

## Helping Professionals and Family Members Understand Elders Living with Dementia

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Patients/clients who exhibit “difficult” behaviors often do not get the mental health care they need. Dementia and the difficult behaviors that come with it, often render the patient/client unable to fully utilize mental health services and can leave clinicians feeling frustrated about how to help. Behavioral problems with elders are often a symptom of underlying anger, frustration, fear and anxiety that they are looking for a way to express. Constant requests to stop, curtail and repress this energy often increase the anger, rather than making it go away. The beast inside grows taller. In this lecture we will discuss how to work with patients/clients who present in more challenging ways and we will share creative ways to invite the emotion to be expressed, metaphorically and energetically, providing a positive way to release pent up feelings.

Mood states are especially important in the elderly population because they are at higher risks of cognitive and emotional decline. Studies have shown that older adults who suffer from symptoms of depression are at a greater risk of developing cognitive impairments, which, can lead to more severe symptoms and the diagnosis of one of dementias or Alzheimer’s disease.

Issues of depression, loneliness, forgetfulness, powerlessness, and communication problems can be painful and difficult to deal with. Elders confronting these challenges who have an outlet by which to express them are less likely to feel isolated and overpowered by the accompanying emotions. Whether institutionalized or not, seniors can benefit from art therapies and other expressive arts. All humans are creative, but for those living with dementia, that impulse may need to be supported and encouraged by others trained to foster creative expression.

Kitwood (1993)<sup>1</sup> describes the forgetfulness in elderly as dependent on multiple factors, unlike the medical establishment that almost forgot about a living person in front of them p. 541). Kitwood proposed that each person who started noticing forgetfulness is influenced by five factors, which include personality, biography, physical health status, neurological health, and social psychology of an individual.

New research on psychological growth and development among the older population has led to a new understanding of our capacity for positive change and creative expression in the second half of life. The latest research on human development confirms that we have an inner drive that fosters psychological growth throughout our lifecycle. Gene Cohen (2006) says, “...As we age, these inner drives manifest themselves in various ways. The changing

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<sup>1</sup> Kitwood, T. (1993). Process and person in dementia. *International Journal of Geriatric Psychiatry*, 8(7), 541-545.

characteristics of a new phase of life and the changing developmental dynamics of the inner push reveal themselves as a series of developmental challenges in the second half of life.<sup>2</sup>

Over the past decade, more and more research has revealed the benefits of the arts on elders, especially those challenged by declining cognitive skills, memory loss, Alzheimer's, and other forms of dementia. Psychologists, gerontologists, and other medical professionals are scrambling to find tools with which to increase our life expectancy and to provide a higher quality of life in our last years. What pops out, again and again, are the mental, emotional, medical, and spiritual benefits of the arts on the aging population, wherever they live.

Although many patients suffering from depression and cognitive decline might lose the ability to talk or make new memories, few of them lose the ability to hear music and be moved by the beauty of the sound. Historically, music is known to move the emotions and to nourish body and soul. Among those benefits:

- Regularly playing a musical instrument can delay the onset of Alzheimer's by up to five years.
- Singing increases quality of life for senior populations.
- Art therapy sessions improve elders' mood and cognition more than just social activities.
- Individuals show more interest, greater sustained attention, more enjoyment, and greater self-esteem when involved in an art program.
- An active and creative life makes it easier to face adversity, including the loss of a loved one.
- Creativity reinforces essential connections between brain cells, promotes well being, and boosts the immune system.
- Creativity reduces the need for psychotropic medications.<sup>3</sup>
- Music-making is therapeutic, especially for Alzheimer's patients; it stimulates cognitive activities and decreases agitation.

For those with dementia, music therapy is one of the most successful interventions. In Canada an estimated 65 percent of music therapists work with the cognitively impaired elderly. In a review of special-care units, staff rated the effectiveness of different interventions, and music therapy was rated the most effective intervention for this population (Gutman, p. 49)<sup>4</sup>.

Art therapy (or art psychotherapy) taps into the creativity within each person and helps enhance that person's well being. Art therapists work with a variety of demographics, including children victimized by domestic violence, suicidal adolescents, refugees

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<sup>2</sup> *Cohen, Gene D (2006). Research on Creativity and Aging: The Positive Impact of the Arts on Health and Illness. In Generations. San Francisco: Spring 2006. Vol. 30, Issue. 1, p. 7-15 (9 pp.)*

<sup>3</sup> D. Aldridge (1994), conducted research with the focus, "Alzheimer's disease: rhythm, timing and music as therapy". In the *Biomedical Pharmacotherapy* journal, vol. 48, no. 7, pp. 275-81, 1994, Through this study he concluded that music-making provided a form of therapy for the Alzheimer's patient that stimulated cognitive activities such that areas subject to progressive failure are maintained.

<sup>4</sup> Gutman, Gloria M., and Judy Killam. *Special Care Units for Dementia: Staff and Family Perceptions*. The Gerontology Research Centre, Simon Fraser University, 1991.

traumatized by war, disaster survivors, war veterans suffering post-traumatic stress disorder, and older adults living with dementia.

Both anecdotal and scientific evidence suggest that the quality of life of Alzheimer's patients is significantly improved with music therapy. D. Aldridge (1994) said "Music therapy, when based on clear treatment objectives can reduce the individual prescription of tranquilizing medication, reduce the use of hypnotics and help overall goals of rehabilitation. Mood improvement and self-expression, the stimulation of speech and organization of mental processes; and sensory stimulation and motor integration are promoted."<sup>5</sup>

An article in *Alzheimer's Australia*<sup>6</sup> explains: "Everyone is creative. Finding ways to express our creativity in dozens of different ways is part of being human. Some people enjoy cooking, others planting gardens, choosing clothes, arranging rooms, or inventing things..." In other words, creative expression is a basic human need.

At a brainstorming forum held at the University of Wisconsin, Milwaukee, in November 2006, leading American researchers acknowledged that although more research was needed in the area of creativity, certain benefits of creativity for those challenged by dementia were indisputable. For instance:

- Positive emotional responses
- Reduced agitation
- Greater social engagement/interaction
- Improved cognitive processes
- Increased verbal fluency
- Functional improvements
- Increased food intake
- Weight gain
- Increased mobility
- Greater physical strength and balance
- Improved mood and attention span
- Less stress (caregivers and receivers alike)
- Elevated quality of life
- Greater understanding of the human condition

### **Challenging behaviors distressing the individual, the professional, and family members**

Alzheimer's disease and related dementias can cause a person to act in different and unpredictable ways.

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<sup>5</sup> D. Aldridge cf.

<sup>6</sup> BAINES, P. (2007) Quality Dementia Care. Nurturing The Heart. Creativity, Art Therapy and Dementia. Australian Government September 2007.

*Some individuals with Dementia, including Alzheimer's:*

- Become anxious or aggressive
- Others repeat certain questions or gestures
- Many misinterpret what they hear
- They become agitated or show apathy
- They get confused
- They become suspicious and paranoid
- Other start wandering

*Behavior May Be Related to:*

- Physical discomfort
- Illnesses or medication
- Overstimulation
- Loud noises or a busy environment
- Unfamiliar surroundings
- Complicated tasks
- Difficulty with activities or chores
- Frustrating interactions
- Inability to communicate effectively
- New places or the inability to recognize home

*Another challenge: How to diffuse anger of a person with dementia? When one explains things to them or not?*

The adults in our lives pounded into our young heads always to tell the truth – and the whole truth. It's difficult for us to unlearn this, but that's a necessary element in caring for a demented person. There comes a time when we need to be selective in what we tell a person with Alzheimer's. Some explanations can be outright cruel. When a person has no short-term memory, every time you repeat something, she's hearing it for the very first time. Some truths are very painful to hear and if a person is powerless to change anything, why sharing in the first place?

The good news for you is that it's not at all difficult to diffuse and distract a person in the advanced stages of Alzheimer's. Try asking the person for help - or for her/his opinion, or give her/him something to hold for you. By reversing your roles in that moment, you have instantly changed her/his focus by making her/him feel useful. This is best to simply stop the explanations that upset them.

Here are a couple of the most common issues that arise for a demented person:

- Going home and asking for mother.

Where am I? Why am I here? When do I go home? (She's likely feeling lonely and unstable.) You may have been trying to tell her the truth: that she's living with you and not going home again because she has Alzheimer's. You don't have to ignore her question, instead tell her that she's "staying with you for a while." The difference sounds insignificant, but to a distraught person, there's a big distinction between the permanence of "living" there and the

temporary “staying for a while.” Her question is prompted by a sense of insecurity, so you may want to add that you really enjoy her company.<sup>7</sup>

- The other common topic: “mother.”

When is my mother picking me up? Where is my mother? Why doesn't my mother come to see me? At that moment her mind has taken her into an altered reality. She's reliving being a child. The worst you can do is to “remind” her that her mother died ages ago. Instead, you can tell her that her mom isn't there right now. If that's not enough to soothe her anxiety, you can add that her mom called to say she's running a little late but will be there as soon as she can. A colleague of mine reminds us that this kind of “loving lie” to a demented person is based in her reality at the moment and thus becomes her truth.

It's futile to explain to her something that may upset her. She either won't believe you or you'll touch a raw nerve. Either way, she's feeling bad, which will be reflected in her attitude and behavior. Studies have shown that people with serious memory problems experience bad feelings much longer and in fuller intensity than the rest of us, so as caregivers we want to maintain as positive a mind-set as best we can.

### **10 quick tips to Respond to These Challenging Behaviors**

1. Remain flexible, patient and calm.
2. Explore pain as a trigger.
3. Respond to the emotion, not the behavior.
4. Don't argue or try to convince.
5. Use memory aids.
6. Acknowledge requests, and respond to them.
7. Look for the reasons behind each behavior.
8. Consult a physician to identify any causes related to medications or illness.
9. Don't take the behavior personally.
10. Share your experiences with others.

### **In Sum**

1. Examine the behavior
  - What was the behavior? Was it harmful to the individual or others?
  - What happened just before the behavior occurred? Did something trigger it?
  - What happened immediately after the behavior occurred? How did you react?
  - Could something be causing the person pain?
  - Consult a physician to identify any causes related to medications or illness.
2. Explore potential solutions
  - What are the needs of the person with dementia?
  - Are they being met?
  - Can adapting the surroundings comfort the person?
  - How can you change your reaction or your approach to the behavior?
  - Are you responding in a calm and supportive way?
3. Try different responses

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<sup>7</sup> Jyette Lokvig, PhD (2011) How do I diffuse Mom's anger when I explain things to her? In Caregiving.com retrieved 10/18/11 <http://www.caring.com/questions/diffusing-anger-from-alzheimers>

- Did your new response help?
- Do you need to explore other potential causes and solutions? If so, what can you do differently?

Being a caregiver of a person in the advanced stage of Alzheimer's can be a roller coaster. The positive side to a person having reached the advanced stage of the disease is that she will respond to your diversions and distractions with no hesitation.

Here are some helpful tips for maintaining communication with people living with dementia who can no longer actively create or express their emotions. To do this well, you need to engage with your own sense of wonder and joy. Try some of the expressive arts interventions like:

### ***Music and Singing with Elders***

Many studies have documented the benefits of music for elders. According to one report, a man in his seventies with Alzheimer's, who previously did not talk, joined a local choir and within weeks showed dramatic improvement. He was able to hold lucid conversations with his spouse and demonstrated a new sense of well-being to witnesses aware of his history. Another report concludes that when Karaoke is offered at an assisted-living facility, elders who are usually quiet suddenly come alive; for a few moments each week, they are able to participate with others in an activity they can still do. Their otherwise cloudy minds become clear; thanks to a rhythm and sound that fosters memories of gone years.

### ***Poetry Therapy with Elders***

Poetry gives each of us a voice. For elders who often feel powerless and forgotten, poetry offers a potent way for their voices to be heard. Read poetry aloud; choose rhythmic verses and both familiar and unfamiliar poems

### ***Sandtray with Elders***

Carl Jung's work with symbols is powerfully illustrated in the use of sandtray<sup>8</sup>. This tool provides the aging population with another language to express emotions, fears, and personal experience.

### ***Using Drama and Play with Elders***

The magic of drama, story, and play can be explored by using theatrical elements to assist elders in playing out unfinished life issues. These elements let us participate in their stories—and support them in the process.

### ***Building a Scrapbook of History and Memories***

Building a scrapbook with our elders can be hugely beneficial for them and for their family members. Photos and stories will spark memories and give them a way to share their personal journey. P. Baines suggests<sup>9</sup> making up a small box of interesting objects that can be taken out, held, and discussed. Women may enjoy bits of lace; fragments of silk; or shiny, colorful objects such as shells, jewelry, or tiny unthreatening animals. Men may prefer

<sup>8</sup> *Sandtray or Sandplay therapy* is a dynamic and expressive form of psychotherapy that allows clients to express their inner worlds through symbol and metaphor towards a goal of healing. Its founder was the Swiss therapist Dora M. Kalff (1904-1990), who based her theories on the principles of Jungian psychology and on the work of Margaret Lowenfeld.

<sup>9</sup> Cf

polished stones, fossils, packets of seeds, drill keys (the one which unlocks four different sizes is a lovely shape), old pipes, toy cars. As a family member you may have access to familiar objects that have been important to your elder.

### ***Scarves, Color and Movement***

The use of color can stimulate, relax, and help elders feel more alert. Color has a direct impact on all of us, but it is especially important for elders who have limited movement. Scarves provide an inspiring way for elders to move and participate with others. Naida Weisberg (2001)<sup>10</sup> believes the movement and colorful aspects of working with scarves help develop connections and express emotions as people attribute emotions and expressions to the fabrics. For wheelchair-bound seniors, scarves allow reaching out and connecting with others. You can add music and create a type of ballet.

### ***Daily Activities Can be Meaningful and Adapted to Your Elder***

If your elder is unable to speak, or speaks only with great difficulty:

- Tell her stories about the world. Describe walking along the beach, watching a sunrise, children playing in the garden . . .
- Go slowly through picture books, like art, garden, or travel books.
- Give her things to hold and feel that have pleasing textures, like shells, leaves, or cotton.

One tragedy of Alzheimer's is the marked deterioration of memory and the loss of connectedness with significant others. Again, this is where art and creative opportunities in a "strengths-based approach" come into play.

According to Gene Cohen, (2006)<sup>11</sup> "The optimal treatment of the patient focuses not just on clinical problems but also on the individual potential of that person. It is only when problems and potential are considered together that health is best promoted and illness best cared for. This is the ultimate art and creativity of medicine and healthcare, bringing hope and clarity to situations that might otherwise be challenged by despair and confusion."

More research needs to be done to reinforce what those of us in the field of Geriatrics already know. As we approach a time when baby-boomers will increasingly populate our nursing homes, people must be educated on the benefits of the arts upon dementia. We need to ensure that our elders' quality of life not suffer the fate of generations before them.

Mr. Eddy, a wise client of mine, taught me<sup>12</sup> that people with dementia are not necessarily de-mented, and that if we make the effort to learn a different language, we can communicate with our elders and understand the richness of their experiences. First, we need to change our views of elders and recognize that despite their diminishing mental abilities, they still possess a soul.

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<sup>10</sup> Weisberg, Naida Ed. (2001). *Expressive Arts with Elders*. Jessica Kingsler Publishers, Ltd. London, England.

<sup>11</sup> Cf

<sup>12</sup> Bersing, D (2006) One clinician's search for the person behind the 'DEMENTIA' *Aging Today: September-October 2006*

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