New Trends in Alzheimer Core

Finding the spirit within

Beverly Moore

New Trends in Alzheimer Care Finding the spirit within Beverly L. Moore

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Strategic Book Publishing and Rights Co. 12620 FM 1960, Suite A4-507 Houston, TX 77065 www.sbpra.com

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This little book is written for willing and reluctant caregivers alike who have struggled to understand how to care for a person with dementia and care enough to help that person stay in control of their own life to the best extent possible. It is my personal journey as an Alzheimer coach and as a family member.

New Trends in Alzheimer Care; Finding the spirit within

Since writing my first book <u>Matters of the Mind...and the Heart</u> for caregivers in 2008 I have looked at Alzheimer care through several new lenses gaining new insights into how the disease affects thinking and ultimately the person's behavior and his caregivers. Developing new understanding about caring respectfully for someone with a cognitive disorder has given my work deeper meaning. I want to share both what I have learned professionally and what I learned as a caregiver myself so that others like you can benefit. This book is divided in half, the first half explores how care has changed with new understanding of the brain's workings, and the second half invites you to accompany me in my caregiving journey with my mother in law.

Through coaching some two thousand family caregivers, I've learned that the caregiver and care recipient alike has need of three (3) things. I have adopted an acronym to remember them; it is **CVS**. The caregiver needs to feel in control of the disease in order to take charge (C) of caring for the person as their ability to care for themselves changes. The caregiver needs to feel validated (V) by someone for what he is doing and, finally, to find satisfaction (S) in the caregiving experience. For this to happen, the caregiver must learn new information about how the brain changes to work effectively and respectfully with their family member.

The care recipient also needs three things (again, CVS). He needs to feel he is in charge (C) of his own life, encouraged to make decisions about everyday life, and to feel in charge of his belongings. He needs to feel valued (V) as a person of worth, with meaning and purpose in life; valued for who he is now, for his history, his accomplishments and talents. Last, he needs to feel safe (S). Physical safety is important; likewise, maybe more important, is emotional safety. When these needs are satisfied, both the caregiver and care recipient feel confident in the journey. The ultimate goal is a more peaceful cooperative experience for all.

Let us look at two new trends in Alzheimer care. Care is more person-centered and process oriented. Instead of focusing on a task accomplished, the focus is on the doing, creation of enjoyment in the present moment.

The trend in Alzheimer care to be person-centered rather than patient-centered is a welcome shift for me as a coach to families who want their family member with dementia to remain at home safely and happily. They also want to maintain relationship with the family member. In addition, caregivers want to feel confident in how they care. An educated caregiver lasts longer in the caregiving role, experiencing less burnout. This is borne out in a 17-year longitudinal study by Mary Mittelman of New York University School of Medicine. It was found that when caregivers were trained and supported as they learned approaches to responding to their family member's changes in behavior and ability, they were able to continue home-based caregiving 1 ½ years longer and experienced fewer psychological symptoms.

A person with Alzheimer's continues to be a whole person with a will, with a rich history of places lived, people met, skills learned, work accomplished and hobbies that brought pleasure in their leisure time. This history is valuable in establishing a trusting relationship. Caring for the person with diminishing initiative, interest, and ability to create pleasurable activities for themselves, puts the responsibility on the caregiver to structure the day for him. This is not an easy task, one that most caregivers struggle with. It is no longer enough to ask, "What do you want to do today?" He won't know what he wants to do; he will depend on you to plan the day. Often the person will waken and ask "What are we doing today? Where are we going? What time is it?" all in an attempt to orient themselves and find purpose in the day when they can not choose to do something and proceed to do it. Apathy is a less recognized symptom of Alzheimer's.

Clearly, finding activities that will satisfy is easier if the caregiver is someone who is familiar, perhaps has experienced a longstanding relationship. If not, there are ways to draw out ones history through different media that tap the emotional memory. If the caregiver is someone hired that person must become familiar with the person's history, personal preferences, fears and pleasures. Those familiar with such information need to write it out. This acquired information notes what their meal schedule is, when they bathe, what music is enjoyed, what pictures please or perhaps other history like hobbies pursued and activities engaged in around the home (tending to plants, building model planes, military paraphernalia, etc.). If the family does not provide this, ask them to do it with you so you can be a better caregiver for their family member. Few would refuse.

Learn of the person's previous history. Did he like dancing? Incorporate it into working with him. Many a person has been 'danced' into a shower or brought to a meal. Did she enjoy being a hostess, caring for people through comfort and food? Engage her in helping you learn how to be a good hostess. Prepare meals together; ask for advice on recipes she enjoys. Ask her to teach you to set a formal table. One creative homecare aide discovered her client had been a drum majorette in high school. Each morning the caregiver put on popular marching music and invited her client to march with her. She was able to bathe her by marching her to an already prepared bath area. Another learned her client was an architect and got some old prints of structures he had built and asked questions about them.

May I have this dance?

Sandra, whose husband had language challenges, had trouble getting him to understand what she wanted him to do. For example, when she came into the living room to tell him dinner was ready, he smiled at her, continued to sit and failed to respond to her request. Reviewing their past life together, I discovered they were avid dancers. Every week they enjoyed ballroom dancing. I also learned he loved semi-classical music. Each meal she put on dance music and, using gestures to indicate dancing asked for a dance. She smiled as she said, "May I have this dance, Hal?" He readily rose, came into her arms and danced right into the dining room with her leading. When there, he had the visual cues of the place setting, so when she invited him to join her, he sat down and ate. How much better this was than getting annoyed that he didn't understand, perhaps thinking it stubbornness or trying to force him out of his seat. That might have led to his defending himself against a perceived threat and becoming combative. How lovely it was, as well, to continue an activity both had enjoyed so long. Procedural memory, that memory of doing something physical, lasts for a very long time into the disease. It merely has to be tapped by a cue, in this case music and an invitation to dance.

Bath for mom

Sometimes a bit of history comes out in unexpected ways. A daughter who drove seventy-five miles each way once a week 'to give her mother a bath' was beside herself with frustration. After several different failed approaches, she felt defeated. I asked her how she approached the task. She said she would come into her mother's home and say, "Today I'm here to give you a bath." Her mother would retort, "I've already bathed and who are you to bathe me? I used to bathe you." She learned that with memory loss, a person often thinks they continue to do tasks when in fact they aren't anymore. "It is a fight every time. I come expecting failure and that is exactly what I get. We don't enjoy each other or the visit."

I suggested she visit and not mention bathing at all. "Just enjoy your mother like you want to do. Bring a sweet, have tea. Reminisce with her." "Ok, I'll try. It is not working this way. I'll try anything. It is a long drive just to get aggravated!" I agreed.

Later that day I got a call from the daughter. "It is a miracle; she took a bath. We were sitting in the kitchen having tea, when she said, 'Remember when I used to give you a bubble bath? You really liked that and we sang together the song I'm forever blowing bubbles?' We started smiling remembering those days, even sang the song together. I was about five then."

I was curious. "Well, what happened?"

"My mother said, 'Well, it's about time you made me a bubble bath. Will you?' And I did. She bathed and we sang; how very strange. Why did that happen?"

What this daughter did was let go of the task and relate to the person. Her mother probably had a thought connection between her daughter and bathing, but because she had visited with a different attitude, the mother was willing. She wasn't being told to do something she thought she did herself, and she was being enjoyed for her person and her relationship with a daughter.

Peter is Still Here

When the person with Alzheimer's has a speech challenge; either understanding what is being said (receptive aphasia) or expressing what he wants to say (expressive aphasia), it is very frustrating for all concerned. It is frustrating for the caregiver who wants to relate satisfactorily. The result is often avoiding talk, leaving both in awkward silence. Most spouses tell me that the thing they miss the most since the diagnosis of Alzheimer's is conversation.

Peter had expressive aphasia. He seemed to understand what was said to him, and could follow conversation, but when he attempted to join in, he would have great difficulty getting words out. You could see the exasperation on his face and his family felt sad for him. There were four grown children and all talked at the same time when together. This presented a real problem for Peter. He began to dislike family gettogethers, often leaving the room to find solace.

During a coaching visit, Peter's wife said, "I don't know about Pete's difficulty. He has no problem speaking when we're in Maine at our summer cottage. Why is that? Is he playing a game with us to get attention?" This is often the conclusion families come to when a behavior isn't consistent.

I turned to Peter and asked, "Is what she says right; do you express yourself easier in Maine?" "Yes." I asked, "Do you know why that is?"

Notice I didn't ask him an open ended question, like, "Why is that Peter?" An open ended question requires a good deal of processing. First he has to hold on to the question which is done by the working memory, most often impaired in Alzheimer's, search for the thought and articulate his answer. This calls upon several parts of the brain working together to formulate a response. That takes too long for most people to wait for an answer. Instead asking a yes or no question, the processing is quicker.

"Yes, I know why." He hesitated. I teasingly asked, "Do you want to tell us?"

Again he took his time responding. I waited. Then, he explained, "Up in our cottage there is a TV without a remote, a regular phone attached to the wall and nothing to remind me of all the things I can't do anymore, like balance a checkbook. I can't even add and subtract now." he said sadly.

This gave us clues about how to simplify the home environment to aid Peter in his language. The children were encouraged to refrain from telephoning during meals so he could concentrate on eating and having casual talk with his wife. Items that confused him were put out of sight. It appeared that a calm uncomplicated place helped Peter organize his thoughts better and say what he wanted to say.

Pacing our actions can be very helpful or unhelpful to a person who gets easily distracted or confused about the use of things. Some small changes can mean the difference in feeling in control or not. Peter had in the past picked up the remote control and tried to dial his daughter. Soon he realized his mistaken identity of the object and threw the remote on the couch, exclaiming, "I'm so stupid." Putting misidentified items out of sight helped Peter feel more confident.

John Zeisels book <u>I'm Still Here</u> brings insight into tapping the spirit of the person, enabling him to be all he can be. Zeisel talks about identifying the primary symptoms of Alzheimer's and not confusing them with the secondary behaviors that result from not responding to the need of the person experiencing these primary symptoms.

The primary symptoms are *difficulty accessing memories, organizing complex* sequences, controlling instincts, keeping track of time, finding words to express feelings, and difficulty initiating meaningful activities. Think of the impact on everyday life these symptoms would have on you.

What to do?

I met Marie, a quiet but engaging woman, while coaching her husband Carlo who worried that Marie had been remaining in bed into late in the morning. She had no known physical challenges, so I wondered, is she staying in bed because she is tired or because she is bored. I asked her this question. After thinking about it awhile, she said, "I'm bored. I can't think of something to do. Carlo is very hard of hearing so we don't talk much and he doesn't offer anything to do." I suggested that she and I tried a page in Lynn Serper's booklet about Eleanor Roosevelt. These books tap semantic memory, that general knowledge of the world we live in. The booklets contain short one-page entertaining stories of famous people. After reading the story aloud, the person with memory loss repeats what she remembers from the story. Marie was able to state three facts from the story on her second try. One Marie found humorous was that Eleanor's mother told her she would have to be smart because her looks were not going to help further her socially. Marie and I laughed at that and marveled at how she had taken her mother's advice. All that Marie needed was someone to structure some pleasurable activities during the day to get her to want to get out of bed. A day program near their apartment complex was the answer. She needed others willing to organize and guide activities and provide socialization.

When untreated this primary symptom of inability to initiate meaningful activity means an inability to do things independently. Lack of activity can lead to delusions (unreal thinking) and depression. Wouldn't anyone become sad finding doing previously understood tasks difficult and finding no one who would help make it easier? My belief is that people don't forget how to do something, they just can no longer initiate or organize it. Using prompts and visual cues help to address this challenge.

Another concept Zeisel talks about is how the person figures out what is happening around them and deciding how to respond to it. He labels these brain activities the Interpreter, the Actor and the Comparer. The Interpreter perceives the world through the senses. What does the person see, hear, feel, smell, taste? The Actor does something in response to what is perceived and the Comparer revises the action based on remembering its likeness to other similar situations. Think for example of a person's automatic response to "How are you?" Even if we feel differently, we say "Fine, how are you?" Similarly, social graces are often intact throughout the disease. This last component, the Comparer is impaired in Alzheimer's, making it harder to determine how to respond when the situation is more complex. The lessened ability to regulate impulses makes it more likely that the person may respond in what seems to others an inappropriate way. Cues to guide behavior help.

Often when I speak with a family about our coaching service, they want their family member with Alzheimer's present. I discourage that as it is not helpful in a coach assessing the deficits the family reports. I teach them that being in a social situation of meeting someone new as a guest in their home, the person will often rally with very appropriate social behavior. The environmental cues say, be social, be a good hostess. In addition the family isn't free to talk about what is really concerning them. By trying to protect the person from embarrassment, nothing helpful is accomplished.

On the other hand, knowing this concept of Observer, Actor and Comparer can be helpful for caregivers to draw out helpful and positive behavioral responses by placing the person in a situation that recalls similar situations. Then the Comparer will do his work.

Can you help, mom?

Julie's mom Nellie spent every weekend with Julia and her two boys four and one. Julia, an only child, loved her mom and was heartsick about her progression into Alzheimer's. She had hired a woman to stay with her mom during the week and keep house while Nell was at a day program. She looked forward to having her mom for the weekends especially since her husband had a nighttime job and wasn't available much on weekends. But, Julie was perplexed; shortly after arriving at her home, after the boys had greeted her with hugs, Nell would soon become restless, walk about, then 'close down', sitting in a chair looking sad or lost. After some weeks of this behavior, Nellie would report, "I don't want to go to Julie's house. She is a bad Julie. I want the good Julie." Julie would try to explain she was Julie and that she loved her and enjoyed her visiting the family. Julie asked me for help to explain this behavior. I asked her to describe the visit from the time Nell entered her home. "Well, she usually asks to do something like wash dishes and I say, 'No, mom, you just relax and enjoy doing nothing. I'll do the dishes.' Then she'll want to help do the wash, and I tell her I will do it later. What am I doing wrong? I want the best for her."

"She is in a less familiar environment than at her apartment. She doesn't know how to fill her time. People with Alzheimer's have to feel they are valued, that they have purpose. What kind of a homemaker was she?"

Julie recounted Nell's immaculate house, her crisp white wash hanging on the clothes line, her ironing all Julia's dresses, and entertaining her little friends growing up. "Did she seem to take pride in this?" I asked. "Oh yes; people would comment on her hard work in addition to holding a job outside the home."

I instructed Julie to ask her mother to help her. We listed tasks she could do that would indeed help Julie; she could feed Tommy, the one year old, empty the dishwasher, fold the clothes, vacuum, dry mop, set the table.

The next weekend Julie made these requests for help. She was astonished to find her mother singing while doing tasks and asking for more to do. Now Nellie says to her neighbors, "I'm going to my good Julie's house Friday. She needs my help."

Think again about the Interpreter, the Actor and the Comparer. Nell looked around Julie's home, saw tasks to do, and the Actor initiated her doing them because the Comparer indicated she'd done these tasks before when she'd had Julia as a baby, their home to keep clean and a family to feed.

This new knowledge made a July 4th party at Julie's go smoothly, engaging her mom to bring out drinks to the guests, fold the red, white and blue napkins before laying them on the picnic table on the deck, spooning out potato salad into large bowls, cutting little sandwiches, and serving her guests. Julia got help and Nell felt like a young woman again, doing what she did best. In addition, Julie had informed her guests of her mother's need to be active. She instructed them to introduce themselves in case her mother did not remember who they were and to ask for her help.

The Copy Editor

There are also more sophisticated ways to evoke memories and arouse the inner spirit. Remember, memories are stored but they are harder for the person with Alzheimer's to retrieve. They have to be tapped, teased out. It is like jumpstarting a sluggish battery. It cannot jumpstart itself; someone needs to do it. My company took part in a pilot program at an Alzheimer specific assisted living in Boston. The program is computer based, offering chance for personalized memoir writing, reminiscing about familiar places, interests and entertainment like movies, art and music, done with a coach who served as a facilitator. The name of the program is Connected Living Now through a company My Way Village based in Quincy. For ten weeks, our team of coaches worked one on one with residents to facilitate evoking memories toward the goal of creating memoirs, and to promote enjoyable social interaction. In turn, these memoirs were shared with family via email.

One day I came as a facilitator. I invited a woman we'll call Helen, to join me at the computer. The screen was a large touch screen. "I'd like to learn about you, your life and your interests." I said. "Oh, I had no life that was special. You won't want to spend time

on me." Was this depression or her inability to pull out any memories to share, I wondered. "Well, just humor me. I need company and I'd like to see what this computer can do." I continued. "I'm not very computer savvy and together we might figure it out." She halfheartedly sat down with me in front of the computer. The pictures were those of items of 40-50 years ago, the first a washboard. "Did you ever use one of these?" I asked. "Oh yes, mostly my mother though. She had the brightest laundry but her hands were always so reddened and sore in the winter. They use that as a musical instrument in hillbilly country, don't they?"

I laughed, "I guess they do. How about this photo? It is an icebox with a red door! Did you ever see one with a red door?" "No, I haven't. My mother had an iceman who always delivered the ice at lunchtime. He knew my mother would offer him a sandwich and a soda. How shrewd huh?" It was becoming obvious that Helen was articulate and could generate thoughtful conversation.

The next photo was one of the first computer, a large processing station of sorts. "That thing filled a whole room. And look at us today, touching a screen on this computer to enjoy pictures. We can lift and move it around, some are even portable called laptops. It spells words for us and offers alternative words when we're stumped which one to use." I explained. "I love that feature. I write a lot."

"Boy I sure could have used a computer like this one when I was a copy editor at Houghton Mifflin. Authors are such poor spellers!" Helen reported. "Oh, so you know how to type. Try this keyboard; it is just like a typewriter." "I'll be rusty." But she tried. She was rusty but began to type what she had seen in the photos. She chatted about her education at Stanford, her husband's writings and their choice not to have children. "We wanted to pursue education and not be bound down with bringing up children. He's a professor at Berkeley you know." I knew Helen's husband had been deceased for years. I said, "I'll bet he's a lovely man. He chose you as his wife." "Oh yes, he is." she answered.

Helen had come alive; she had a life an interesting full one. Perhaps we could help give her a full life now. I heard later she was the first one next morning at the computer, demanding to be first to work on it. This reminds me of three myths of Alzheimer's that John Zeisel spoke about in his book. The first myth is that a person with this disease cannot learn. Helen obviously dispelled that myth. The computer was like something she had used for years. The second myth is that they are no longer a person. When stimulated to remember, the person comes alive. Helen became alive.

The third myth is that they have no future. Then, none of us knows how much future we have. Do we have a week, a year, decades? If only a day, we would want someone to fill it with comfort and meaning.

Sing along with me

Coaches reported two interesting interventions at a team meeting recently. We often share interventions that worked for families and explore alternatives to those that were not successful. The first had to do with repetitive questions and the other to do with restless behavior in the afternoon, often called 'sundowning'. It is often not the behavior but the response we give that changes our attitude toward a behavior. The first was a daughter who wanted to take her mother for short scenic drives around town but couldn't stand her repetitive questions, "Where are we going" "When are we getting there? Where are we going anyway?" she would ask over and over. The daughter would then repeat the answer over and over. One day driving she became beside herself with the repetition and snapped on the radio blaring to drown out the questions. It happened to land on an oldies station. Her mother started to sing along with the radio in a loud voice, knowing all the words and the melody. The daughter, surprised, joined in, happy to see her mother's joy and an end to the questions. After a while, she found herself becoming hoarse and began to laugh, first at her own initial impatience and secondly how coincidental that the radio station would solve the problem so easily. Will it work tomorrow? Who knows, but it relieved her today. Maybe it wouldn't have to be blaring loud next time.

Judge Judy to the rescue

Another daughter, talking to her coach, complained that her mother, upon returning home from the day program, was irritable, restless and often argued with her daughter about nothing in particular. She began dreading afternoons, she reported. "I can't wait until four o'clock when Judge Judy comes on TV. She loves Judge Judy."

"Why not tape a few shows of Judge Judy and play them as soon as she arrives home?" the coach suggested.

Sometimes the solution to a problem behavior is simple; but when we are in the midst of it and are irritated, we become blind. The coach looked brilliant. She was merely able to think beyond the problem; it wasn't **her** mother!

Letting go of the task

The second trend in Alzheimer care is to let go of the task. This can be done in two ways; encourage as much self-care as possible by empowering the person to access memory of how to do something (this is called procedural memory, those tasks that are hard-wired in our cortex), or modifying our approach to the task at hand (habilitation mode).

Let's look at what is meant by letting go of the task. Like the daughter learned who came 'to give her mother a bath', relationship comes first, then the task. Starting a task without relating to the person as a person is never successful. Often slowing our pace, putting off the task until another time, and determining how important that the task get done now will give us the solution to resistance. If someone told you it was time for you to take a bath, what would your response be? If someone began to take off your blouse or unzip your trousers without first asking, especially a stranger to you, what would you do? These scenarios are part of sensitivity training by caregiver educators like Mal Allard's *In Their World* that helps caregivers experience the feelings stirred up in the person with Alzheimer's.

Knowing what most persons have difficulty with (back to the primary symptoms of Alzheimer's) we can adjust our approach to care accordingly.

We must make sure our intentions are understood. Our approach must be calm. We should instruct simply rather than order, invite off handedly rather than demand. Instead of saying "You must do this now," say, "Can you come with me please? I'd like your company." No one wants to be told what to do, we want to be asked.

Another way to let go of the task is to set up the surroundings to remind the person what to do. Cues are helpful to initiate wanted behavior. The Comparer may be sluggish in Alzheimer's but it is still there, especially for those hard-wired procedural memories. In a bathroom there are familiar objects a person has used for decades. When presented with the correct grooming object in the bathroom (not the kitchen or the living room), a person will more often than not know how to use it. Present tasks in the room where they've taken place many times before. The Comparer will know what to do.

Recently I read a caregiver must be patient and creative. This is true. Patience, because we move at a pace that is annoying, sometimes impossible for a person with Alzheimer's to tolerate, so we have to wait, slow our pace in speech and movement. Creative in that we must think beyond ourselves and be other-oriented. We need to think outside the box, as it were. We need to learn to speak in a new way, I call uncommon common sense. Common sense courtesy says explain, instruct in detail, plan with the person, remind. Once one understands the changes in brain function, he can learn to speak in a different way. Avoid explaining, go one step at a time, stay in the present. Avoid sharing plans as the plan will be forgotten but emotional angst will remain. It is better for the person with memory loss to be 'surprised' and not have to try to remember what and when the event is to happen. Often the person with memory loss will refuse to go to a pleasurable event like a party or a family gathering only because they were told too far in advance. It is best to relieve them of having to 'hold on to' what is planned.

When we move quickly we confuse, and the person may leave the area or push you away. This is not resistance to care or aggression; this is protective. If we are frightened, we fight or take flight. So does the person with Alzheimer's.

I taught a class called 'what's in a label'. It explored how labeling behaviors is dangerous; we often remain stuck in the label. The course was about child and adolescent behavior. We looked at attention deficit disorder as a label. We found we had preconceived notions about how a child with this label would behave and tended to fit each child with that label into those notions. In the world of Alzheimer's what does resistance to care mean? What does combative mean? What does aggression look like? What does aphasic mean? Look at behavior as speaking to you of her emotional state at the time and respond to the emotion, **not** react to the behavior. It is better to acknowledge her feeling of anxiety and say, "I was going too fast. Let's slow down. We were both getting mixed up in the hurry. I'm sorry. Can we start over?" Affect is contagious; a fretful anxious rushed caregiver will evoke fretfulness and fear in the person cared for. I often tell caregivers they must slow down to the speed of life as it is now.

Mistaken purpose

In a nursing home memory unit an aide who was well known to a resident, noticed he was restless in his chair. She asked, "Do you need the bathroom?"

"Oh yes, thank you." Once in the bathroom, the aide who was used to his needing frequent toileting, proceeded to undo his belt and button on his trousers. He turned and pushed her away hard. Staff normally would have labeled this behavior aggressive, but instead asked him if he knew what provoked his anger. He said, "I didn't like her taking off my pants. I just wanted to wash my hands." We need to ask permission, ask what the person needs, before proceeding with what we think they wanted. "Do you need to toilet?" "Do you want to wash your hands after lunch?"

Aggression

Let's explore aggression. What causes it? How do we minimize or eliminate aggression? It is an important question. We want to understand what makes a person respond aggressively and keep safety a priority. Persons who before Alzheimer's were aggressive will probably respond to frustration or a perception of threat in an aggressive manner. It will be of utmost importance to keep frustration at a minimum and that what is said is not threatening. Arranging the environment to give clear clues as to what is expected behaviorally will be helpful. Pacing working with him will be important as well. Acknowledging his feeling threatened can help. "I've upset you. I don't want to do that. Let's let it go for now, OK?"

For people who don't have an aggressive nature, we can understand their becoming so if they are frightened or perceive threat. Sometimes very mild-mannered people cannot figure out what is going on will lash out in the fight or flight response. They may apologize right afterwards, making caregivers assume they knew what they were doing and could have decided not to be aggressive. Impulse control is a problem for persons with frontal lobe damage or disease involvement and those with vascular dementia and Pick's dementia.

One can be aggressive physically of course, but also verbally. A male patient in a nursing facility was verbally berating the front line staff when bathing was suggested. He would call them names, hurtful names that ridiculed their looks, their body weight, their culture or their color. Shortly after an outburst, seeing the staff member's reaction, he would apologize and ask forgiveness. Family members reported this rude behavior was atypical of him throughout his life. Since he was now labeled 'difficult, aggressive, nasty' two workers had been instructed to always be in attendance when working with him to monitor behavior. Imagine being in a small bathroom with two aides, anticipating negative behavior during personal care tasks. His anxiety would be heightened, making outbursts the more certain to occur. The staff was taught to all respond in the same way, "This is not helpful; I will be back later to help you get bathed." Pro-active approaches might have been to get to know him and his history better so that joining him each day in easy conversation when there was no task planned may have dissuaded him from verbally trying to distance himself with rude talk when introduced to a task.

An aside about the needs of the caregiver; the caregiver is grieving

Sometimes the caregiver becomes a non-person to others in the family. It appears he is doing well and doesn't need help. He may not ask for help so it is assumed he is 'doing ok'. Some children are reluctant to interfere in their parents lives and don't, out of respect. Others do not know what to do or don't want to be involved for personal reasons. A husband I coached knew his five children loved their mother and him but also knew they had no idea how sad it was for him to live with the changes in her. He had not shared his feelings about his loss with his children, relieving them of worrying about him and her. She had been a competent homemaker, a good decision maker, hardly needing to confer with her husband about decisions, only when it that decision would impact the whole family. It was hard for him to tell them what he was experiencing in words, but wanted their help. He wrote each a letter describing his grief, his daily routine and his wanting this disease to go away. He put the letter inside a book on Alzheimer's called Learning to Speak Alzheimer's by Joanne Koenig Coste. He entreated their help through

regular visits and perhaps even relieving him of care for a short time on weekend days. He had given up his exercise routine and other interests and was feeling very alone. True to his assumptions about his children, they agreed to a family meeting to make plans for sharing the caregiving. All were grieving the loss and had chosen to avoid seeing what it was doing to their mother. They were unaware of what it was doing to their father. All came forward with help and expressed gratitude he reached out. Some had felt he didn't want help; others avoided them for their own reasons of grief. Sometimes all we have to do is ASK.

Delirium

Delirium is a sudden change in alertness, consciousness, thinking, memory, pscychomotor behavior, perception and emotion (Lishman, 1997)Delirium and dementia are often found together. It is important to distinguish between the two so treating or hopefully preventing delirium isn't overlooked. Half the elders who are hospitalized develop delirium due to the changes in environment, deficits in hearing and vision, medical conditions, invasive procedures, and medications. Persons with dementia are much more susceptible because their ability to understand their surroundings may be impaired. Slow processing of information told them and staff that are not trained well, do not understand the challenges a person with dementia faces and continue to move at their usual fast pace instead of slowing to the pace of their patient. It is important that some familiar objects and people are there with the elder with dementia to ease the confusion of the hospital.

My story as caregiver

Caring for my mother in law brought me insight into the how personal and emotional caring for someone with Alzheimer's can be. I recorded my response to changes in her behavior. I learned (albeit slowly at times) to tune into her mood, to examine what worked and what did not. I discovered what gave her meaning and purpose and how to provide it for her. I am including my journey through Alzheimer's with her from 1996 to 2009 for your learning. Much of what I share in this book is a result of my caregiving journey with her. It often exposes feelings that were hard for me to accept. I had always considered myself a patient compassionate person. At times through this unasked for work I was ashamed at some of my responses. It called on me to leave self out of the experience and concentrate on her needs.

I should call this <u>Confessions of an Alzheimer Coach</u>. As I read back on the last 14 years of caring for Bette, I am aware of how much I learned when I thought at the time that I knew a lot about Alzheimer care. In 1996 I was becoming aware in my work as a mental health worker in home care that one has to work very differently with the person with memory deficits. I also became acutely aware of the lack of information families had when a family member was diagnosed with Alzheimer's. The Alzheimer's Association was only ten years old and the new caregiving model call Habilitation was being taught. I was intrigued with this approach and studied it, subsequently teaching it to other professionals and paraprofessionals in the company where I worked. Some of the approaches I had used in mental health nursing, and found they were useful but now they had a label.

In 1999 I was laid off from that job just months before the company failed economically, and decided to serve families with information that would ease the caregiving journey.

It was after my father in law died of Alzheimer's in 1996, that I realized Bette would require, probably demand, more attention. I didn't know then just how much attention she would need and how little of what she needed she'd be willing to accept. I confess I was a very reluctant caregiver, only agreeing to become primary caregiver to relieve my husband of a job he was ill-equipped to handle mainly because he loved her too much and was blind to the changes in ability she demonstrated. This is often referred to as denial. I think it is avoidance, an unwillingness to start adjusting to something new. His sister, although living nearby her mother, didn't drive due to low vision and had limited knowledge of Alzheimer's and the medical systems her mother would need. So, I accepted the position that would prove very challenging, frustrating, frightening in its impact on my marriage, my caring for my own mother and my feeling of emotional well being.

I am writing this for one reason only; that caregivers can console themselves for the mistakes, the failures in care and the lack of heart for the job of caregiving. And, now almost two years after her death at 99 years of age, I can stand back and assess what kind of caregivers we were. As a professional, a nurse and owning a business coaching Alzheimer caregivers, I can adopt the professional stance when working with families. I often look very smart and am often introduced as an expert on Alzheimer's. I have studied a great deal about the disease and caring with Habilitation Therapy approaches, but I don't really believe there are any experts on Alzheimer archetype to go by, no concrete model or typical patient. Each person is unique as he should be. A person expresses this crazy disease out of his experience coping with the world and its challenges. Whatever coping style worked in the past to make a person feel competent in the world will continue in their response to the disease.

Probably the most difficult person to care for who has Alzheimer's or any related dementia is the independent strong-minded person who never felt they needed anyone. They handled life the way they saw it; they coped well, or perhaps sometimes not so well by others' viewpoint, adopting no one else's way but their own. I coached a man once whose wife had many difficult to manage behaviors. She resisted care, wandered, refused to wear protective underwear for her incontinence, and became belligerent when bathing or dressing. Feeling frustrated that I hadn't been able to find good solutions to these problems, I asked him on our last coaching visit, "Is there anything in caring for your wife that is positive for you?" "Oh, yes." He exclaimed, "She needs me. She's never needed me before, always so competent. It's the first time in our 48 years of marriage that I feel essential. That feels good!" I was in awe of his attitude.

My mother in law was a woman who took charge. It didn't feel good to me, however.

I first met Bette in 1985, a woman ready to marry her son after having been a widow for fifteen years. I had not had in-laws as my first husband's parents were deceased long before I married him. I'd heard all kinds of satirically funny and some not so humorous mother in law stories. I was about to find a story of my own.

Before Leonard, my father in law, was diagnosed with Alzheimer's disease in 1996, my contact with Bette was strictly social. We shared holiday meals mostly at their home

in Andover, Massachusetts with their daughter Marilyn, along with the rest of my new blended extended family. After his diagnosis, we saw them a bit more often, but Bette did things her way and did not accept help or advice. Two representatives from the Alzheimer's Association came to teach her how to keep the home safe for Leonard, as the disease had compromised his balance. She politely listened, observed as they padded corners of furniture and moved things to help him move about easier, then after they left, promptly moved every piece back into its prior place and removed all the padding. "This will not do!" she exclaimed. "It is not pretty and I won't hear of it."

Leonard died, while recuperating post hospitalization in a rehabilitation unit after a fall at home in their bedroom, The bureau which it had been suggested be moved closer to the bed for ease of his rising, had been placed back to its original space three or more feet from the bed. He had fallen into its corner. I was angry with her insistence to do things her way. Besides, my sweet father in law was gone.

Soon we became aware Bette was not doing well living alone in her home. She was never mechanical and could not maintain a home without help from her son, Curt, grandsons and neighbors. It wasn't long before we looked for an apartment for her to simplify her life. We reasoned she was ready for less to care for. We arranged a yard sale, with tables filled with some of the items she could not make herself dispose of. There were hats from the fifties, shoes long ago forgotten and trinkets of all kinds. It was a potpourri of 'stuff'. Many buyers came early and things were bought quickly. Too quickly for Bette to absorb, she began taking her treasures back in the house, once vanking a purchase right out of a buyer's hands. She became more and more agitated as she dragged item after item back into the house. We were frustrated, but not aware then of her beginning dementia. She was unable to comprehend fully what was happening and became anxious. That, and her wanting to be in control of everything to do with her life, it made sense to us she would get upset. We were jolted awake however when she saw Leonard's belongings and couldn't figure out why she had a man's clothing in her house. Had she already lost memory of dad? We were all alarmed at her forgetting him so soon. Why should she ever forget him at all? They'd been married 64 years and were a close couple who did most everything together. We chalked this blip in her thinking to stress or her uncanny ability to block out unpleasant events from her mind.

With the help of family we narrowed down her belongings hoping to fit the remaining furniture into an ample sized apartment for her. Going from a seven-room home with a yard on a cul-de-sac to a four-room apartment took some planning and we knew it would take some adjusting on her part. We had no idea at the time she had beginning dementia; we didn't know she wouldn't be able to adjust easily. We looked at apartments in smaller developments and in the same town she had lived in for twenty years to make it easier to shop in familiar markets, keep her same doctor and see old friends and acquaintances. She belonged to an art guild that was a delight to her. Moving her out the town she'd lived in for forty or more years would be too difficult a transition for her.

She chose a lovely complex of individual six apartment buildings with a swimming pool and recreation area. Each apartment had two baths, two bedrooms and a dining area as well as a small balcony facing a grove. It was perfect for her, close to where she used to live, access to familiar areas, and a short drive to her daughter's home. We hoped she would get settled and make new friends. She was a social woman, enjoyed being a hostess, joined associations and liked attending concerts and theatre. For a while things seemed to be working out. She made overtures of joining with other women in walks around the complex, talked about going to the clubhouse and pool area, but all were very short-lived. She spent more and more time in her apartment or driving somewhere local. She often drove to Marilyn's home which was a half-mile walk away. We began to worry something more than normal reaction to moving was brewing.

Bette loved to drive, having had cars since she was 14 (1923). She was an only child and her father owned several Buick dealerships. Riding with her as driver was similar to riding on an old rickety bus lurching between frequent stops. She had always been distractible, gawking left and right as she drove, intermittently pumping the brake and lightly pressing on the gas. Being 4 foot 9 inches, other drivers could barely see there was anyone behind the wheel. Whenever possible, we drove, unless she insisted we take her car. She abhorred highway driving, was afraid of driving over bridges and when anxious, drove slower than her normal 25 mph. She had never had an accident. I think people, seeing a white haired miniscule lady behind the wheel, stayed clear of her.

My mother in law Bette was a peculiar woman, at once rigid in social correctness, and irrational and illogical in her thinking. She was as well opinionated about many things that had to do with how someone or something looked. If she noted that certain colors were unmatched, according to her taste, she'd let people know without hesitation. Appearance was everything to her. Hairstyles were a big issue. I had long curly hair when we first met in 1985. For years, she said, very sweetly of course, "How lovely you'd look in a bob! Why would anyone want that long hair?" I learned after being annoyed for a few years, to ignore her comments.

But let's get on with the real story; one of her with Alzheimer's disease, and me, a reluctant care partner. Since 1999 I've kept a journal of our journey into Alzheimer's. I needed to write, so I would remember how my reluctance to be her caregiver gave way to downright resentment, annoyance, and finally compassion for her struggle.

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