Learning To Speak Alzheimer's

A Groundbreaking Approach for Everyone Dealing with the Disease

By: Joanne Koenig Coste

Alzheimer’s disease is one of the great scourges of old age in the 21st Century. Devastating, irreversible and progressive, it robs millions of older Americans of their use of language, reasoning, memory, and judgment. Alzheimer’s destroys a lifetime of memories and whittles away at the core of a person’s identity. Alzheimer’s is the third most costly disease after heart disease and cancer. Alzheimer’s places an enormous burden on the US health care system. The Author, Joanne Coste, in 1975 became the founding director of the NIA and identified the study of Alzheimer’s and other dementias as a key priority. Up to that time “Senility” was the popular term used to describe all the dementias. After her husband had a major stroke (at a young age) paralyzing him on one side he gradually developed a progression of dementia at most times not recognizing her or the children. After the social worker suggested putting her husband in an institution, which she refused, she developed a system that she could safely use at home, and later for the use of other patients with dementias. The following are the Tenets the Author developed.

1. Make the Physical Environment Work.
2. Know that Communication Remains Possible.
3. Focus Only on Remaining Skills.
4. Live in the Patient’s World.
5. Enrich the Patient’s Life.

Some Nursing Homes (institutions) say they have specialized care but do little more than secure the doors. Without trained staff, ongoing education, and a habilitation philosophy of care adopted by the whole staff, the unit is not “Special.”

According to the National Alzheimer’s Association, Alzheimer’s disease has ten warning signs:

1. Loss memory
2. Difficulty performing familiar tasks
3. Problems with language
4. Disorientation
5. Poor or declining judgment
6. Problems with abstract thinking
7. Misplacing things
8. Changes in mood and behavior
9. Changes in personality
10. Loss of initiative

An impairment in or loss of mental powers is called dementia, but dementia is a symptom, not a diagnosis. A finding of dementia cries out for more precise medical evaluation to rule out illnesses that may be not only treatable but curable. Other conditions that can appear to be Alzheimer’s disease include the following: alcohol abuse, drug interactions, emotional problems, endocrine imbalance, infection, metabolic disorder, poor nutrition, and trauma. Until recently, a diagnosis of Alzheimer’s was quite difficult to prove; it could only be done after death. The German neurologist, Alois Alzheimer first identified the disease when he examined the brain of a deceased 51-year-old woman. During the autopsy he discovered that nerve-cell fibers in her brain were entwined in what he called “neurofibrillary tangles.” He named the areas of marked deterioration “plaques.” Tangles and Plaques remain the markers of Alzheimer’s disease. A host of scientists are now using state-of-the-art technology to examine all potential causes of Alzheimer’s, including genetic, viral, biochemical, and environmental problems, hoping to better understand the disease and find new treatments and, if possible, ways to halt or cure it. Some federally approved medications show varying amounts of success in reducing symptoms of Alzheimer’s disease. Each patient differs in the degree of responsiveness to the drugs.

Every newly diagnosed Alzheimer’s patient should learn that he or she is not simply, “going crazy,” that any changes in functioning are rooted in a physical disease. In the progression of Alzheimer’s disease, the clinicians typically refer to three stages of Alzheimer’s disease; Early, Middle and Late. Each stage may be as brief as one year or as long as ten years and there are wide variations from individual to individual.

When caring for the person with Alzheimer’s at home, in an assisted-living situation, or in a nursing home or similar facility; it is important to develop a plan of care to make sure the patient’s physical, social, emotional and spiritual needs are being met. The behaviors and needs of people with Alzheimer’s change constantly as the disease and symptoms progress, the plan must be reviewed and updated on a regular basis.

Reality orientation is the antithesis of habilitation. Habilitation teaches care partners to place themselves in the patient’s world, no matter where that world is. This teaching, live in the patient’s world, is the fourth tent of habilitation. The habilitation approach also acknowledges that reasoning with someone who has lost the power to reason only ensure confrontation. It is important to not as well, that the patient requires less time and fewer staff resources with the habilitation model—a compelling advantage in an era when the people who run nursing homes and other care facilities complain that there is never enough time or enough staff to practice new methods.

Every care person/partner must find a balance between allowing the person with Alzheimer’s enough independence to have opportunities to succeed, but not so much as to cause new failures. Formulating and consistently revising a workable plan of care will help the caregiver assess the person’s abilities. The habilitation model produces critically important results, they are: Optimizes Function, Minimizes Stress, Promotes Positive Emotions and Maximizes Success. As care partner/person fosters independence and self-respect, another aspect of habilitation to consider is what Dr. Paul Raia calls, “Domains.”

There are six Domains: physical, functional, communication, emotional, social and sensory. Physical issues, such as grooming and dressing, and the patient’s emotional styles are the foundation blocks of a meaningful habilitation program, along with functional support, which includes elements of the environment such as paint, lighting, and colors. With those three bricks in place, the care partner can concentrate on the patient’s sense of the world and his interactions with others. When the bricks are balanced, the patient can communicate meaningfully with others even without using words. But if one brick is removed, the others will fall down as well.

Painting a bathroom in a deep bright color draws the patient's attention to the contrasting white toilet seat. Such changes give patients the greatest chance of being able to function at their highest level for a longer time.

The Functional Domain is the routines that the patient followed before she/he was afflicted by Alzheimer's. The care person can offer simple prompts to foster the patient's remaining skills in activities of daily living, which include bathing, dressing, eating, toileting, and sleeping. For example: place the toothpaste on the toothbrush before they go into the bathroom, and lay out the clothes in the order that they will put them on. Also at the dining table, the caregiver should eliminate meaningless utensils and many condiments, because several choices may prove to be overstimulating.

The Social Domain tells us that almost all of us have an innate desire to be social. We perform better, laugh more, and feel more emotionally secure when we feel the closeness of other people and perhaps pets. People with progressive dementias who spend much of their time doing nothing show many more signs of anxiety, depression and paranoia. To prevent social problems from building, care persons (staff) should constantly include patients in conversation, reminiscing, music, children, pets and religious events. This can provide feelings of enrichment and accomplishment.

The Sensory Domain tells us that researchers have long identified the senses as an area of particular interest. This domain involves both receiving the sensory signals: sights, sounds, odors, tastes and textures and processing these signals in the brain.

Alzheimer's disease may scramble the processing of these signals to the point that the patient is unable to share information about what she/he is seeing, smelling, hearing, tasting, or touching. Yet sensory signals still enter the brain, and they may affect the person on a deep, emotional level, for good or ill. As the disease progresses, perceptions become ever more problematic until, finally; from all the senses become tangled. We need to see the world from the patient's perspective. To the patient, a diagnosis of progressive dementia means the recognition of a disease that is already active and that will, presumably, continue for a relatively long time. The caregiver thinks they should treat the person differently, without recognizing their existing abilities. Listening is the best way for the caregiver to seal a positive pact with the afflicted person. The language that the patient uses is of little importance. In talking to a person with Alzheimer's the goal is to stimulate conversation and win trust on a personal level before expecting them to open up.

The Five Tenets of Habilitation

There are Five Tenets of Habilitation. To work properly, however, the tenets must be applied all together; the difficult part is often learning how to apply them in a particular situation.

Tenet #1

Consider how the person's surroundings may affect the changes in perception. You can and should alter the environment so that it helps prevent problems for the patient. The overarching idea is to make the surroundings as simple as possible. Start by thinking through how lighting can help control behavior, increase safety, and offer comfort and a feeling of security to the patient. The goal of lighting is to mimic daylight, which is the most comfortable kind of light for patients. Having a number of lamps on creates too many shadows, which an Alzheimer's patient may misinterpret or find threatening.

You can also help an Alzheimer's patient by choosing indoor and outdoor color schemes carefully. Research has found that the disease affects patient's reactions to colors. Try to find wall colors that contrast with the functional objects in a room. In the facility, scenes or designs can be painted on doors to help deceive the residents while ensuring their safety. Bright borders, such as cactus and tumbleweed designs for Texas, cornfields for Oklahoma, and so forth, can direct residents to activity rooms, while colorful arrows can show the way to the bathroom. An awning hangs over the entrance to the dining room in one of my favorite facilities.
Remove furniture that is difficult to get into and out of. As the person's motor skills diminish, balance becomes more tenuous. As directions become more difficult and memory less reliable, use images of items to supplant words. They can be placed in the dining room, bathroom and showers. Many devices can make a patient's surroundings safer. Frequently assess the environment to adjust or compensate for changes in the patient.

Noise is also part of the environment. The patient's ability to hear does not change, but they interpret sounds differently as times goes on. Research as shown that many of the sounds we take for granted actually disturb patients. They function best in a quiet space. Monitor the patient for signs that she is not able to understand words or separate sounds or that they are scared of noises. Emotions behind failing words are far more important than the words themselves, and it is the emotions that need to be validated. Although many losses occur with this disease, assume that the patient can still register feelings that matter.

Tenet #2

Difficulties with language often cause emotional outbursts. When a person with Alzheimer's is word searching or using clearly incorrect words, he or she may still be able to understand spoken language. If the person does not seem to understand you, break down your sentences into less complex patterns, establish eye contact when possible, and use simple, short statements to alleviate the stress related to failing communication.

When visiting an Alzheimer's unit in a long-term care facility, I frequently come across small groups or pairs of people relating to each other as dear old friends. I can only assume that Alzheimer's patients focus on the speaker's eyes and determine meaning through tone and gestures, must the way we can watch television without the sound on and still understand the plot.

Here are some specific guidelines for communicating positively:

1- Approach the person in a calm, gentle way, and always from the front to foster trust.
2- Set the stage for discourse with a tone that reflects respect.

3- Speak slowly in a low tone, using simple sentences rather than complicated language patterns.
4- Be patient; the person with dementia takes extra time to process information.
5- Use simple language because idioms, metaphors, slang and other speech variations are extremely difficult for a person with Alzheimer's to interpret. If you suggest to a patient that she is "pulling your leg," be prepared for her to literally do just that.
6- Focus only on the skills that the patient still has. Value whatever abilities remain. Help them compensate for any lost abilities without bring them to their attention.

Tenet #3

Those of us without dementia can go through our activities of daily living (ADL) without thinking or rehearsal. Several problems may crop up each time a person with Alzheimer's faces a bath or shower. Such as:
1- The patient may perceive the bath or shower as a first-time ordeal every time. He simply may not remember the expectations of bath time.
2- Removing clothing or having it removed can increase feelings of loss of control.
3- The sound of running water may induce fear due to failing auditory perception.
4- Impaired perception of color, depth, and contrast may keep the patient from seeing clear water.
5- The feeling of water suddenly splashed on the face can cause fear, wash the patient's face and hands separately.
6- The odor of an unfamiliar kind of soap may induce fear. The person's shortened attention span may cause another problem. Do not ever suggest that the patient "wait a minute" while you get something ready. In helping a patient dress, never act as if you are in a hurry if you need to assist a patient dressing. A person with Alzheimer's disease needs considerably more time to process information and can usually handle only one command at a time. Patients can have trouble dining for several reasons, including the following:
7- Inability to recognize how items are used
8- Failing visual perception
9- Diminishing attention span
10- Language difficulties
11- Declining motor skills
12- Reduced social graces

Introduce finger foods when the patient is in the early stages of the disease, before the need becomes imperative. Finger foods are the best choice for maintaining dignity, providing opportunities for success, and encouraging proper nutrition. Problems with toileting may arise in early stages or may not be a threat until the late state. Over the past few decades, most clinicians who have worked with Alzheimer's patients have concurred that early in the disease, incontinence is not related to medical or physical causes so much as to environmental or other treatable conditions. The basic assessment for habilitation toileting includes learning whether the patient can find the bathroom, can indicate that she needs to use the toilet, and can undress quickly enough without wetting themselves.

Tenet #4

Tenet #4 is, “Live in the Patient’s World.” Never question, chastise or try to reason with the patient, join them in their current place or time, no matter when or where they may be, and find joy with him there. Aggressive or challenging behaviors can stem from many problems related to Alzheimer’s disease. Paranoia, hallucinations, repetitive behaviors, continual anxiety, changing sexual desires, or illness may cause the patient to act out or overreact. Using the habilitation approach, care persons, and others, who deal with patients with progressive dementia, can come up with different, successful game plans to deal with challenging behaviors. One way to reduce challenging behavior is to keep a behavior log.

Now consider some common triggers that can result in challenging behaviors, and how care partners/staff can deal with these situations.
1- Many people with Alzheimer’s have Paranoia and Hallucinations at some time during the disease. A person might say, “I hear people talking to me,” or blame others for things she has done, “Where did you hide my keys?” The way to calm such a person is to address the underlying feelings of fear, anxiety or sadness and to find ways to change the environment to lessen the problems.
2- Continual anxiety: when a patient who appears anxious can also create challenging situations. Challenging behavior becomes far less likely when the person with Alzheimer’s feels that she is still a functioning part of the family.
3- Sexual Behavior is another challenging behavior. They may have problems describing or acting on their sexual urges and in determining where and with whom the actions are appropriate.
4- Depression, which may require medical intervention.

Tenet #5

Tenet# 5 says: Create moments for success, eliminate possible moment of failure, and praise frequently and with sincerity. Attempt to find joy wherever possible. Enrichment also means involving the person in tasks or chores. They will be interested in tasks for only a short period, because of reduced attention span and limited patience.

Another way to enhance a patient’s life is to work on the mental enrichment activities. The goal of the activities is to help the patient hold on to existing memory skills by stimulating parts of the brain that have not yet been used. Physical activities provide benefits beyond increasing strength, flexibility, and cardiovascular health. Exercising together affords both companionship and opportunities to participate in sensory activity. While walking, for instance, the care person can talk about various odors in the air, can compare the bark on different trees, touch leaves on bushes along the way or listen to bird songs. Keep in mind that activities are whatever we engage in to keep busy; they are the opposite of sitting with nothing to do or not knowing how to do anything. Keep the patient busy to fill leisure time and feel connected to the world through activity.

Although much is lost, much remains. Focus on what is left, not on what is gone. Plan for contingencies, prepare for the terrible times, but use the techniques of habilitation to celebrate what can still be celebrated!

Again, it is important to remember Alzheimer's disease is one of the great scourges of old age in the twenty-first century. Devastating, irreversible, and progressive, it robs millions of older Americans of their use of language, reasoning, memory, and judgment. Alzheimer's destroys a lifetime of memories and whittles away at the core of a person's identity. With the aging of the baby boomers, government experts estimate that the number of people diagnosed with Alzheimer's disease will dramatically increase, and cost will become unsustainable. Clearly, it is critically important to accelerate drug research and find more effective means of prevention and treatment. Our society must rise to this scientific and cultural challenge. At no time does an Alzheimer's patient feel more threatened than when facing the decision to stop driving, particularly when they have not recognized or has denied that there is even a problem. The issue now is not previous driving history, but what the future holds. The nature of the disease, which is hallmarked by problems with reflexes, judgment, way finding, reaction time, decision making, and other cognitive functions, will at some point make driving impossible.

A special-care unit (SCU) is an area within an assisted-living facility, nursing home or other health care facility specifically intended for people with progressive dementia. These units vary from facility to facility. An SCU may be no different from the rest of the facility except for being behind locked doors, or it may have a special philosophy, well-trained and plentiful staff, and an environment that meets the specific needs of patients with Alzheimer's.

Alzheimer's disease behavior log is a record of data on a patient's problematic behavior. It includes time of day, location, and environmental factors, in order to determine the cause of the behavior. By keeping a record of these factors for each specific behavior and, generally within 10 entries you will see a pattern emerge. Some experts speak of Alzheimer's as a disease of behavior, I think of it as a disease of emotions. By understanding, working with, and to some extent controlling the patient's emotions, it is possible to encourage behavior that is acceptable with most people.