Experiencing Memory Loss

Cheryl J. Wilson, M.S.

advocacy4seniors@gmail.com

Cheryl is a public speaker, author, and gerontologist specializing in dementia and long-term care. She has dedicated the last 30 years to improving the quality of life for seniors in the community and educating their families on issues they face as they age. After earning her master's degree in Gerontology in 2004, Cheryl was promoted to Director of Ombudsman Services for the St. Louis Ombudsman program, now known as VOYCE. During her 17 years with the Ombudsman Program, she co-founded the SERVE Program, which provided victim services to seniors and their families when allegations of abuse were filed. Through her work, Cheryl has helped thousands of seniors and their families improve their well-being and prevent further unnecessary pain and suffering while they navigate the aging process.

Cheryl's unique experience working in long-term care, having family members in long-term care, and being a long-term care advocate for residents allows her to consider and understand all perspectives when dealing with situations involving seniors.

In 2020, as the world shut down when the Pandemic struck, Cheryl decided to use the extra time to write her first book, which was published in April 2021. "I Am The Resident -Becoming the Advocate For Your Loved One's Needs" was such a success that Cheryl published her second book, "A Complete Guide to Placing a Loved One In A Long-Term Care Facility," in November 2023. She is now working on book three which will focus on her mom's journey through dementia and what she learned.

Cheryl's compassion for helping people is not limited to her career. After her father passed away in 2016, Cheryl took on the role of caregiver for her mother and her older brother. She is also an amazing aunt to 12 nieces and nephews and 12 great nieces and nephews whom she loves to spoil and spend time with when she's not working. Most recently, Cheryl became a leader in her church's Anchor of Hope ministry, where she educates families with seniors on struggles they may be facing and what to expect as their loved ones age. In her free time, Cheryl also volunteers with Aging Ahead, serving as the vice-chairperson for their Advisory Council.



Education

The term “Dementia” is an umbrella term that encompasses all types of dementia.

- Alzheimer’s is the most common type of dementia
- Vascular: caused by Stoke, TIA’s (mini strokes)
- Lewy Bodies
- Frontotemporal: Pick’s Disease (45-65 age of onset, runs in families) 10-20%.
- There are over 100 different types of dementia. Some professionals believe there are as many as 400 different forms of dementia

People with dementia **DO NOT** have behavior problems; they have lost the ability to communicate their needs. People with dementia have communication problems.

- They may have to go to the bathroom but can’t tell you, so they become fidgety or anxious.
- They may wander into a room they are not supposed to be in and get yelled at by the person in the room. This may make them mad, but they can’t tell you they are mad, so they may hit someone or something to express their anger.
- Wandering—Most of the time, when a person with dementia is wandering, they are looking for someone or something. Many women will start wandering and trying to leave their homes around 3:30. They are trying to get to the bus stop to pick up their children but can’t tell you that. If you suspect that, ask them if they are trying to get to the bus stop and tell them someone else, like a friend, has gone to pick up their children.

Example 1- A man who was in a skilled nursing home tried to leave every day at 2 pm.

- What was his job? *He was a used car salesman*.
- What was his job responsibility every day at 2 pm? *It was his turn to check the lot*.
- What are the names of his co-workers? *John, David, and Doug*
- Suggested that every day at 1:45 pm, a staff member go to this man and tell him that one of his co-workers would check the lot; he did not have to.

When this was done, he stopped trying to leave the home.

Example 2 -A woman who was agitated and started aggressively pacing.

- I matched her pace and just started pacing with her for a few minutes.
- I asked her what was wrong. *She told me that the teacher would not let her in school*.
- I asked her what grade she was in. (This was to determine her cognitive status.) *She was in 3rd grade*.
- I asked her why the teacher would not let her go back in school. *She told me that her hands were dirty*.
- I asked her to show me her hands. They were caked with dried BM.
- I told her I knew someone who could clean her hands, and then I bet the teacher would like her back in school.
- I took her to the nurse’s station and had them clean her hands.

- When I went back to check on this woman, she was sitting down watching television.
- **THERE IS <u>ALWAYS</u> A REASON FOR THE BEHAVIOR – IF YOU FIND THE REASON FOR THE BEHAVIOR YOU CAN OFTEN RESOLVE THE ISSUE.**

Tips for working with a person with dementia

1. Ask questions in a way they can understand. I worked with a woman who had been verbally abused by a staff member. When I entered the woman's room, she was in a wheelchair, talking to her children (several dolls sitting on a shelf.) I asked her how she was, and she told me she was fine but worried about her children. I asked her what was wrong with her children. She told me she worried her children might get kicked out of school. I asked her why. She told me she was worried they might repeat some bad words in school, and the teacher would kick them out. I asked her if her children were still hearing those "bad words," and she said "yes," and sometimes it scares them. I asked her if **she was still hearing those "bad words," and they frightened** her. She said, "Yes." I told this woman that I was sorry that she was still hearing words that scarred her and that I was going to talk to the nurses and make sure no one ever spoke to her that way again.

   It was later determined that one of the staff members had been in a verbal altercation with her boyfriend over the phone right outside this woman's door. When this woman heard the staff member cursing at her boyfriend over the phone, she became frightened.

NOTE: Verbal abuse is anything said to a resident OR within hearing distance of the resident that causes them harm. Although the staff member did not intend to harm this resident, she did by having that conversation outside the resident's door, where she overheard what was said and became fearful that she would be in trouble.

Redirect

- I can't find my mom; NEVER say, "Your mom died a long time ago." Instead, say something like, "What was your favorite thing to do with your mom or tell me about your mom. (They are thinking about their mom so let them talk about her until the moment passes.)

Learn to Laugh

  - Example – 1 - Zelma
    - Zelma wandered into another resident's room and went through her drawers.
    - The lady yelled at Zelma and told her to get out. As Zelma left, the woman told her to "Go to hell!"
    - As Zelma wheeled herself out of the room, she looked over her shoulder and said, "***You know I've been there, and I don't like the way you run it!"***
  - Example 2 – A gentleman I did not know approached me at a Memory Care Unit

- He asked me if I knew what today was.
- He told me he was so excited that he was going to be cremated at 2 pm today, and he could not wait!
- I responded by wishing him a happy cremation day. (I realize he had mixed up his words and that whatever he was thinking of made him very happy, so why would I crush him by saying, "Do you know what you just said?"

Note: Individuals with dementia are no longer able to process and think like we do, so we must go into their world and work to understand them. It is up to us to change our thinking; they can no longer change!

Fixations: Very common, same questions/phrases

- Singing the same song over and over
- Repeating the exact phrase over and over
- Being fixated on their bowel and bladder routine is very common.

Telling a person with dementia to stop this will NOT make them stop – you must either redirect them at that moment or answer the question over and over again.

Pick your Battles

If what the person with dementia is doing is not causing harm or could cause harm to someone else harm – let it go!

Example: I worked with a husband whose wife has advanced dementia. He would get furious because she would not put her dirty spoons in the dishwasher. I suggested he use plastic spoons, but she refused and wanted her to put her spoons in the dishwasher after every use. One day, this woman got up early and made French Toast for herself and her husband for breakfast. He told me he took one bite and realized she had used the moldy bread in the kitchen. He stopped eating his but allowed her to finish eating the French Toast on the same moldy bread. I asked him why he did that, and he said he did not want another fight with his wife. I told him she should have removed that moldy food from his wife and given her something else. I also told him that it was not okay to argue with her about a dirty spoon and allow her to eat something that had the potential to make her sick! PICK YOU BATTLES!!

Don't resort to medication if there's not a problem.

- If the visual/auditory hallucination is not upsetting the person with dementia, you don't need to medicate them.

Other tips

- If the individual with dementia is not in danger of hurting themselves or someone else - walk away and let them calm down on their own.
- Never force your will on them!
- The best gift you can give a loved one with dementia is as much control of their life as they can handle.

    - Let them choose what clothes they want to wear each morning. By doing this, you give them some control of their life. The more choices they can make for themselves, the more control they will have and the happier they will be.
- Don’t argue with their reality – YOU WILL NEVER WIN!!!
    - If they are doing something you don’t think is right, as long as they are not in danger of hurting themselves or someone else, let it go.
- Again, Pick your battles – don’t expect them to live by what you believe; their reality has changed, and learn to accept their reality.

As you go about advocating for your loved one with dementia, I hope you will remember this exercise. Try to see things through the eyes of people attempting to live with this awful disease.

I'm Not Done Yet!

I may be 60, 70, 80, 90, or over 100, but I'm not done yet!
My hair may be thin, gray, or have no hair, but I'm not done yet!
My vision may be lacking or gone, but I'm not done yet!
My hearing may be fading, or I may not be able to hear you, but I'm not done yet!
My bones may be brittle, I may walk with a limp or a cane, or maybe I am in a wheelchair, but I am not done yet!

My mind may fade in and out, and I may forget things, but I'm not done yet!
I do have life experience and the wisdom to know that life lessons are learned by the scars we carry and the valleys we go through; that's where we learn our greatest lessons. I have learned that you can't master loving people without experiencing grief. The greater we love, the greater we experience grief when we lose those we love.

Although my body has aged and may not be as quick to process and react, I can still be a valuable resource for the next generation if given a chance. Those who take advantage of my experiences can learn from them and not make the same mistakes I did, giving them more time to explore new opportunities.

I hope you get to experience the gift of aging and become a senior. Next time you meet a senior, instead of seeing what they have lost over time, think of all you can learn from them. Think of seniors in wheelchairs as wisdom sitting in a chair and take advantage of all they have to share. If we work together, hand in hand, we can make this world a better place for all! Remember, I am not done yet!

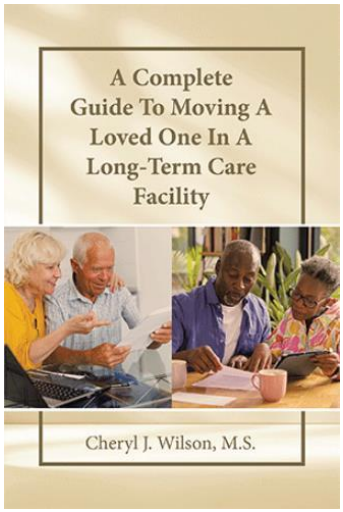
Author,

Cheryl J. Wilson, M.S

A Complete Guide To Moving A Loved One In A Long-Term Care Community

Publisher – Westbow – Link to purchase book ($16.99)

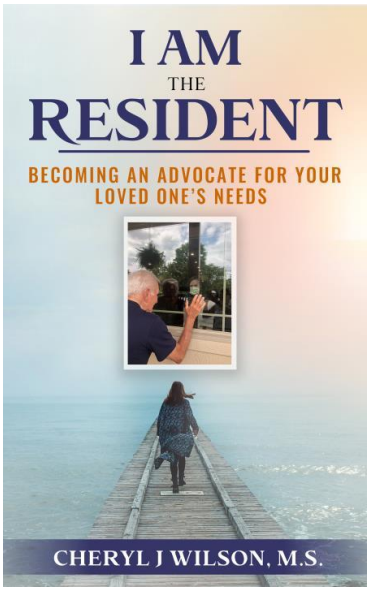
https://www.westbowpress.com/en/bookstore/bookdetails/853888-a-complete-guide-to-moving-a-loved-one-in-a-long-term-care-facility



I Am The Resident – Becoming An Advocate For Your Loved One's Needs

Publisher – Book Baby – Link to purchase book ($20.00)

https://store.bookbaby.com/book/i-am-the-resident



Note: Both books are available on Amazon.