CAREConnections

Information and Inspiration for Caregivers

A Publication of Boulder County Area Agency on Aging *July/August 2016*

INSIDE

Dear Caregiver,

More and more people are caring for a loved one with Alzheimer's disease or another dementia, and they're facing some of the toughest challenges that can come with caregiving. Losing memory and other mental capabilities is equated with losing one's self, and thus Alzheimer's is one of the most feared—if not *the* most feared—disease. Our hearts break when it affects those we love, perhaps especially when they lose shared memories that help define who *we* are as well.

This issue is about caring for a loved one with Alzheimer's or another dementia (all forms of dementia share certain characteristics), and it includes articles about medications, validation therapy, activities, and creating a safe environment, as well as the stories of caregivers themselves. We hope it will be meaningful to you.

It takes a lot of courage, ingenuity, and tenacity to be a dementia caregiver, and we applaud the many thousands of people who give their best, day after day, to assist their loved ones with memory loss. They're all heroes.

The Editors

Validation Therapy for Disorientation

by Teresa DeAnni

I can vividly recall the days when I worked as a caregiver for people with various forms of dementia and disorientation. I remember many people, but I particularly recall the person who taught me the most valuable lesson.

Mary was an 80-year-old woman diagnosed with Alzheimer's disease. She often did not realize that her husband had passed away years ago and that she was in a nursing home. Usually she was agitated and paced up and down the hallway, going in and out of other people's rooms. The usual care plan was distraction and/or reality orientation. Reality orientation consisted of telling her that her husband was dead and that she was living in a nursing home—information that seemed to make her more agitated. Distraction worked, but there was something that felt unfinished about that.

I truly thought I was being helpful, but I realized that I was wasting energy trying to convince Mary of a reality that consisted of the exact day and year, location, and situation. I'm not sure what I expected. Perhaps that some day, through this constant gentle reminding, she

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would just sit down, tap herself on the forehead, and finally get it that it was February 1992, and she was in a home, had lost her husband, and had a few mementos perched on her dresser.

I began to ask her about her husband. I focused on her present sense of reality and did not resist or insist that she see things the way I did. I felt more engaged and challenged, and likened it to part detective work and part improvisational performance. Mary seemed to relax, as well, and showed a sense of humor. I also realized that there is meaning behind most behaviors. There is a wisdom, and it is our task to be skillful enough to unearth it. What I did not realize is that this intuitive approach had a name: validation.

What Is Validation?

Validation Therapy originated in the 1960s in Cleveland, Ohio, under the auspices of Naomi Feil. This therapy for the disoriented has been embraced in Europe, but has had slow recognition in the U.S.

Validation is a tested model of practice that helps disoriented elders reduce their stress and enhance their dignity and happiness. Validation accepts the old person who returns to the past. Its mission is to help those in the throes of disorientation to accomplish their final life task: dying in peace.

The basic tenets of validation are simple: acceptance and empathy. Validating caregivers must be able to put aside their own judgments and expectations of behavior and learn to be sensitive to the logic behind disorientation in very old people. There are fourteen techniques of validation. They include centering for the caregiver, observing and matching the person's motions and emotions, and linking the behavior with the unmet need.

Validation is the ability to recognize someone else's truth or individual reality. It does not imply a passive acceptance. It utilizes the clues that someone gives and turns them into a passage to their own truth. If a person with disorientation says, "Look at that bird at the foot of the bed," a caregiver utilizing Validation Therapy might say, "Do you like to look at birds?" or "Did you have a bird as a pet?" The caregiver does not attempt to simply placate the person by saying, "Isn't he sweet?" and certainly doesn't say, "There is no bird, Mrs. Johnson."

Often, what we consider problem behaviors, such as hallucinations or paranoid delusions, can be addressed with Validation techniques. There are many examples in Naomi Feil's books [listed at the end of this article] that help cut through the frustrating elements of this behavior, both for the care recipient and the caregiver.

Positive Results of Validation Therapy

Some documented results of Validation Therapy are a reduction in crying, pacing, aggression, and need for chemical and physical restraint. Improvements in gait and verbal and non-verbal communication also have been shown.

A 1980 study found that utilization of Validation Therapy provided positive outcomes for staff in a long-term care facility. Less aggressive behavior by the residents resulted in less staff turnover. Another study found that after training in Validation Therapy, nursing home staff began to see residents not as mind-vacant beings but as people with intuitive wisdom.

Benefits for family members include less frustration, better communication with their loved ones, and relief that their loved ones show improvement in speech and social functioning.

With Validation Therapy, caregivers tune in to the world of the elderly. Travelling back in time with them, caregivers can begin to understand the underlying life themes expressed. By careful listening, pacing body rhythms, eye contact, and touch, the caregiver can build a sense of mutual respect and trust with the elder. Most important, feelings can be understood and interpreted.

This article first appeared in the November/December 2000 issue of Care Connections. Teresa DeAnni is now the Healthy Aging Programs Manager for Boulder County Area Agency on Aging. To learn more about Validation Therapy, read The Validation Breakthrough, by Naomi Feil, or go to www.vfvalidation.org .

"The ordinary acts we practice
every day at home are of
more importance to the soul
than their simplicity might suggest."
— Jack Kornfield

VISIT WITH A CAREGIVER

John and Margaret (not their real names) met over thirty years ago, and they've been sweethearts and best friends ever since. They traveled all over the U.S.—hitting the ballparks and jazz festivals—but now Margaret's travels are over, and John's are limited to his daily trips to the nursing home where Margaret lives. In the advanced stages of dementia, Margaret has lost even the memories of their former life together.

Care Connections: John, how did your caregiving for Margaret begin?

John: It started about six years ago when she had hydrocephalus [water on the brain] with tremendous headaches and dementia. The doctor was able to drain the fluid with spinal taps for the first year. Then they tried a brain shunt, but she had already had some brain damage that was irreversible. I was still working at the time, but I quit so I could take care of her.

CC: You kept her at home for a while. How did that go for you?

John: The physical care—bathing, showering, dressing, toileting—was hard. And it was stressful because I didn't always know where she was. When she was upstairs, I blocked the steps with a gate so she wouldn't fall, but her attention span was short and she'd get tired of watching TV. She wandered away from home and got lost a couple of times. Once she was over a mile away, and another time she was just around the corner but couldn't find her way back home.

I was getting only two or three hours of sleep a night, and my blood pressure went sky-high. I was afraid my health would go, and then I wouldn't be there for her at all. I started taking her to an adult day program. The first time she cried all the way over, but by the end of the day she didn't want to come home. She went from going one day a week, to three, then to five a year ago when I just couldn't manage her care at home. But last January, they said they couldn't take care of her anymore, and I thought, "If *you* can't take care of her, how can *I*?"

CC: Did you consider a long-term care home at that point?

John: Yes, I started looking at long-term care homes in Longmont and Boulder and moved her in February to an assisted living home that could deal with dementia. In May, though, she had a real setback. She became very difficult, and the home said she should go to the hospital to have her medications adjusted. She spent ten days in the hospital, and then she moved to a nursing home in Longmont.

CC: How are you involved in her care now?

John: I visit her daily. It's always hard to leave because she cries and wants to come home, but I tell her that I just can't take care of her like they can there. I used to feel very guilty, but now that I know how caring the staff is, I feel good about her being at the nursing home. When I walk around with her, lots of people say hello to her, and that gives me a good feeling. I expect that she'll stay there the rest of her life.

CC: How do you keep your spirits up?

John: I just take it one day at a time and try to keep a positive attitude. If you're negative, it blows up in your face. I've always been a positive individual; I never really got into blowing off steam. She's my friend, and I love her—I don't want to say anything negative about her.

Initially it was hard to accept, but now I see that I'm not the only one in this boat. I go to the nursing home and see fifty patients, and I say hello and try to help them be happy too. And I go to a caregiver support group because I know that sharing is important. When a new person comes, we try to help them feel more positive.

CC: Do you feel that you still have a meaningful relationship with your wife?

John: Oh, yes. I'm not sure she remembers that I'm her husband, but she knows me because I come every day. She's comfortable with me. She remembers the chocolate I bring—she has her mouth wide open for it! She's aware of some things, though it's fleeting. She hardly talks now—mostly just gibberish.

My son died last year, but Margaret doesn't know. I try to help her remember her brothers and sisters, but she doesn't think she has any. She's past being able to talk about her childhood. Last summer all of her sisters came to see her, and they went out on the patio and sang old songs. She was happy and hummed along—she can still be exuberant sometimes.

We were lovers and the best of friends. I've lost my wife, in many ways, and also my best friend. But to me, every day is a bonus. I just try to make the best of it.

CC: What's the most difficult part of your situation?

John: The hardest thing is living alone and not doing the things I used to do. Though I still bowl and golf and get together a couple times a month with friends, there's a lot that I've given up. But, really, after being married fourteen years, the worst part is living alone, period.

CC: And what are some of the positives?

John: I had to change in order to take care of Margaret—we were both so independent. I think I'm more caring now. When I see that she needs help, I'm "Johnny on the spot." I'm willing to do whatever it requires to take care of her.

CC: Margaret is lucky to have you.

John: I feel the same way. I'm lucky to have her.

This interview first appeared in the January/February 2005 issue of Care Connections.

The Dangers of Medication Non-Compliance in Dementia

by Haleh Nekoorad-Long, MD

Nearly 92% of older adults have at least one chronic condition, and 77% have at least two. 36% of adults over the age of 65 have some type of disability (e.g. difficulty in hearing, vision, cognition, ambulation, self-care, or independent living). Seniors represent just over 13% of the population, but consume 40% of prescription drugs and 35% of all over the counter drugs. On average, individuals 65 to 69 years old take nearly 14 prescriptions per year; individuals aged 80 to 84 take an average of 18 prescriptions per year.

Adverse drug reactions and noncompliance are responsible for 28% of hospitalizations of the elderly. Non-adherence with medication regimens among adults varies from 49–75%. These rates are similar to those found in younger populations, but older people have specific age-related risk factors for non-adherence and specific barriers to the correct use of medication. One of the barriers to taking medications as prescribed can be cognitive decline and dementia.

One in nine people over the age of 65 suffer from dementia. Age is the number one risk for memory loss and developing dementia, and as our population is living longer, we will see increasing numbers of older adults suffering from dementia. Dementia causes memory loss, especially forgetting recently learned information. Some may experience changes in their ability to develop and follow a plan or work with numbers. They often find it hard to complete daily tasks. They can lose track of days and the passage of time. They experience changes in judgment or decision-making including medical decisions. All of these symptoms can contribute to difficulty managing medications. A task that many of us take for granted can become daunting and dangerous for someone with dementia. Depending on the level of dementia, there are different reasons and challenges to keep someone on track and safe.

It has been estimated that 28% of all hospital admissions in older adults are drug related, and 40% are the result of medication non-adherence. In addition, it has been suggested that nearly one-quarter of nursing home referrals result in part from an inability of the aged to manage their use of prescription and non-prescription drugs. For example, when someone with congestive heart failure keeps showing up in the ER because of shortness of breath, it may be due to their inability to take their water pill on a regular basis because of dementia.

The degree of assistance required is dependent on the level of dementia. Early stage dementia is characterized by the patient's desire to maintain independence, denial of issues or disease, and a refusal to take medications due to feeling angry. In late-stage dementia, older adults often refuse medications because of delusional or suspicious thinking, which results in caregivers assuming responsibility for managing their medications. The outcomes of non-adherence are serious for the patient, including increased mortality, hospitalizations, and costs.

Medication compliance is a complex cognitive task for older adults who are also experiencing age-related declines in cognitive function. Adherence to medication regimen involves several cognitive components, including ordering medications correctly and on time, picking up the medications from the pharmacy or receiving them in the mail, understanding the instructions for each medication, knowing the generic names, constructing a daily medication schedule, and, finally, remembering to take the medication at the appropriate time and understanding and reporting any possible side effects.

Research indicates that dementia is a significant predictor of medication non-adherence in older adults. As a result, the response of older patients to drug therapy is often unpredictable, and the health risks associated with not taking medications according to plan are greater. Patients with dementia are less likely to question a prescription or a change in medicine, are less aware of potential side effects, and therefore are more likely to fail to identify a potential error. For example, most insurance companies now require mail ordering, which is an even more complex task than picking up from a local pharmacy. A new medication might arrive two weeks after being ordered by the physician, but may have already been discontinued due to a side effect, and the person with dementia may not notice and may restart the medication again by mistake.

Strategies to improve medication compliance in patients with dementia include prescribing as few medicines as possible, tailoring dose regimens to personal habits, and coordinating all drug dosing schedules to only once or twice a day. Research has shown that older individuals rely more heavily on internal memory strategies (e.g. relating medication taking with other daily activities) than external memory strategies (e.g. leaving reminder notes or using pill organizers).

When providing medication organizers, it is important to evaluate and observe the patient's ability to use the devices appropriately. The device may help them with reminders, but they may not be able to use the device due to physical issues such as poor vision or poor dexterity and inability to open the containers.

The big question is when to switch patient medication self-management to another person's responsibility when cognitive decline progresses. This is not an easy task; most patients resist giving up control over their medications because they view this as a loss of independence. Many family members may feel guilty about taking away the independence, but safety should be the first concern in all cases. As mentioned above, judgment is impaired in many cases with dementia, so the person may not realize the dangers of continuing to manage their own medications. As a caregiver we have to step up do what is in the best interest for our loved ones!

Dr. Haleh Nekoorad-Long, MD, a certified geriatric psychiatrist, is the full-time medical director at AltaVita Centre (www.AltaVitaLiving.com) in Longmont. As a geriatric psychiatrist, she primarily works with aging adults and issues regarding dementia, depression, and behavior related to dementia.

* * *

Creating a Safe Environment for People with Dementia

by Marcy Smallridge

When you are caring at home for a loved one with Alzheimer's disease (or another dementia), safety and accessibility are important concerns. The person in your care may experience changes in judgment, orientation, behavior, physical ability, and the senses. With some creativity, flexibility, and problem-solving, you can adapt your home to support these changes.

Before modifying your home, start with these basics:

- Identify possible hazards.
- Focus on adapting, not teaching.
- Simplify and de-stress activities.
- Support the person's needs without creating an environment that is too restrictive.
- Be realistic about what you can do. You will never be able to prevent every problem. Rely on your common sense while paying close attention to objects or activities that could be dangerous.

Once you have identified potential safety problems, take the following steps to modify your home:

- Make potentially dangerous places less accessible.
- Lock or disguise hazardous areas (for instance, cover doors and locks with a painted mural or cloth).
- Use swinging or folding doors to hide entrances to the kitchen, stairwell, workroom, and storage areas.
- Install locks out of sight. Place deadbolts either high or low on doors to make it difficult for the person to wander out of the house.
- Remove locks in bathrooms or bedrooms so the person is unable to lock him/herself inside.
- Use childproof locks and doorknobs to help limit access to places where knives, appliances, equipment, cleaning fluids, and other dangerous products are stored.
- Use automatic shut-off devices for appliances such as irons, toaster ovens, or coffee makers.

As the disease progresses, changes in vision may make it difficult for the person to distinguish colors and understand what is being seen. Consider the following:

- Reduce glaring light by removing or covering mirrors, glass tops, and highly polished furniture.
- Cover windows to block bright sunlight.
- Because changes in levels of light can be disorienting, add extra lighting in entryways, outside landings, areas between rooms, stairways, and bathrooms.
- Place contrasting colored rugs in front of doors or steps to help the person anticipate staircases and room entrances. However, avoid using very dark colored rungs since they may be perceived as holes.
- Apply colored decals to glass doors and large windows so the person doesn't think they are open doors.
- Use nightlights in hallways, bedrooms, and bathrooms to prevent accidents and reduce disorientation, especially if the person wanders.

Even the most basic appliance or household object can become dangerous to the person with Alzheimer's. To reduce the risk of injury, limit the use of certain appliances and equipment.

- Remove electrical appliances, such as an electric razor or a hairdryer, from the bathroom to reduce the risk of electrical shock.
- Put away kitchen appliances and other equipment including knives, mixers, grills, guns, lawnmowers, or power tools, since the person may not remember how to use them safely.
- Consider removing the knobs on the stove or installing a hidden gas valve or circuit breaker so the person cannot turn the stove on.

Always supervise smoking and alcohol consumption. Alcohol can have many negative effects, especially when mixed with medication. Keep walking areas clear to create safe wandering areas and reduce the possibility of injury. Be prepared for the unexpected! Persons with Alzheimer's have been known to eat items such as small rocks, dirt, plants, flowers, and bulbs. Take precaution by removing toxic plants and any decorative fruits that the person may think are real. Also remove vitamins and prescription drugs from the kitchen table and counters.

Since the majority of accidents in the home occur during daily activities such as bathing, toileting, and eating, it is important to take special precautions at these times. As the disease progresses, the person may have a decreased sensitivity to temperature. Consider installing automatic-mixing or anti-scalding devices on the faucets. It's also important to check the temperatures of foods before serving to ensure that they are not too hot or too cold to consume. Shower seats and commode chairs also are helpful if the person has limited mobility. Add textured decals to slippery surfaces and apply adhesives to keep throw rugs and carpeting in place, or remove them altogether. Always supervise taking prescription and over-the-counter medications. Consider using locked pill dispensers operated on a self-timer.

While it is important to make the environment safe, it is equally important to create an atmosphere that supports the changing needs of the individual with Alzheimer's.

- With your supervision, involve in preparing meals, rinsing the dishes, folding clothes, raking leaves, and other such activities. They will enhance self-esteem and help the person feel more valued around the home.
- Use the surroundings to initiate activities: leave out scrapbooks, photo albums, or old magazines that encourage conversation and help the person reminisce.
- Create safe access to the outdoors. A backyard with a secure fence allows the person to safely go outside.
- If the person is unable to go outdoors, consider doing indoor activities in a room with many windows or on an enclosed porch.

Finally, enroll the person in the MedicAlert® + Alzheimer's Association Safe Return, a 24-hour nationwide emergency response service for individuals with Alzheimer's or a related dementia who wander or have a medical emergency. Call 1-888-572-8566 or visit *www.medicalert.org/safereturn* .

This article first appeared in the January/February 2002 issue of Care Connections, when Marcy Smallridge was with the Alzheimer's Association Colorado Chapter.

> **"They may forget what you said,**
>
> **but they will never forget**
>
> **how you made them feel."**
>
> *— Carl W. Buehnerk*

Taking Our Turn

by Colleen Conant

My mother came to live with us in 1981. A widow since 1968, she had just retired from her position as office manager for a dentist. After a dream trip to Europe, she was ready to settle down to a new phase of life.

My husband and I had just bought a big, old house with plenty of room for our two sons and a separate suite for Mom. Our older son was six and the baby was just six months old. My husband and I were both working full-time, and Mom offered to take care of the boys and keep the house.

It seemed like a perfect arrangement. And it was.

Our boys had the pleasure of staying home and having a very special relationship with their grandmother. They came home from school to homemade cookies and milk, and we all enjoyed wonderful home-cooked meals.

The years flew by. My job caused us to make three moves from Florida to Tennessee, then back to Florida, and finally to Colorado. In 1997, when we left Florida the last time, Mom had just turned 80 and had decided to give up her car. We are so thankful she made the decision on her own. Even though she usually only drove to the grocery store and the beauty parlor, both just a few blocks away, she was beginning to lose her way and get lost coming home.

All those years she had taken care of us. Now it was our turn to take care of her. And we did.

Since we moved to Colorado, her memory has continued to fade and he has become more and more frail. The first sign of her dementia was the Christmas of 1999. She just couldn't remember whether she had done any shopping or mailed any cards. In fact, I had taken her shopping, but she had no memory of our excursions.

During that next year, I began to take over more and more of the things she had always done.

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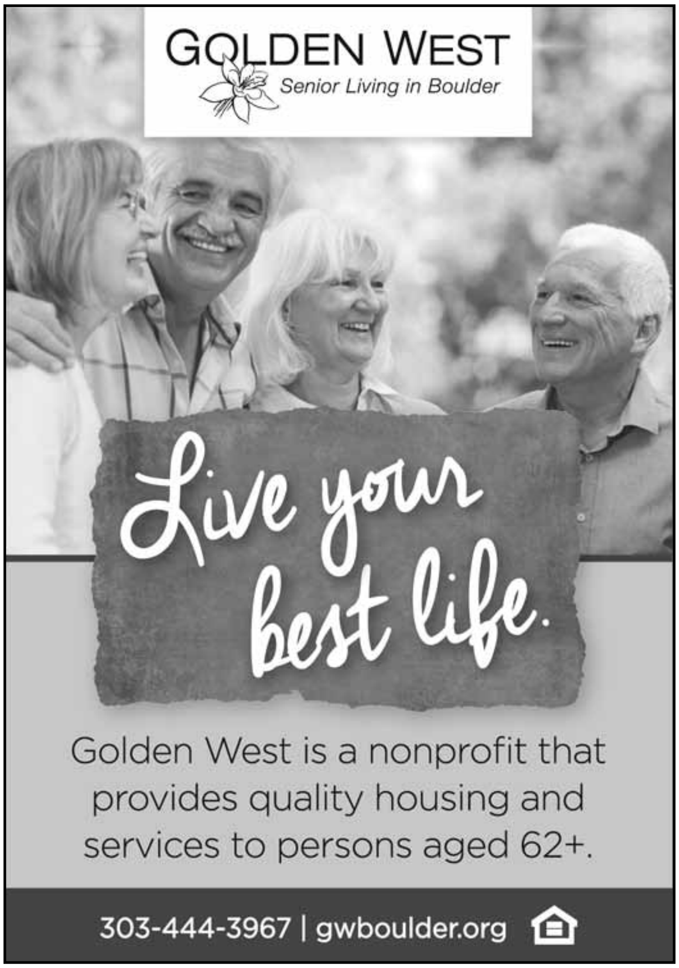

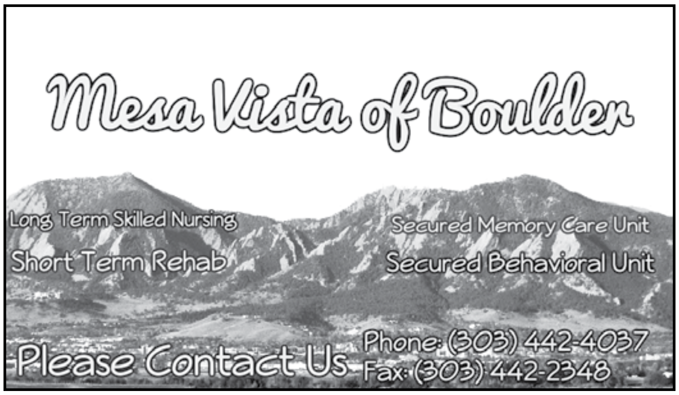

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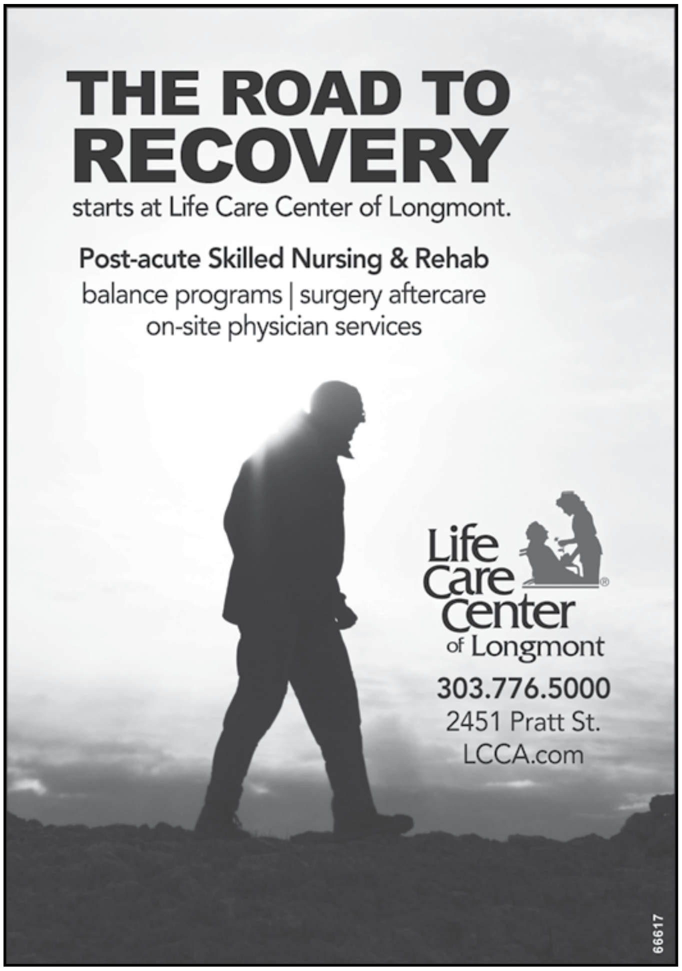

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She stopped cooking and would forget to eat unless reminded. In fact, she forgot to do the everyday things unless reminded. She is disoriented and confused about most things. And she has grown more frail. A lunch outing, which she used to love, exhausts her.

Still, she has kept her sense of humor and loves to read the newspaper. We tease her, telling her we get more value from the newspaper than anybody because she reads it over and over.

Early last year, she had a fall and broke her sacrum. She spent two weeks in the hospital and four weeks in rehabilitation. Thanks to the many helpful hands in Boulder County, including home care professionals and the county's senior services, we managed to bring her home. My husband and I became her caregivers 24/7. It is the hardest work we've ever done.

I used to marvel at the professionals in the hospital and the rehabilitation facility who cared for Mom during her stays there. "How do they do it?" I wondered.

Now I know.

To be sure, they are angels on earth to take up this work. Still, at the end of their shift, they have homes and families of their own to go to. When family is the caregiver, there is no respite. Mom resisted in-home elder care and day care. When a volunteer came to visit, it caused so much anxiety we elected not to continue.

The emotional stress of caring for an elderly parent is draining and the physical work is exhausting. It's heartbreaking to see the person you have known and loved for all your life simply fade away, knowing there's nothing you can do about it.

The hardest part for us has been trying to figure out what's best for Mom and what's best for us. It's impossible not to feel self-involved and guilty about almost every decision.

Finally, in August, Mom moved to a nursing facility. Telling her was agony, even though she didn't remember the news thirty seconds later. Packing her things and driving her there was harder still.

She is safe and well-cared for; she eats well and visits with other residents. She's getting far more social interaction than we were able to provide.

Intellectually, I'm certain we made the right decision. Still, it's heartbreaking to see her continue to fade away. In her lucid moments, she sometimes says, "You shouldn't have taken such good care of me," and asks, "Why do you suppose I live so long?"

"We don't get to choose," is my best answer.

This article first appeared in the November/December 2004 issue of Care Connections.

Locked Doors

by Beth Hayward

The door is locked. The windows shuttered. A cold breeze whistles through the cracks. Silence greets the visitor. Mother lies in her bed, curled in a fetal position, locked in her private world. I wait.

As morning dawns, the aides come. They try to rouse Mother so they can dress her.

"Wake up, Deary," they say to Mother. "Let's wake up. It's breakfast time."

Mother groans, not opening her eyes. She says, "Have you seen my parents? They were here earlier."

"No, Mother," I answer. "We'll look after breakfast."

Mother's arms are squeezed tight against her chest with a strength that belies her 98 years. The aides almost pry her arms apart to enable her nightshirt to come off and her blouse to go on. The aides struggle and I cajole. Finally we have Mother upright and sitting in her wheelchair, with all her clothes on and buttoned.

I brush her hair, adjust her glasses, wiggle her dentures into her mouth. I wheel her to the dining room.

Everyone greets Mother with cheery attention. "Good morning." "Hello, Ester." No response from Mother. She used to smile and respond to all around her.

Breakfast is pancakes and scrambled eggs. The syrup smells so tantalizing. Mother can feed herself, but today she chooses not to. She opens her mouth for each morsel, chews, and swallows, more from habit than from enjoying the food. She reaches for her orange juice with unsteady fingers, and it spills. We mop it up and pour her some more.

After breakfast, we return to her apartment and look for something to entertain her. I try the newspaper, the coloring crayons, dominoes. Nothing catches her interest today.

"Mother, do you know who I am?" I ask.

"No. You're not a relative. You're that lady who comes to sit with me."

So we sit in silence for a while. I hold her hand, stroke her hair. She's calm today. The medication prevents her from living the recurrent nightmare of being in charge of her baby sister when the sister gets lost and she panics. The screaming is heartbreaking. There's no consoling her. There's no peace for Mom. Pills do have their place.

Then Mother states with certainty, "Six."

"Six what?" I ask. "Are you counting something?"

"Six of one and half a dozen of another," she says, all in a rush.

After a few minutes, Mother giggles, "I'm jumping on the bed." Then, totally changing the subject, "I'm leading the parade around the Maypole."

In another conversation, she told me about another parade: she marched in front of the White House when she was in the army. Since she never served in the army, that parade was a fantasy. The Maypole parade really happened.

I arrange the flowers I brought and ask Mother to smell them. "Do these smell like your flowers from home?" She sniffs and smiles, but no answer.

I gather up the laundry from the closet and tidy the room. When it looks like Mother has fallen asleep, I tiptoe toward the door. A half smile tickles the corners of her mouth. Maybe she's smelling the roses from home. Maybe she's parading at the White House. Maybe she sees her parents again.

"I love you, Mom." There's silence in the room. A cool breeze stirs the air. The eyes are shuttered. The mind is locked. I've lost Mother for today.

This article first appeared in the November/ December 2005 issue of Care Connections.

Activities and Alzheimer's: What's the Big To Do?

by Pat Holley

Throughout our lives we are defined by what we "do." Children may become involved in sports, dance, or scouting at a young age. As adults we tend to identify ourselves by the field of work we have chosen. The question "What do you do for a living?" is considered a polite conversation starter in many circles. As we grow older and retire, many folks participate in social clubs, travel, hobbies, or other leisure activities. These endeavors enrich our lives and increase the quality of our daily existence.

When a person develops Alzheimer's disease or another form of dementia, many of the skills and cognitive abilities necessary to successfully participate in former activities are diminished or

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COMMUNITY RESOURCES

This column provides information about events and classes, services, and other resources that may be of interest to family caregivers in Boulder County. Please remember that it is each person's right and responsibility to research a service provider or event before taking action. See "Information and Assistance in Boulder County" on the back page for ways to learn more about these and other resources. (To share information about a resource for family caregivers, email InfoCaregiver@bouldercounty.org or call 303-678-6116. The deadline for the September/ October 2016 issue is July 25.)

Alzheimer's Association Colorado Chapter offers these programs for people with early memory loss: **Louisville Memory Café**, a welcoming gathering place where people living with memory loss and their partners can socialize while enjoying coffee and an activity or presentation, on Mondays, July 11 and August 1, 10 – 11:30 a.m., at Louisville Recreation Center, 900 Via Appia Way, Louisville; **Nature Walk**, a multi-sensory exploration of nature with a naturalist, on Tuesday, August 9, 10 a.m. – 12 p.m. (location to be announced); and **Soldier Shelters: Hide, Protect, and Serve**, a visit to an interactive exhibit about a soldier's story, on Friday, August 26, 10:30 a.m. – 12 p.m., at Boulder Museum of Contemporary Art, 1750 13th Street, Boulder. These programs are free. To register or for more information, call 303-813-1669 or email *Kera at kmagarill@alz.org* .

Longmont Senior Services offers **What Is Elder Abuse?**, about what constitutes abuse, neglect, and financial exploitation of an older person, with Longmont Police detectives Steve Desmond and Chris Merkle, on Thursday, July 14, 2 – 4 p.m.; **Home Safety Strategies**, about recognizing and mitigating hazards to help you or a loved one age in place, with Krista Covell-Pierson, Covell Care and Rehabilitation, on Thursday, August 4, 2 – 3 p.m.; and **Communicating with a Listening Heart**, about approaches for communicating more effectively with loved ones and care receivers, with Kenna L. Quiller, author and former corporate psychologist, on Monday, August 8, 9:30 – 11:30 a.m. ($36 for Longmont residents; $40 for non-residents); all at Longmont Senior Center, 910 Longs Peak Avenue, Longmont. Unless noted, classes are free. Pre-registration is required, at 303-651-8411.

Alzheimer's Association Colorado Chapter presents **Effective Communication Strategies**, on Thursday, July 21, 1 – 3 p.m., at West Boulder Senior Center, 909 Arapahoe Avenue, Boulder; **Know the 10 Signs: Early Detection Matters**, on Tuesday, July 26, 3 – 4:30 p.m., at Atria Longmont, 2310 9th Avenue, Longmont; **The Basics: Memory Loss, Dementia and Alzheimer's**, on Monday, August 8, 3 – 5 p.m., at Kaiser Permanente Baseline Clinic, Boulder, and on Monday, August 22, 9 – 11 a.m., at Longmont Senior Center, 910 Longs Peak Avenue, Longmont; **Healthy Living for Your Brain and Body: Tips from the Latest Research**, on Monday, July 11, 9 – 10:30 a.m., at Longmont Senior Center (address above), and on Thursday, August 11, 5 – 6 p.m., at Balfour Cherrywood Village, 282 McCaslin Boulevard, Louisville; and **Living with Alzheimer's: For Middle Stage Caregivers** (two-part), on Wednesdays, August 24 and August 31, 9 a.m. – 12 p.m., at West Boulder Senior Center (address above). Pre-registration is required, at 800-272-3900. Class descriptions are available at *www.alz.org/co* (Classes and Workshops).

Boulder County Area Agency on Aging offers the **National Caregiver Training Program**, an 18-hour course, taught by a registered nurse, that helps family caregivers acquire skills needed to provide safe, confident home care for frail older loved ones, on Thursdays, July 21 – August 25, 5 – 8 p.m., in Longmont (open to Boulder County residents only). Boulder County Area Agency on Aging and Weld County Area Agency on Aging jointly offer **Powerful Tools for Caregivers**, a 15-hour course that gives family caregivers the tools to help them take care of themselves, reduce their stress, communicate effectively, and thrive—not just survive—while caring for an older loved one, on Wednesdays, September 7 – October 12, 1 – 3:30 p.m., at Erie Community Center, 450 Powers Street, Erie (open to Boulder County and Weld County residents). There is no charge for either course, but donations are appreciated. Financial assistance for respite care (substitute elder care during class periods) is available to Boulder County residents. For more information or to register, call 303-678-6116 or email *InfoCaregiver@bouldercounty.org* .

Medicare Counselors with Boulder County Area Agency on Aging hold **Medicare Basics Classes** for anyone wanting to learn more about enrollment, benefits, costs, and choices under Medicare, on Thursdays, September 1 and October 6, 2 – 4 p.m., at East Boulder Senior Center, 5660 Sioux Drive, Boulder (call 303-441-1546 to register); on Mondays, September 19 and October 25, 10 a.m. – 12 p.m., at Longmont Senior Center, 910 Longs Peak Avenue, Longmont (call 303-651-8411 to register); and on Wednesday, September 21, 1:30 – 3:30 p.m., at Louisville Senior Center, 900 W. Via Appia, Louisville (call 303-666-7400 to register). These classes are free, but donations are appreciated.

A new **Alzheimer's Association Caregiver Support Group**, conducted by trained facilitators and offering a safe place for current or former caregivers, family, and friends of persons with dementia to exchange practical tips on caregiving, talk through issues, develop coping mechanisms, share feelings, and learn about community resources, is held on the first Thursday of every month, 4 – 5:30 p.m., at Erie Community Center, 450 Powers Street, Erie. To register or for more information, call 970-392-9202.

Boulder County CareConnect, a 43-year-old nonprofit, provides volunteer-powered safety net services for local seniors who are in need. Volunteers shop for and deliver nutritious food and other groceries, complete minor home repairs and install grab bars, provide basic yard maintenance and snow shoveling, and give escorted rides to and from medical appointments. For more information or to enroll, visit *www.careconnectbc.org* or call 303-443-1933.

The **Respite Assistance Program** of Boulder County Area Agency on Aging offers financial assistance for respite care to Boulder County residents caring for loved ones age 60 and over (or of any age if they have dementia). The program provides up to $500 per calendar year in reimbursement for the costs of hiring a substitute caregiver so the primary caregiver can take a needed break—or respite. The substitute care can be provided by a friend, relative, home health care agency, adult day program, or long-term care facility. To apply, contact your local Resource Specialist (see back page for phone numbers) or the ADRC Helpline, at 303-441-1617.

For a complete list of **caregiver support groups** that meet in Boulder County, call 303-678-6116 or email *InfoCaregiver@bouldercounty.org* .

Activities and Alzheimer's: What's the Big To Do?

(continued from page 10)

absent. The previously active person may decline to participate in once favorite activities when invited or stare blankly at a television screen for hours on end. Caregivers are sometimes frustrated by what they view as disinterest and stubborn refusal, but what they may, in fact, be witnessing is the person's inability to participate due to the brain changes that have occurred as a result of the illness.

An activity that may at one time have been simple and pleasurable can become an arduous task, too frustrating and difficult to even attempt. Unfortunately, when this occurs the person is left with a void where that enjoyment once was and a diminished quality of life. The keys to providing enjoyable activities to a person with dementia are recognizing the intact strengths in the person and understanding the person's interests and preferences. For example, a formerly avid fly fisherman may no longer be physically or cognitively able to stand in a river and cast for trout, but perhaps he would enjoy flipping through a photo album with snapshots of prized past catches or looking at a fly fishing video or magazine. A person with Alzheimer's may lack the initiative to instigate an activity; however, if the caregiver helps to get them started, they may jump right in with a smile.

Activities are beneficial to both the person with Alzheimer's and the caregiver. When a person with dementia has had a busy day full of meaningful activities they will be less restless and may sleep better at night. Behaviors which may be challenging to caregivers can be alleviated by providing activities to distract and/or comfort the fearful or confused person with dementia. Activities can be as simple as assisting with household chores or listening to a favorite piece of music. By providing interesting and ability-appropriate activities, caregivers decrease anxiety and increase quality of life for both the person with dementia and themselves, and that is a very good thing to "do."

This article first appeared in the July/August 2007 issue of Care Connections, when Pat Holley was Family Services Director for the Alzheimer's Association Colorado Chapter. For more information about activities or other aspects of dementia care, call the Alzheimer's Association at 1-800-272-3900 or go to www.alz.org .

The Loneliness of the Alzheimer's Caregiver

by Emily Cooper

Being a caregiver can be a lonely experience, and there is a special loneliness that comes with caring for someone with Alzheimer's disease. When my mother was the primary caregiver for my father, who had Alzheimer's, she lost contact with many of their long-time friends and she lost much of the familiar connection with her husband of sixty years. The resulting sense of isolation was one of her greatest challenges as a caregiver.

Though my parents had socialized regularly with a group of friends for years, those friends were all but invisible when Dad began to lose his memory. The friends didn't know how to handle his confusion and frustration, and they didn't understand what Mom was experiencing as his caregiver. So they just stopped coming around.

Mom was lonely for their friends, but she was lonely for her husband even more. Dad had never been much of a talker, but he and Mom were comfortable with each other and with their routine. Mom knew that Dad would maintain the house, make repairs, and do the bookkeeping, and she was content to do the shopping, cooking, and cleaning.

As Dad's abilities decreased, it took a long time for Mom to realize that she had to take over his "areas," and it took even longer for Dad to accept her intrusion into his domain. Mom felt the heavy responsibility of having to do everything around the house. Paying the bills, driving, maintaining the house and yard, getting the taxes done, making the medical appointments … she did it all *in addition* to caring for Dad. She wanted to share the decision-making with him as she always had, but eventually she realized that Dad could no longer participate as a full partner.

There were still many ways that Mom could interact with Dad, but he was so *different*. He wasn't the husband she knew. I once read that when you become the caregiver of a spouse with Alzheimer's, you have to be willing to "divorce" the person you first married and "remarry" the different person they have become. Mom's marriage was nothing like it had ever been, and she missed the familiarity of the man she had known—with all of his predictable imperfections.

It was lonely being at home with this "new" husband, but neither did Mom feel that going out with him worked very well. Their small, rural town didn't have a senior center or an adult day program, so there was no place for them to go where Dad would be fully welcomed and understood. He had been a respected businessman, and Mom wanted to preserve his dignity as long as she could. She was embarrassed for him.

During the early stages of Dad's Alzheimer's, Mom felt she could safely leave him at home while she went to social gatherings. But Dad would get anxious while she was gone and would burst out in anger when she returned, so getting out just didn't seem worth the bother. Finally she hired a companion to stay with Dad while she went out. He still got a little anxious, but he enjoyed the companion's visits, and Mom was able to get away for some needed time with others.

After Dad moved to a nursing home, Mom visited him there every day. She still felt a huge responsibility, but at least she began to focus a little on her own health and she was able to get out more to be with other people. Interestingly, once Dad moved to the home, the friends who'd been virtually absent began to visit him regularly. Perhaps that was because they realized he wouldn't live for long, or because the structured setting felt more secure. Regardless, Mom and Dad were glad for their visits, and it helped Mom to feel more connected to them in the last months of Dad's life.

It's been five years since Dad died, and widowhood has brought a whole different kind of isolation for Mom. It isn't easy, but she knows that relationships are important to her, so she does her best to stay connected. Thus, though her life is very different from what it was before Dad's illness and death, it is still rich and well worth living.

This article first appeared in the January/February 2004 issue of Care Connections. Emily Cooper is Information & Referral Specialist – Caregiver Programs for Boulder County Area Agency on Aging.

"Between stimulus and response
there is a space. In that space
is our power to choose our response.
In our response lies our growth
and our freedom."
— Viktor E. Frankl

CARE Connections
Boulder County Area Agency on Aging
P. O. Box 471
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Boulder County
AREA AGENCY ON AGING
Community Services Department

INFORMATION AND ASSISTANCE IN BOULDER COUNTY

Within Boulder County, there are several ways to access information and assistance about resources and services for older adults and their family caregivers:

- Check out **Network of Care for Seniors and People with Disabilities**, a comprehensive online service directory, at *www.BoulderCountyHelp.org*
- Call the **ADRC Help Line**, at 303-441-1617, and Boulder County Area Agency on Aging staff will respond to your message.
- Call the **resource specialist** in your community (numbers below). Services vary by community but include identifying needs, exploring options, finding solutions, and providing in-depth assistance.

Allenspark area	303-747-2592
City of Boulder	303-441-4388 (bilingüe: 303-441-3918)
City of Lafayette	303-661-1499
City of Longmont	303-651-8716 (bilingüe: 303-774-4372)
City of Louisville	303-335-4919
Erie	303-441-1617
Lyons area	303-823-9016
Nederland area	303-258-3068
Niwot area	303-441-1617
Superior	303-441-1617

ADRC
Aging and Disability Resources for Colorado