insights, and ways of seeing the world. In that vein, storytelling and socializing become central to the program.

Wendy Woon: What's interesting to think about is how this program can inform other educational programs.

Amir Parsa: On an even grander scale, I would add that the process of creating innovative programs for different audiences can provide opportunities for art museums to revisit and reframe the forms and functions of education, museums, and art.

Carrie McGee: It makes you wonder why museum programs for adults don't encourage socialization and

personal connection more often. I guess it's thought that providing space for the personal, emotional side of interpretation somehow detracts from the intellectual exploration. We've learned from this program that it doesn't, it enhances it.

Francesca Rosenberg: A good educator can weave it all together and make the experience that much richer. By encouraging participants to share their perspectives, we are asking them to connect the works to their own lives, to make them relevant. That in turn may tap into an emotional memory that, as we've learned, can have a stronger or longer-lasting impact than other types of memory. Also, at Meet Me at MoMA there is equal participation between participants with dementia and caregivers. It's because of this narrative aspect. Everyone has a story to share.

Wendy Woon: Francesca, going back to what you were saying earlier about educators — what should educators be mindful of when working with this audience?

Francesca Rosenberg: It is essential for the educator to be attuned to all signs of engagement. In order to effectively communicate and connect, the educator must not only listen to participants' words but also read their facial expressions and body language. One becomes highly aware of the level of engagement by concentrating on these various factors. This is true for all good teaching. I think it is important to emphasize nonverbal communication and that nonverbal signs can be just as meaningful as the words that come out of someone's mouth.

Amir Parsa: Through teaching the program you gain insight into the nature of engagement and how we determine and measure it. We've really come to the conclusion that it doesn't just take one shape or form. There are various forms of engagement and they don't manifest themselves in one particular way.



Wendy Woon: I would say the same thing about learning in general and forms of communication, including life-long learning and digital learning.

Laurel Humble: In addition to how we communicate with participants when discussing art, we've also learned how important it is to communicate the overall goals of the program to everyone from the outset, to make sure they understand that it will be an interactive experience and that we want everyone's opinions. You have to take steps to break down any barriers that might hinder communication and be explicit when describing what is expected during the program and when encouraging group participation.

Wendy Woon: Why do you enjoy working with this audience in particular?

Francesca Rosenberg: In this program there truly is a reciprocal relationship between participants and staff. As museum educators we learn a great deal from the participants during each and every program. Older adults have lived! Using works of art as a starting point, they, and they alone, can teach us about what it was like to live through World War II, to experience Coney Island in its heyday, and to participate in the Civil Rights movement. The participants open my eyes to elements of the paintings and interpretations that I had not considered. We are the students and they are the teachers.

Carrie McGee: Yes, many of the participants were alive when many of the works of art in our collection were made. They provide perspectives that no other generation can provide. They share such a wealth of information, which adds a new layer of interpretation. Once this generation is gone that can never happen again.

Amir Parsa: If you value how people see the world differently, and how cognitive changes allow for that change in perspective, then you can also be transformed. That's what happens. You learn and you are transformed by your interactions and the interpretations and the stories and the experiences of others.

Wendy Woon: How has the program changed or evolved since its inception?

Carrie McGee: It looks very different than when it first began three years ago. In addition to participating in training led by staff from the New York City Chapter of the Alzheimer's Association and Mount Sinai School of Medicine, we've gone to conferences across the country to be sure we're staying current as the field develops. We've taken what we've learned and applied it directly to our practice.

Amir Parsa: We've rethought the components of the program, devised new strategies for engaging participants, reexamined the types of artwork that can be used, and really transformed the essence of the program.

Francesca Rosenberg: The key to maintaining a successful and effective program is constant reassessment and evaluation. We hear directly from the participants as well as our staff about what is working and what is not working. We try to improve our teaching by observing other educators and critiquing our own practice. The staff need to be reflective and self-aware. If you establish a program just to check off a box, you won't provide a meaningful experience for anyone.

Laurel Humble: Also, over the course of the last year and a half, as we've traveled the country and been in contact with museum and other professionals establishing similar programs, we've heard of numerous adaptations that are all wonderful ideas. There isn't any



one answer. It's great to connect the specific logistics and structure of the program to the particularities of your collection, gallery or facility spaces, and audience.

Amir Parsa: We're leading training, as well, and by presenting and modeling our program we have the opportunity to analyze in depth every aspect of what we do. That allows us to fine-tune the details of our practice while learning from families affected by the disease, museum professionals, and staff from care organizations.

Wendy Woon: Why is a museum the right venue for a program for people with dementia?

Amir Parsa: A museum is a clean space, a contemplative space. It's a safe and stimulating space. More importantly though, it is where meaningful experiences can take place. Meaningful, leading to personal growth, but also leading to interactions and conversations that have multiple psychosocial benefits.

Laurel Humble: With this program there is a sense of ownership in your experience. Yes, we decide ahead of time which works to discuss and then lead the groups through the galleries, but you are there when the Museum is closed, and you have the galleries all to yourself. You have a personal educator who will not only share art-historical information and answer your questions but also listen closely to your insights and then connect them to the interpretations of others. So while your experience is highly individualized, at the same time it is linked to the experiences of others, which I think is very reaffirming. It is validating and situates you within a greater group.

Amir Parsa: That's right. It allows you to connect to the efforts, ideas, struggles, and visions of others, including the artists. It also allows you to reconnect to yourself, in addition to feeling that you are still

an important part of the social fabric, a valued human being engaging with the world.

Carrie McGee: It's also important to note that, as valued cultural institutions, museums are in a position to help deconstruct the stigma surrounding this disease. Time and time again individuals with Alzheimer's say that one of the greatest challenges they face is the overwhelming stigma surrounding the disease and its effect on the way they are treated in society. Museums can set an example by showing that people with dementia are, as Amir said, valued members of the community.

Francesca Rosenberg: Part of our goal is to act as a catalyst for change. We would like to help people affected by the disease think differently about the possibilities for a life with Alzheimer's disease or other dementia. There are ample opportunities to remain active members in the community through engaging in meaningful activities. For those who are less familiar with the disease, the program can serve as a learning experience to make them aware and demystify it. It's not a role that we necessarily think of for the Museum but it is in a way our responsibility.

Laurel Humble: It is definitely our responsibility. We should remember that museums serve as model institutions. They have the potential to set an example for the public through engagement with the community.

Francesca Rosenberg: In fact MoMA was founded as an educational institution with this idea in mind. People affected by dementia form a significant portion of the community, and with the changing demographics this segment of the population will only continue to grow.

Wendy Woon: What have each of you taken away from your experience with the Meet Me at MoMA program?





