

Arts in Dementia Care:

'This is not the end... it's the end of this chapter.'

By Anne Davis Basting

I'd been visiting Martha for weeks, but nothing much had come of it. I talked; she stared out the window. She didn't seem upset, but I didn't think she was really listening. I

thought she was simply enjoying the sound of my voice. So I started to ramble. I talked about whatever came into my head. One day, I mentioned something about Christmas. She pulled her head away from the window and looked directly at me. I asked her, "What did you do for Christmas when you were young?" To my great surprise, Martha began to sing in what I later learned was Swedish. She sang a song that had been a family tradition, three complete verses, with the chorus in between. Her face appeared lit from within.

Over the past decade while working in the arts with people who have dementia, I've witnessed several such miracles, as I consider them to be. People who have edited themselves into silence for fear of saying the wrong thing, or shut themselves down to avoid contact they cannot understand, can use the arts to reconnect with themselves and the people who care for them. And perhaps most important, the arts offer a chance for people with dementia to connect with the people who have forgotten them—their communities at large. The arts offer great

*Using art to reconnect
with others—and oneself.*

value to people with dementia and warrant tremendous hope for the future.

'THE ARTS' AND 'DEMENTIA' DEFINED

I would like to define these two broad concepts before I remark on their mutual benefits. First, by the term *the arts*, I mean any medium used for creative expression, including not just paint (visual arts) and costumes (dramatic arts), but words (poetry, storytelling), plants (gardening), food (cooking), fabric (weaving, fiber arts), clay (pottery), and the human body (dance). If it can be used to convey meaning, it is a tool for creative self-expression.

Second, by the term *dementia*, I refer to the umbrella category of deteriorated mentality that includes Alzheimer's disease, multi-infarct dementia, Pick's disease, Parkinson's disease, and vascular dementia. The latest figures suggest that these conditions affect up to 75 percent of older adults living in skilled nursing facilities and up to 50 percent of all people 85 years of age and older. We are also now learning more about dementia as it affects younger people, including those with multiple sclerosis, Down's syndrome, or AIDS. People with dementia can use creative expression, no matter the cause of the dementia and no matter where they

live—at home with a home health aide or family members or in communal living arrangements such as assisted living centers and skilled nursing facilities.

WHAT THE ARTS BRING

To people with dementia, the arts bring tools that enable them to express themselves and their vision of the world and are particularly powerful for this group because the arts operate on an emotional level. One needn't have control of rational language to write a poem, create a dance, or take a photograph. Where rational language and factual memory have failed people with dementia, the arts offer an avenue for communication and connection with caregivers, loved ones, and the greater world.

More specifically, researchers have tried to understand exactly how the arts benefit people with dementia, focusing mainly on quality of life, particularly by reading the faces of people with dementia to assess their interest, engagement, and pleasure, and by observing any reductions in what are called "problem behaviors," such as wandering, verbal outbursts, or aggressiveness. While such studies have found the arts to be effective, the numbers of people studied (sample sizes) are too small for the studies to be conclusive. In general, there are very few control studies of the effect of the arts on people with dementia in which arts programs are compared with other types of activities.

'MEDICAL' VS 'SOCIAL' ARTS PROGRAMS

Two basic and overlapping modes of arts programs are being used for people with dementia—medical and social programs. The differences between the two reside most often in the training of facilitators and in whether health-care payers consider the program to be a medical treatment for which they will reimburse the patient for expenditure.

Successful programs of both kinds share common characteristics: the arts are used to build skill (mastery), yield products in which the artists and their community can take pride, build sense of self, build social networks, and present no risk of failure. Effective arts programs are designed to go beyond keeping people with dementia busy. These programs are meant to

provide access to connection with friends, family, and extended community and access to ways of giving meaning to experiences, feelings, and observations.

Arts programs that are reimbursable as medical treatments are facilitated by certified therapists. The National Coalition of Creative Arts Therapies Associations (NCCATA) supports members certified in visual-arts therapy, dance/movement therapy, music therapy, poetry therapy, drama therapy, and psychodrama. The NCCATA fact sheet suggests that for people with Alzheimer's disease, "creative arts therapies can make the difference between demoralization and dignity, with arts experiences from the person's past to trigger short- and long-term memory, decrease agitation, and enhance reality orientation."

Many certified therapists who work in the medical model do not limit their work to strict therapeutic goals (which are to show documented individual improvement), aiming to expand their impact beyond the traditional medical narratives to address spiritual needs, maintain function, build community, and sometimes achieve an immeasurable but clearly positive impact on quality of life. Unfortunately, however, the overwhelming demands of paperwork and documentation that come with reimbursement can limit the focus of reimbursable arts programs for people with dementia.

On the other hand, social arts programs can be implemented by anyone with a passion for creative expression and with skills in working with people with dementia. The advantage of this kind of program is that it can be run by direct-care workers, volunteers, or family members. Additionally, staff-run, social-model arts programs empower the staff to loosen up the schedule of activity programming by integrating arts activities into the day as it unfolds naturally, as demonstrated by care models in the "culture change" movement.

Some social-model arts programs are run by professional artists trained to work with people with dementia. Arts for Alzheimer's (A4A) in New York City and Arts for the Aged in Bethesda, Maryland, are two programs of this kind. The best of these professional arts programs treat the person with dementia as more

than simply someone with an illness: They focus on developing the person's skills as an artist. Again, I want to emphasize that these two approaches, social and medical, are far from mutually exclusive. In fact, I believe they work best in tandem.

EXAMPLES OF PROGRAMS

The best arts programs are those that emerge naturally from the interests of caregivers and people with dementia. I suggest doing an inventory of interests in which staff, family, and volunteers write down all the things they do to express who they are. The list can grow quite long. My own includes things as diverse as photography, drawing, selecting music, road tripping, and baking. Meaningful arts activities for people with dementia can emerge from the individual passions found within the care teams. For example, as a staff member, I might lead a program in which conversations about car travel lead to the creation of a collage that captures the feeling of places I've been and the freedom of a road trip.

The second step is to do a similar inventory of interests for people with dementia. I might discover someone shares my passion for road trips or that someone's hidden interest sparks in me a desire to learn something new.

Although the best programs emerge naturally, several structured arts programs are available to assist staff, family, and volunteers who need a little help or inspiration. Following are some examples.

Memories in the making—visual art. Memories in the Making was started by LaDoris "Sam" Heinly in the Orange County (California) Alzheimer's Association chapter in 1987 and is designed for people in the early and middle stages of dementia. An artist facilitator, with knowledge of dementia, guides individuals as they create and express themselves through the visual arts, using, for example, paints or pencil to depict a memory. Men and women of all walks of life who have been diagnosed with Alzheimer's disease or other dementia are eligible for this program. No previous painting and drawing experience is necessary.

One of the benefits of established arts programs for people with dementia is that program training can be replicated and the impact tested.

Memories in the Making has been tested in several different settings. The most thorough testing (Kinney and Rentz, 2005) suggested that participants with dementia "demonstrated significantly higher levels of interest, sustained attention, pleasure, self-esteem, and normalcy during the activity," compared with the levels demonstrated during another activity (Kinney and Rentz, 2005). Again, however, the sample size was very small.

TimeSlips creative storytelling. TimeSlips is a program I know well; I developed it in 1996 while volunteering at a long-term-care facility in Milwaukee, Wisconsin. Instead of asking people with dementia to remember or reminisce, TimeSlips asks them to imagine a new story based on a provocative image. Working in small groups, TimeSlips facilitators ask open-ended questions ("What should we call her?" "Where should we say this is?") and accept all responses—be they movements, sounds, or words. Facilitators echo the responses back to the participant to confirm, and then weave the responses into the fabric of the story as they retell it. Anyone can be trained to facilitate a TimeSlips storytelling session, and anyone can be a storyteller. I find TimeSlips most effective with people in the middle to late stages of dementia. I am most moved by storytelling sessions facilitated by direct-care workers who overcome challenges having to do with literacy, language, and confidence to take great pride in their own accomplishments and those of the storytellers.

TimeSlips follows a ritualized structure, making it easy to teach and assess. The most recent study on the impact of TimeSlips (Basting et al., unpublished manuscript) asked whether it improved relationships between staff and residents in residential skilled nursing settings. In the first ten homes studied (five were test sites and five control), researchers found that the homes that received TimeSlips training had a significantly higher number of interactions between staff and residents. Qualitative studies found that TimeSlips increased the communication skills of people with dementia and also improved the job satisfaction of staff.

Reminiscence and life writing. The researcher and author Gene Cohen (see article, this issue) developed a noncompetitive board game, Mak-

ing Memories Together, to assist families in sharing memories and reminiscing with loved ones with dementia. Bi-Folkal Productions provides reminiscence kits on particular topics that contain sensory props (objects that people with dementia can touch, smell, hear, and see). But I would not categorize either of these approaches as “art” per se. Instead, reminiscence and life review prompted by these approaches might be the raw materials used for an arts program, for creations such as a visual collage of images in a memory box, bulletin board, or scrap book; a poem or verbal collage; a tape recording of stories told by the person with dementia; or a collection of movements that emotionally capture the person’s feelings on a particular topic.

One example, the Age Exchange Theatre and Reminiscence Centre in England does not differentiate between arts and reminiscence programs. For people with dementia, the center offers programs that spark reminiscence through the arts and then in turn channel those memories into creative outlets. Some of the most inspiring arts programs involving older adults that I’ve seen have come from Age Exchange and their European colleagues in the European Reminiscence Network.

Other programs of interest. A number of other innovative arts programs are available for people with dementia. Among these are Kairos Dance Theatre’s The Dancing Heart; Age Exchange Theatre’s Remembering Yesterday Caring Today; Judith Kate Friedman’s Songwriting Works; and Luther Manor’s ArtCare program.

EFFECTIVENESS

Researchers and artists alike strive to get more answers to this question to add to a wealth of anecdotal evidence. Ask any activity director—or anyone involved in dementia care on a professional level—and they can likely tell you of the magical effect of singing and dancing with people with dementia. But the real data lag behind the anecdotal. Therapeutic research has largely been on a small scale, single subject or small studies in single facilities without control groups. A study of TimeSlips in twenty nursing homes supported by the Commonwealth Fund was the largest and farthest reaching of its kind.

The Center on Age and Community hopes to build on what it learned from this study by holding a forum, “Creativity and Dementia: Moving Forward in Research,” an effort that will bring together researchers, artists, and care providers to think about how best to test the impact of the arts in dementia-care settings of various kinds. The proceedings will be available on the center website in the summer of 2006.

BARRIERS TO USE OF THE ARTS

If the arts are inexpensive and effective ways of helping people with dementia, why aren’t we using these tools? There are several barriers, some more challenging to overcome than others.

Professionalization of the arts. It used to be that we memorized poems in school and wrote poems for family holidays. But somewhere along the way, poetry became something written by people with master’s degrees and all but disappeared from the public realm. The story is similar in other arts. Professionalization of the arts is a good thing in that it offers a career ladder for those who wish to pursue it. But it also yields at least a generation of people who think they are not capable of being “artistic.” This group might include staff and older adults alike.

One of the big challenges in encouraging the use of the arts in dementia care is to convince staff of all levels and people with dementia that they can indeed be “creative.” They can see that they are creative through simple games and exercises that are designed to be “failure free.” Such exercises should not be heavily dependent on rational language (writing or reading), as this can be a challenge for people with dementia as well as for staff with language difficulties.

Focus on loss. Watching a loved one struggle with dementia can be very painful. Many people describe it as watching the person you love fade away, leaving behind a shell. It is difficult not to become overwhelmed by the losses dementia entails. But if one only focuses on loss, one can lose sight of the capacity of the person who remains. It can be challenging for families and staff to look past the loss and open themselves to recognizing and nurturing the strengths of the person with dementia. The arts provide a way to do this, but not everyone can come to enjoy the art-making process with people with

dementia. It might simply be too painful.

Time and money. While the arts and creative expression are open to everyone, arts programs work best if staff, family, or volunteers have some training. Training requires both time and money. Staff, family, or volunteers must take time from their caregiving tasks to participate in training and to conduct the arts program, and the training must be paid for. Moreover, the long-term-care industry is heavily regulated, and many specific types of training are mandated. In order for arts programs to successfully compete for time and money, we need research that clearly demonstrates the benefits of arts programs for the quality of life of people with dementia, and we need families who insist on the use of the arts to bring life to the daily routines of people with dementia in order to ensure that long-term-care managers prioritize both time and money for arts programs.

CONCLUSION

We as Americans, through our taxes and the price of our pharmaceuticals, support massive amounts of funding for Alzheimer's disease research. The vast majority of this research goes toward the expensive and laborious task of finding both cause and cure. The arts will not provide a cure. But the arts programs I have personally facilitated and observed have provided dramatic improvements in quality of life for caregivers and for people with dementia. We should certainly continue investing in the search for a cure, but we should also invest in research, design, and implementation that clearly improves lives today. Creative expression among people with dementia—social, medical, and

overlapping models alike—offers us the chance to bring hope to the lives of people with dementia and those who care for them.

In one TimeSlips storytelling session at the Jewish Home in Milwaukee, Wisconsin, storytellers in middle to late stages of dementia had just engaged in a raucous storytelling workshop for over an hour. Based on a picture of a baby in an old-fashioned doctor's bag, the storytellers toyed with where the baby wanted to go (on a cold Wisconsin afternoon). "Let's send him to the Bahamas!" said one woman. "Where else could he go?" someone asked. "To the Land of Peppermint Airplanes," another storyteller responded. Finally, as the story wound down, one storyteller said, "That's the end of this chapter. Listen in next week. No, this is not the end—it's the end of this chapter. We have nothing else to do but write more chapters." ☺

Anne Davis Basting, Ph.D., is director, Center on Age & Community, University of Wisconsin-Milwaukee, and associate professor of theater, Peck School of the Arts. She is founder and director of the National TimeSlips Project.

REFERENCES

- Basting, A., et al. Unpublished manuscript. "Effects of TimeSlips on Staff/Resident Interactions."
- Kinney, J. M., and Rentz, C. A. 2005. "Observed Well-Being Among Individuals with Dementia: Memories in the Making, an Art Program, versus Other Structured Activity?" *American Journal of Alzheimer's Disease and Other Dementias* 20(4): 220–7.
- Pepin, K., et al. In press. "Evaluating the Effectiveness of Arts Activities for Elderly Patients with Alzheimer's Disease." *Activity Director's Quarterly for Alzheimer's & Other Dementia Patients*.

Copyright of *Generations* is the property of American Society on Aging and its content may not be copied or emailed to multiple sites or posted to a listserv without the copyright holder's express written permission. However, users may print, download, or email articles for individual use.