

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.

