

Keeping Those With Alzheimer's Engaged



Marilynn K. Yee/The New York Times

Above, Francesca Rosenberg, of Meet Me at MoMA, offers insight on a tour, as Lee Robbins, center, a patient, listens.

By KAREN JONES Published: March 12, 2009

KAREN HENES was only 61 when her Alzheimer's disease was diagnosed in 2007, but she was determined not to let it crush her spirit. "It is a tough disease for a lot of reasons," said Mrs. Henes, a former financial planner who lives in Croton-on-Hudson, N.Y., with her husband, Michael. "One, you forget things, and two, there is no cure."

She said that even though the beginning is hard "because you are slowly saying goodbye to yourself," she considered it essential to stay active and "find things that stimulate you and support groups with people like you."

Part of staying active for Mrs. Henes means attending Meet Me at [MoMA](#), a program for early- and moderate-stage Alzheimer's patients and their caregivers held once a month at the Museum of Modern Art in New York. When the museum is closed, Meet Me at MoMA's trained educators escort groups of patients and caregivers to selected artworks for observation and discussion.

"I think it is awesome and another way to stimulate the brain," Mrs. Henes said. "I really don't know much about art, but they are very good at presenting everything so you really learn."

Mrs. Henes's daughter Rachel, 31 and a social worker, accompanied her on a recent Meet Me at MoMA tour at which they explored the work of Édouard Vuillard, Pierre Bonnard, Paul Gauguin and Henri de Toulouse-Lautrec. "I think the program is great in recognizing the strengths and talents people continue to have even in the face of a disease that might be limiting them in certain capabilities," Mrs. Henes said.

“Respect for people’s thoughts, opinions and perspectives is important in keeping their spirits alive. That can be a hard part of early Alzheimer’s.”

Rachel Henes said her mother was “very excited” to talk about what she had learned, extending the shared experience for both of them. “Being isolated, staying at home and stepping out of life can make the illness much harder,” she said. “I see a difference in Mom when she is active and participating in these kinds of activities as opposed to before she knew about them.”

Begun in 2006, Meet Me at MoMA grew out of years of research, pilot programs, focus groups and working with Alzheimer’s organizations to determine whether viewing and discussing art offered people with Alzheimer’s an opportunity for positive social engagement, self-expression and brain stimulation.

There has been plenty of anecdotal evidence to endorse the program, said Francesca Rosenberg of MoMA’s education department, but the museum wanted more confirmation. “We thought it was very important to have evidence-based research,” she said.

As part of a grant from the MetLife Foundation, MoMA commissioned New York University School of Medicine to study the effect of the program on Alzheimer’s patients and their caregivers, if any. Working with MoMA staff, N.Y.U. researchers spent nine months observing the tours, recording impressions, compiling before-and-after questionnaires and organizing detailed focus groups with participants.

“We came in to find out if we could show if the program was effective in any way,” said Dr. Mary S. Mittelman, director of psychosocial research and support at the Center of Excellence on Brain Aging and Dementia at N.Y.U. and principal investigator of the study. “The first time we went there, we were overwhelmed by how involved the participants were,” she said. “It spoke to the fact that people with dementia in the early stages are people first. They have an illness, and it affects certain areas of their functioning but not all. It is obvious they are enjoying the art and responding to their educators.”

Dr. Mittelman confirms that the study, which will be published this year by MoMA, provides the first scientific evidence of overall improvement in mood for a majority of participants as well as intellectual stimulation and positive social interaction. Also documented are the benefits of a shared experience of viewing and discussing art in an “accepting environment.” “The well spouse was able to see the ill spouse could still take part in ordinary, normative activity,” Dr. Mittelman said. Because there is no stigma within the group, caregivers “can really enjoy themselves.” They can see that the spouse is reacting, “which means he is really still there,” she said.

More than 2,000 visitors have participated in Meet Me at MoMA, with 95 percent returning more than once. Based on this success, the museum has also started the MoMA Alzheimer’s Project, an initiative to

help other museums and professional caregivers develop their own programs for people living with dementia and Alzheimer's. It includes print and online training guides and nationwide workshops, and, like Meet Me at MoMA, it is free.

More than 40 museums have contacted MoMA for information or participated in one of the workshops. "They were a huge influence," said Celeste Fetta, manager of adult and higher education at the Virginia Museum of Fine Arts, which conducts a tour for people with Alzheimer's called ArtLinks. "We couldn't have done it without them."

There are nearly five million people living with Alzheimer's disease in the United States, 10 percent of them under the age of 65, according to Jed Levine, executive vice president and director of program services of the Alzheimer's Association's New York City chapter. "One of the myths of this disease is that it is only for older people," said Mr. Levine, adding that another major misconception is that with a diagnosis "you immediately lose functional ability."

Mr. Levine helped to lead one of the first support groups for early-stage Alzheimer's patients, in 1991, and says that much more is known now about caring for a person in the early and moderate stages. "Given the proper supports, people can stay in their home, in their communities and participate in life in a very meaningful way," he said.

He calls the Meet Me at MoMA program "exquisitely well run" and emblematic of the changing perceptions toward people with dementia. "We are finally looking at all the residual strengths, like participating in art and enriching activities, rather than focusing on the multiple losses."

Natalie Robbins, 75, a former educator, started attending Meet Me at MoMA when her husband, Lee Robbins, 80, was in the early stages of Alzheimer's. A former lawyer, he was responsive and animated with their favorite educator, recalled Mrs. Robbins, adding that the program "really opened up his horizons." Though Mr. Robbins is now in a moderate stage of the disease and can no longer respond during the tour, they still attend faithfully.

"He is always happy to be there," she said, "and when I tell him we are going, he says 'good.'" The monthly outing has taken on an even greater meaning in their lives, since the other activities they shared through 42 years of marriage, like theater, travel and dining out, have had to slowly drop away.

"He needs stimulation in a comfortable environment," Mrs. Robbins said. "As he becomes less able, MoMA becomes more important. He can no longer articulate, but he can look, and he can smile."

<http://www.nytimes.com/2009/03/19/arts/artsspecial/19MENTAL.html?%2334;Karen>

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