Understanding the Mindset of Dementia Patients

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For many volunteers, the opportunity to visit with patients and families is the main motivation behind their desire to give of their time. We read frequently on their applications that they want to “help people on their journey” or “bring a little joy to someone” or “give the family support.” But what happens when the patient doesn’t respond to the visit and, most likely, never will? Or the person is pleasant enough, but may never remember the volunteer was there?

About two years ago, we realized that there was an unusual turnover of volunteers in one particular Extended Care Facility (ECF). We certainly allow our volunteers to change roles as they feel the need, but the burn-out rate had gone from years to six months or less. After meeting with all the ECF volunteers, we realized that the patients in this particular location had an additional diagnosis of dementia and that the volunteers felt their visits were frustrating and meaningless. Even though we were instructing them in the basics of visiting with dementia and Alzheimer’s patients, they felt they were sometimes making the patients feel unsettled by their presence.

Lessons from Aunt Lynn

We recognized an excellent educational opportunity in this situation—and called in an expert to assist us. Over the course of five months, we offered eight in-service sessions with Lynn Ritter, PhD, the education coordinator for the Northwest Ohio Chapter of the Alzheimer’s Association. Dr. Ritter, who is a dynamo of a presenter, explained all of the medical aspects of the disease—but then assumed the persona of “Aunt Lynn,” an 86-year-old with dementia, to help us understand what it’s truly like to have the disease and how we could make a difference. Here are some of the things “Aunt Lynn” shared with us:

- In the early stages of the illness, I know there is something wrong, but I am unable to identify the cause and feel helpless to fix it. As a result, I can become frustrated, angry and confused.
- Please don’t bring your purse, coat or anything else that you are not willing to leave with me. My reasoning and judgment are changing and I think those items may be mine. I may also think that when you prepare to leave that I should be going with you and will become upset and confused when you won’t take me with you.
- During the visit, try not to ask me too many questions. I may not be able to accurately remember the answer and may become frustrated at realizing I should know the answer, but I don’t. It also may be that I know the answer, but you can’t understand the words I’m using and they confuse you—not me.
- Always treat me as the adult that I am when choosing your words and tone of voice. Please never argue with me if I think you are someone you are not. Correcting me is rude and it makes me think that you don’t know who you are. It’s okay to be my sister or brother, or other familiar person on any given day.
- Do have conversations with me, even if I don’t talk, because I may recognize your voice from previous visits. Tell me your name again, tell me you are glad to be with me, tell me the weather, and tell me about the seasons as they change. Talk to me about my family, bring me examples of my hobbies, show me the photo album again, and play my favorite
music for me. You may have done these things dozens of times before, but to me it’s familiar and comforting, whether I can express that to you or not.

- If I become unsettled while you are with me, it may be that I need to use the rest room, may be having pain, may be hungry, may be feeling too hot or too cold, or experiencing something only known to me. There is usually a reason for my expression of emotion.
- If I should fall asleep, sit quietly and do not be offended; the gift of sleep is a sign that I am relaxed in your company.
- When it’s time to leave me, please go quickly and without much ado. Say “please excuse me” or “I’ve enjoyed our time today” and then make your way to the door quietly. Trying to explain to me that you will be back again in two days or next Thursday only makes me anxious about when that is and what will happen to me in the meantime. If you put on your coat, go for the keys, and say a hearty “goodbye,” I will definitely and naturally want to go with you! Then, your departure will cause me much unhappiness, confusion and distress.

Aunt Lynn also reassured volunteers that they do make a positive difference with each visit by simply offering acceptance to patients, just as they are. She says what they are thinking, but perhaps not communicating, is “Thank you for coming, thank you for caring, and please come back.”

**Stimulating Positive Responses in Patients**

Finding out as much as you can about the life story of the patient from the staff and family will help you direct topics of interest and familiarity. Likes and dislikes, hobbies, work experiences, music preferences, and family history are very important to “framing” a quality visit. Likewise, creating a “goodie bag” with inexpensive items to help stimulate memories, feelings and comfort can help you connect with patients.

For example, volunteer Tim Galvin was assigned to a gentleman in an inner city ECF who was uncommunicative and angry. Tim did his homework and found out that at one time, years before, the patient liked to play cards. Tim had a deck of cards in his goodie bag, but the patient did not seem interested. On his next visit, Tim brought an UNO deck which sparked the patient’s interest. They ended up playing cards for hours. Afterwards, the ECF staff remarked on how the patient’s anger seemed to diminish, he cooperated more easily, and his appetite improved.

As another example, volunteer Fred Dannhauser and his therapy dog, Tango, were visiting with a hospice patient at a local ECF. While Tango was, of course, the center of attention during the visits, Fred played a big part in involving the other seven patients in on the fun. After the hospice patient died, the ECF staff asked Fred and Tango to continue their visits because the residents were always more calm afterwards and slept much better.

**Positive Effects on Volunteer Turnover**

Our volunteer turnover in ECFs has improved since we conducted the training with Dr. Ritter. The ECF staffs welcome the volunteer visits and team leader, Cathy Richards, RN, CHPCN, tells us that patients’ families are comforted in knowing that, with additional visits from volunteers, their loved ones not only benefit from companionship, but also in having another advocate for excellent care.

*Deborah Braun has 15 years of volunteer administration experience and is certified with the Council for Certification in Volunteer Administration. She has served as director of volunteer services for Hospice of Northwest Ohio (Perrysburg, Ohio) since 2001, where she oversees the work of 425 volunteers.*

Visit the Web site of the Alzheimer’s Association, to learn about programs and services available in your area, including educational workshops: alz.org

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