

Building Empathy-Based Care Through Creative Expression

Presented by: Michael Smith, Eileen Smith & Kelly Papa
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ALZHEIMER'S RESOURCE CENTER
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Webster's dictionary defines empathy as *"Identification with and understanding of another's feelings, situation and motives."* In Greek, the word *empathia* means passion, yet our culture connects empathy with compassion rather than passion. The challenges presented in caring for people with Alzheimer's disease or related dementia gives us an opportunity to reconsider empathy as passion; a passion to create a connection with someone who has become disconnected due to this illness.

Understanding the perspective of the person with dementia is difficult for caregivers, family and friends. For individuals with dementia, the familiar is made strange each time their brain attempts to process routine information. The mind discharges its ordinary associations and distinctions, reversing perspectives, questioning some meanings and ignoring others, resulting in impaired memory judgment and communication.

People with Alzheimer's disease have difficulty finding ways to express themselves, but they still have expressive abilities that are imaginative, insightful, humorous, poetic and even inspirational. Directed exploration of the Arts and Humanities and new approaches to sensory stimulation reveal capabilities and comprehension hidden by the disease progression and by our cultural expectations of people with dementia. Self-expression through the creative arts enables us to build personal and meaningful connections with individuals affected by Alzheimer's disease, creating rich and empathic relationships with the people for whom we provide care.

Discovering the power of creative self-expression in long-term care started with art and music and has expanded to include the performing arts and multi-media approaches. Through these activities, people with dementia can harness their creative force, access it and express it. The following approaches have been used successfully and the stories are from actual events.

Studio Arts

An innovative strategy based on studio arts involves more than paint, pencils, a variety paper or clay, all of which are engaging and entertaining and inform us about a person's talents and interests. Integrating guided exploration into arts activities requires people with dementia to use visualization, reflection, examination, dialogue and replication to express the feelings, memories or stories generated by a painting, drawing or sculpture.

Imagine being told to "paint" or to "draw" something on a blank piece of paper. Now imagine being in a group that is asked open-ended questions such as, *"What do you see in this sculpture?"* or, *"How do you feel looking at this painting?"* or, *"Does this picture remind you of anything?"* Responses such as, *"I see a big red, juicy tomato just like on the farm"* and, *"It looks like swimming in the ocean"*, give care providers a window into personal history or childhood passions that nourish empathy, connecting us at a different level with the people for whom we provide care.

Performing Arts

The Performing Arts offer rich opportunities to connect with someone with dementia through drama, improvisational theater, humor and movement. Simple questions can lead to improvisation that tunes into verbal and non-verbal spontaneous expression. Here's a good example: *"If you could be a color, what color would you be?"* Lillian responded she would be the color blue. She was then asked, *"How would that color look? Using your body, act out what the color would look like"*. Lillian stood up and waved her hands slowly and rhythmically over her head and said, *"I'm the color of the sky, soft blue and calming"*. This moment for Lillian was filled with a

spontaneous gift to the entire group despite her being in the midst of memory loss and confusion. In this moment she was “being present.”

A very quiet resident, Al, was asked, “If you could be anything you wanted to be, what would it be?” Al shared that he always wanted to be a pitcher for the major leagues and he was asked to demonstrate getting ready to pitch a ball. A bit shaky and with some assistance, Al stood up and demonstrated his wind up and throw. He beamed with pride. When asked what advice he would give to a child who wants to be a MLB pitcher, he replied, “Practice, practice, practice. Never stop trying.”

Sensory Stimulation Through Music

For the person with advanced dementia, large group programs can be overwhelming and not enjoyable. The person may no longer be able to communicate verbally or interact in a group setting. As the disease progresses and their ability to engage changes, they may benefit from sensory stimulating activities that stimulate and calm the senses.

Music therapy is form of sensory stimulation that offers the person with dementia a familiar way to express themselves. A music therapist uses instrumental and vocal strategies to enhance memory and enrich communication. Because music memories are stored in many areas of the mind, individuals with dementia may be able to connect with melody and rhythm more readily than through speech and language.

When music is used as entertainment, people enjoy the program, whether listening to the talent of the musician and singing along with the lyrics. In contrast, when music is used to create a connection between people with dementia and their care providers, family or friends, it offers a moment to be present, sharing joy through the relationship created by the music.

Debby suffers from advanced Alzheimer’s disease. She sits quietly with her eyes closed rubbing her hands along the arm rests of her chair and on the table. She mumbles comforting sounds when approached but does not attempt to engage with her family or caregivers. Debby’s eyes lit up when her caregiver sat with her, held her hand and slowly hummed a familiar hymn. Debby reached for her caregiver’s face and caressed it slowly. In that moment of connection, Debby sang the words to the hymn. She and her caregiver were “present”, a connection nurtured by sensory stimulation and the memory of music.

Music can be incorporated into all aspect of caregiving. Singing or humming a familiar tune during daily physical care helps the caregiver build a connection before initiating a task. The rhythm of the song sets a tempo for the care and reminds the caregiver not to rush. Humming during care makes the caregiver more inclined to offer meaningful visual cues instead of verbal cues, and helps to avoid making physical care a rushed and disconnected task.

Humanities

Traditionally, recreational activities consist of entertainment, games, trivia, cooking, crafts, music, gardening, animals and sensory stimulation. All of these programs can be engaging, fulfilling and entertaining, as they offer us the opportunity to learn about the person with dementia and what brought them joy in their lives.

We don’t generally think of activities using literature, culture, spirituality, poetry, philosophy, or story-telling for people with Alzheimer’s disease or dementia, but the Humanities offer us opportunity to connect with residents on a deeper level of meaningfulness and imagination. The conventions of grammar and sentence structure can be ignored for poetry and story-telling, and so people are free to express themselves without regard for success or failure.

Group poems can be amazingly descriptive and reveal feelings, emotions, personal stories and humor that offer wonderful moments of connection. Poems are simple to start with phrases like “**I am a...**” in response to directed questions.

“If you were an animal what would you be?”

I am a lady bug and I fly away lighting the world.

I am a dog in a bubble bath.

I like cats. Meow.

“If you were a fruit what would you be?”

I am a juicy peach.

Blueberry pie.

“If you were an article of clothing what would you be?”

I am a diamond bright and sparkly.

I am a fur coat. I like to warm with a smile.

Creative Connections

When you hold a seashell in your hands, do you bring it to your ear to listen for the sound of waves? Does it remind you of a day on the beach with loved ones? For a person with Alzheimer’s disease, sensory stimulating objects are wonderful ways to build connections throughout the day.

Sensory stimulating boxes can be prepared for themes your residents enjoy such as the beach, sports, tools, birds, dogs or music. Another approach involves staff from all departments and residents’ families working together to create personalized sensory boxes. “We wanted to take our boxes of sensory stimulating objects a little bit further and make them more personal for our residents.” Mary Strauss MSW, LCSW, Director of Humanities, describes the evolution of the sensory stimulation boxes into Creative Connection boxes.

Staff selected a resident and learned more about them by spending time with them, reading their Life Remembrance forms and by talking with their families. Working individually or in small teams, the staff created and filled boxes, bags, baskets, photo albums, scrap books and other containers with a variety of mementos that were meaningful to their chosen resident. The finished boxes had trumpets, records and record players, sewing boxes, tool kits, gardening tools, old photos, information on and maps from the towns and cities where the resident lived and objects that reflected each person’s hobbies or special interests.

The residents’ families were especially touched by the ways people found to tell their family member’s life story. The containers were on display for a few days during which staff, family and guests admired the details and artifacts from people lives that were included in the baskets. Frequently, staff shared comments such as, “I thought I really knew the residents, but I learned so much more about them during this process.”

The Passion to Connect

Creative expression through the Arts, the Humanities and sensory stimulation enables individuals with dementia to communicate their feelings, identity and thoughts in new ways and builds empathic connections through shared emotions, reflections and life stories. This approach offers dignified, meaningful ways to enjoy time, evoke memories, build relationships and create a sense of belonging. Using innovative approaches to engage the person with dementia can be rewarding for both the person with the disease, their family member and their caregivers.