



Engaging Aging

Being Mind-full about Dementia

By Ms. Dayna Larson-Hurst, RN, MSOD

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So often when we are with a person with dementia, we struggle over the losses and the challenges. We are saddened by responsive behaviors we do not understand. We long for the past and the relationship we once had. We can be frustrated and downright annoyed at times when things are not going the way we wish they would.

While those of us without a medical background would struggle to comprehend the physiological complexities of dementia, I believe that we all can benefit by considering the behaviors that manifest with this disease. We will quickly see that even a behavioral focus has a wide scope. Dementia is a general term used for brain damage or disease whose symptoms impact thinking, reasoning and memory to such an extent that they interfere with functioning in daily life. So, in conjunction with a behavioral focus, we will consider the importance of evaluating the environment that the person with dementia is living in to determine its potential impact on their behavior. Most importantly, we will examine the significance of relationships and how they positively or negatively affect a person's quality of life. This includes understanding one's self and one's ability to effectively interact in order to provide the greatest support to members you care so deeply about.

"I've learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel."

Maya Angelou

Ms. Dayna Larson-Hurst has worked in Catholic health care for over twenty years. As a leader and consultant, she has a passion for devising innovative ways to help congregations develop and implement strategic change initiatives that support a culture of well-being as we age, particularly for those with dementia. She is currently an affiliated independent consultant with NRRO as well as a consultant for Catholic religious congregations throughout the United States. Dayna is a registered nurse with a bachelor's degree in business and a master's degree in organization development. She is a Certified Montessori Dementia Care Professional and a Nationally Certified Dementia Practitioner Trainer and Teepa Snow PAC Trainer.



Being Mind-full about Dementia, continued

Early Detection

It is important that we recognize sooner rather than later any neurocognitive changes such as forgetfulness, or unusual behaviors. If detected early, there are some causes of dementia-like symptoms that can and should be addressed. These include depression, dehydration, alcoholism, thyroid problems and tumors, just to name a few. To aid us in early detection, the Alzheimer's Association teaches the following ten early signs of Alzheimer's Disease:

- Memory loss that disrupts daily life
- Challenges in planning or problem solving
- Difficulty completing familiar tasks at home, at work or at leisure
- Confusion with time or place
- Trouble understanding visual images and spatial relationships
- New problems with words in speaking or writing
- Misplacing things and losing the ability to retrace steps
- Decreased or poor judgment
- Withdrawal from work or social activities
- Changes in mood and personality

As we age, it's not unusual to forget or be slow to remember some things. Sometimes we want quiet when previously we enjoyed large group activities. This is not necessarily dementia. But when we find keys in the refrigerator, find ourselves lost in familiar places, or no longer have the ability to schedule appointments, it is important to be evaluated by a specialist.

Responsive Behavior

This term is used to describe behaviors or speech that may or may not make sense to us but often makes sense to the person with dementia. In the past we have used the phrase "challenging behaviors" when we are provoked

by something a person is doing, such as asking a question multiple times or asking to "go home" when he is already home. Saying that their behavior is "challenging" implies that it is the person with dementia who is the problem. Instead, we should recognize that often the problem is not the individual, but something that is triggering the behavior. Unfortunately, what is occurring is related to something the person is experiencing, and all too often what is triggering their behavior is related to us. I say this not to place blame but to help us understand how important it is to become aware of the impact caused by ineffective interactions, the environment, and the disease process itself. The best way to deal effectively with these situations is to become curious and to try to understand what the person is actually trying to tell us in their behavior. Consider the following examples of responsive behavior.

Attempting to leave

In the past, we used the word "wandering." We no longer use that word because it implies that the person does not know where he is going, which may not be the case. Recently, I was visiting a person with dementia. He got up from his chair and went to the door, opened it, and looked into his garage. Then he closed the door and returned to his chair. Attempting to leave his apartment was not a normal behavior for this man. His care partner and I observed him doing this several times. We finally realized that what he was actually looking for was not to go outside but to use the bathroom. It would have been very common for one of us to say to him, "no you can't go outside." But by knowing him and observing his behavior, we were finally able to deduce that it was not exit seeking behavior but a physiological need.

Saying "I want to go home"

This behavior is very common. Often our response is to say, "You are home; this is where

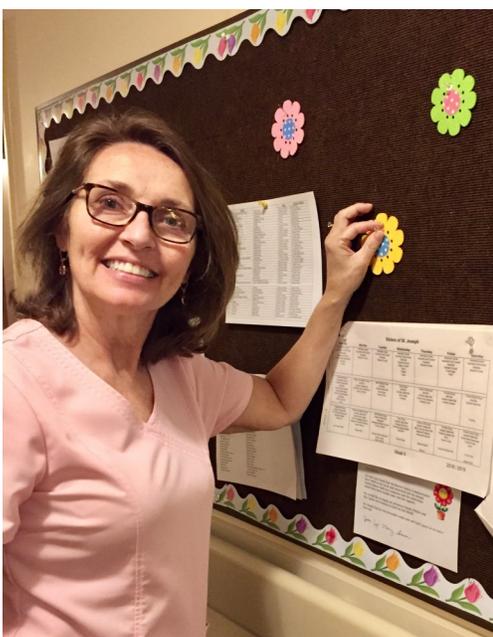
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you live.” Responding in this way, while logical to us, is often ineffective and can actually increase the person’s anxiety. What message could the person be trying to send? Perhaps, “I’m hungry, thirsty, tired, or bored.” Maybe she is trying to convey that she is feeling overwhelmed, scared, unsafe, or in need of assurance.

So, how could we respond? Again, observe the situation to see if there is some physical need that requires tending to. Attempt to connect with that person through eye contact, with an empathetic expression and by touch, if appropriate. If she is attempting to walk, join her and try to distract her with conversation related to her life.

Repetitive conversation or questioning

A variety of things can be occurring in the midst of the repetition. Sometimes, people simply have a desire to connect. Their language skills are limited but they still have the desire to be connected with you. It can also be that they are unable to express what they really are trying to say, so they use a term or phrase they are comfortable with. Answering questions like these each time as if it were the first time they were asked and biting our tongue when we may want



Nurse Ginger Kazil, LPN, works to add seasonal reminders to the bulletin board in the supportive living area of the St. Joseph Motherhouse, Baden, PA. Seemingly small details such as these can serve as points of orientation. Photo used with permission of Sisters of St. Joseph

to say, “I just told you,” gives us the opportunity to be gracious in return and support the other’s need to be connected.

Another reason that a person is asking a question multiple times is that he is actually trying to remember, but damage to the brain no longer allows him to retain the information. I often hear from people with early to mid-dementia say how embarrassing it is to ask questions multiple times, especially when they feel frustration from the person to whom they are speaking. Rather than grow frustrated, it might be very helpful to write the information they are requesting and put it in a place that they will easily see and consistently go to for the information. I am often amazed how dependent we are on using our own calendars, but when a person has dementia, we don’t think to help him put it on his calendar. If you are assisting someone with a calendar, it’s important that you first assess his ability to read it and then make sure it is in a consistent location.

These are just a few common examples of responsive behaviors that are often exhibited by people with dementia. What’s most important is that we become curious, patient and creative in order to understand what they need so that we can assist them more effectively. We also need to understand how we can best engage and interact. Jennifer Brush, in her book *I Care* says we need to realize “the key is to effective management, not control”. When we learn to use tools and techniques to the point they become natural to us, we can become more effective as we work to support persons with dementia.

Saying I’m sorry

Teepa Snow, an internationally recognized dementia expert, stresses the importance of learning to say, “I’m sorry.” It is not that you have necessarily done something wrong; rather, you are acknowledging the other person’s

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feelings. The goal is to work more effectively with this person who is struggling and to let go of your need to be “right.” Imagine this scenario. You arrive at Sister’s door to bring her to a doctor’s appointment and find her in her night clothes. She tells you she did not know about the appointment. You know that you reminded her three times. You have a choice to make. You can show your frustration and explain to her you have contacted her multiple times about this appointment. As you know, this often leads to a squabble. The other option is to say, “I’m so sorry. I thought you knew. Would you help me now by getting ready so we can get to this appointment on time?” This is not easy and I know it does not always work. However, your effectiveness, on the whole, will be greater than if you get into a power struggle over who is right and who is wrong.

The Alzheimer’s Association offers these valuable pointers for “compassionate communication” with persons with dementia.

- Do not try to reason with, argue, convince, confront, blame, or insist.
- Do not say “Don’t you remember?” or take what they say personally.
- Do speak in short sentences and allow extended time for them to comprehend, even three times longer than you might expect.
- Do accept the blame when challenges occur and respond to their feelings instead of their words.
- Practice, practice, practice generosity

Whenever something is not working, stop what you are doing, step away, take three deep breaths and reconsider your approach. This may include getting assistance from another person.

Montessori Methods

Maria Montessori [1870-1952] is best known for her work with early childhood education. The

Montessori Method is a theory of learning based on self-directed activity, hands-on learning and collaborative play. It is intended to “create a match between the child’s natural interest and the available activities, encouraging children to learn through their own experience and at their own pace.

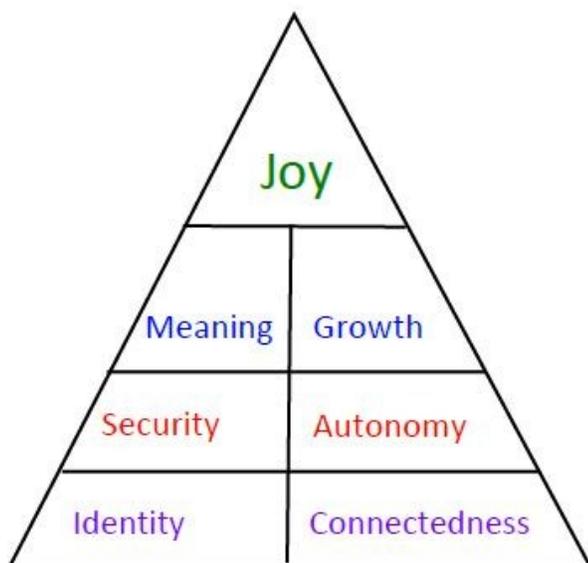
Given this description, we immediately see how many of these same pedagogical principles can serve as guides for those who support people with dementia. Here are a few principles, based primarily on the Montessori Method, to keep in mind:

- When possible do “with” a person rather than “for.” It is not always possible and often can take more time, but in the long run it offers the opportunity for relationship building, empowerment, skill building and a sense of purpose.
- Be aware of the person’s dominant side which will tend to engage them more and utilize their muscle memory.
- Prepare what you will be doing in advance so you are not searching for needed items while others are waiting and losing interest.
- Remember that consistency is very important in building routines and skills.
- Remove unnecessary clutter.
- Ask the person to help you. This can often serve to gain a positive response.

Pyramid Model for Creating Joy

G. Allen Powers, author of *Dementia Beyond Disease*, has focused much of his work on changing the paradigm of how we look at dementia and how we support persons with the disease. He has created a pyramid model depicting seven domains of well-being, placing joy at the top. In his model, progression towards joy, while not easy, can occur when the individual domains are addressed.

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The Eden Domains of Well-BeingSM, adapted by GA Power (*Dementia Beyond Disease*, c.2017, Health Professions Press)

The two initial domains that form the foundation of the pyramid are identity and connectedness. Whenever we are supporting someone with dementia, it is extremely important that we seek to know him, his likes and dislikes, history (family and friends, missions, ministries, etc.), what gives him joy and what has given him pain. Connectedness helps each of us to feel part of something. Having dementia and not knowing where we are or where we belong can be extremely anxiety producing, so it is important to a person with dementia to know that she is known.

Security and autonomy are the next domains. My ability to understand what is going on in my world gives me a sense of security. Autonomy can be defined as being able to make choices and do what I can myself. Autonomy gives me a sense of control in a world that often feels out of control.

Next in the pyramid are meaning and growth. Meaning gives my life a sense of purpose and a reason to get up in the morning. Growth gives

me the opportunity to continue to learn and develop, even with dementia.

We know through scientific research that neuroplasticity, the ability of the brain to develop, can still occur in the brain of a person who has dementia. This is why creating opportunities for an individual to experience new things based on their areas of interest and skill is so important. By intentionally working on these first six domains, we can accomplish the goal of helping the person with dementia still experience joy.

Supporting Existing Abilities

Throughout this article, I have intentionally used the word “support” instead of “care.” Obviously, you care for the members of your community and provide support when it is needed. However, it is important that you are conscious of not “over-caring.” This means that you should aim to provide only as much support as necessary to empower the individual to do as much as he or she is able to accomplish. Cameron Camp, in his work with the Montessori method, calls this creating “cognitive ramps”. The idea is to remove barriers and provide opportunities for the person to feel a sense of purpose, value and connection. Camp states, “We are not getting rid of dementia; we are working around it.” The goal is to work around the deficits and focus on abilities that are retained. For example, skills that we have developed throughout our lifetime such as brushing our teeth, eating our meals, singing and praying are often retained well into the disease process. What can happen in an effort to care is that even with good intentions, we step in too quickly and take over. Consequently, the person we are trying to help becomes slowly disempowered, possibly depressed or anxious, and eventually disengages due to fear of failure. Too much help doesn’t serve the person.

Being Mind-full about Dementia, continued

Richard Taylor, Ph.D., who himself had Alzheimer's disease, was a well-known advocate for improving the quality of life for people with dementia. In a video, "Be with Me Today" he talks about how easy it is for a person with good intentions to disempower persons by taking care of something rather than figuring out how to assist them so they are still in control.

It is often said that much of the expedited loss with dementia is related to disuse. Maria Montessori is quoted as saying, "What you do for me, you take away for me." Our goal in providing the greatest support we can should be to adapt the social and physical environment to accommodate the persons' deficits so that they can retain their autonomy and accomplish as much as they can on their own. How do we begin to do this?

Adapt with Cognitive Ramps

It is important to always evaluate the environment and consider the needs of those using it in order to create cognitive ramps. Just like physical ramps, cognitive ramps are adaptations that help those with dementia utilize the skills they have. For example, when there is damage to the occipital area of the brain, vision is impacted. While still able to see and read, a person may lose depth perception and often does not have the ability to discriminate and understand what she is seeing. Consider, for example, bathrooms. Often, bathroom floors and walls are light colored and toilets are white. One's ability to see the toilet against a similar colored background is impeded. You can create a cognitive ramp, something that will help one to see,

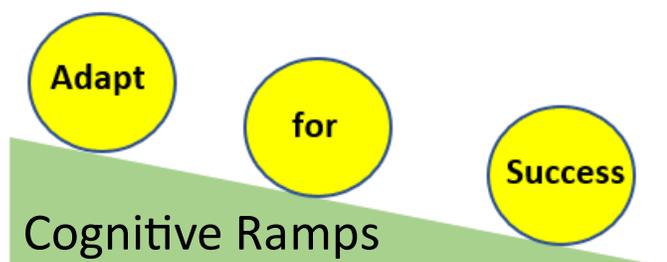
simply by painting the wall behind the toilet with a strong color to create contrast and improve the potential for recognizing the toilet. As another example, floors buffed to a high shine interact with overhead lighting in such a way as to create shadows that can appear as obstacles to someone with dementia. Careful attention must be given to details often taken for granted.

Yet another example of a cognitive ramp is signage placed on a person's dresser drawers, depicting visually what is in each drawer. A short attention span is a common symptom of dementia. When a person is attempting to dress himself, he may lose his train of thought and forget what he's looking for. When signage is put on the drawers it gives him a visual cue.

Often, one of the challenges Congregational Leaders face is the decision to move someone with dementia to another location. Once the move begins, well-intentioned helpers want to clean out the old and create a new start for the member. However, it is important to be intentional about every aspect of the move. Consistency and minimal disruptions to routine will help the person in question. Endeavor to make the new room look as much like the previous living space as possible. Cognitive ramps can take the form of familiar pictures on the wall, furniture that has meaning, and a favorite chair. These can be very effective in helping a person transition to new location.

Use of Self

Finally, it is important that we understand how valuable we are in supporting an individual with dementia. It takes effort from us to both fill our minds with knowledge about dementia and also to be mindful of how we behave as we provide support. As the brain is deteriorating, people with dementia become hypersensitive to their environment. Have you ever experienced walking into a room and sensing that someone is unhappy or something is going on, even when no



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words have been said? A person with dementia is often in a similar state of hyper-awareness, almost like a survival mode. In their efforts to understand what is going on, they tend to be very sensitive to others. However, because they often don't have the executive functioning that would allow them to reason what is occurring, they tend to take us, literally, at "face value". Therefore, it is extremely important that we are aware of our facial expressions, our tone of voice and our body language in order to use ourselves effectively when we are with people with dementia.

My mother, Susan, had Alzheimer's disease. One day when I arrived for a visit it was obvious she was having a difficult day. She was pacing in the kitchen, appearing a bit lost. As I walked up to greet her with a smile on my face, she looked up and smiled back at me. It was clear she did not know my name or exactly who I was, but she knew I was someone who loved her. She reached out gently touched my cheek and said, "You are so kind." We are often saddened when we realize persons with dementia do not remember our name or how we are connected to them. But that day, I experienced what Maya Angelou meant when she wrote, "I've learned that people will forget what you said; people forget what you did, but they will never forget how you made them feel."

Knowing how important it is that we are responsible for how we behave, we need to be mindful that taking care of others begins with taking care of ourselves. There are times when we are tired and we need to rest. There are times when others need to step in and assist. We need to learn when we can no longer do this alone and we need help. So often, we believe there's something wrong with us if we can't do it ourselves, but that is not true. We need to tend to ourselves so we can better care for others.

Recognizing how important it is that we are aware of how we use ourselves makes me wonder if this is an opportunity to help us learn how to grow as individuals. What if supporting people with dementia gives us the opportunity to expand our understanding of what it means to be kind, patient and to love? What if we see supporting an individual who has dementia as an opportunity to be a good Samaritan? Could this be our opportunity to learn about ourselves and our level of patience, kindness and acceptance? What if we encounter this challenge so that we may learn how to truly show mercy?

Helping someone with dementia to feel acknowledged, loved and supported takes three things: understanding the behaviors related to the disease; learning what to do to best assist the individual; and recognizing the significance of relationships. Our ability to be truly supportive, loving and kind depends greatly on our ability to be mindful, supportive, loving and kind to ourselves.

Resources

Camp, C. J. *Montessori-Based Activities for Persons with Dementia*. Meyers Research Institute, 1999.

Mills, K.C. and Brush, J.A. *I Care: A Handbook for Care Partners of People with Dementia*. Author Solutions, 2014.

Calendar 2019

June 24—28

- Direct Care Assistance checks will be mailed

August 20

- NRRO Webinar: Topic to be announced

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National Religious Retirement Office
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3211 4th Street, NE
Washington, DC 20017-1194

Phone: (202) 541-3215

Fax: (202) 541-3053

Email: retirement@usccb.org

Websites:

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Staff

Executive Director

Sister Stephanie Still, PBVM
sstill@usccb.org

Grants Specialist

Monica Glover
mglover@usccb.org

Program Associate

Karen Canas
kcanas@usccb.org

Affiliated Independent Consultants

Sister Anna Marie Tag, RSM
NRROConsult-AMTag@usccb.org

Ms. Dayna Larson-Hurst
NRROConsult-DLHurst@usccb.org