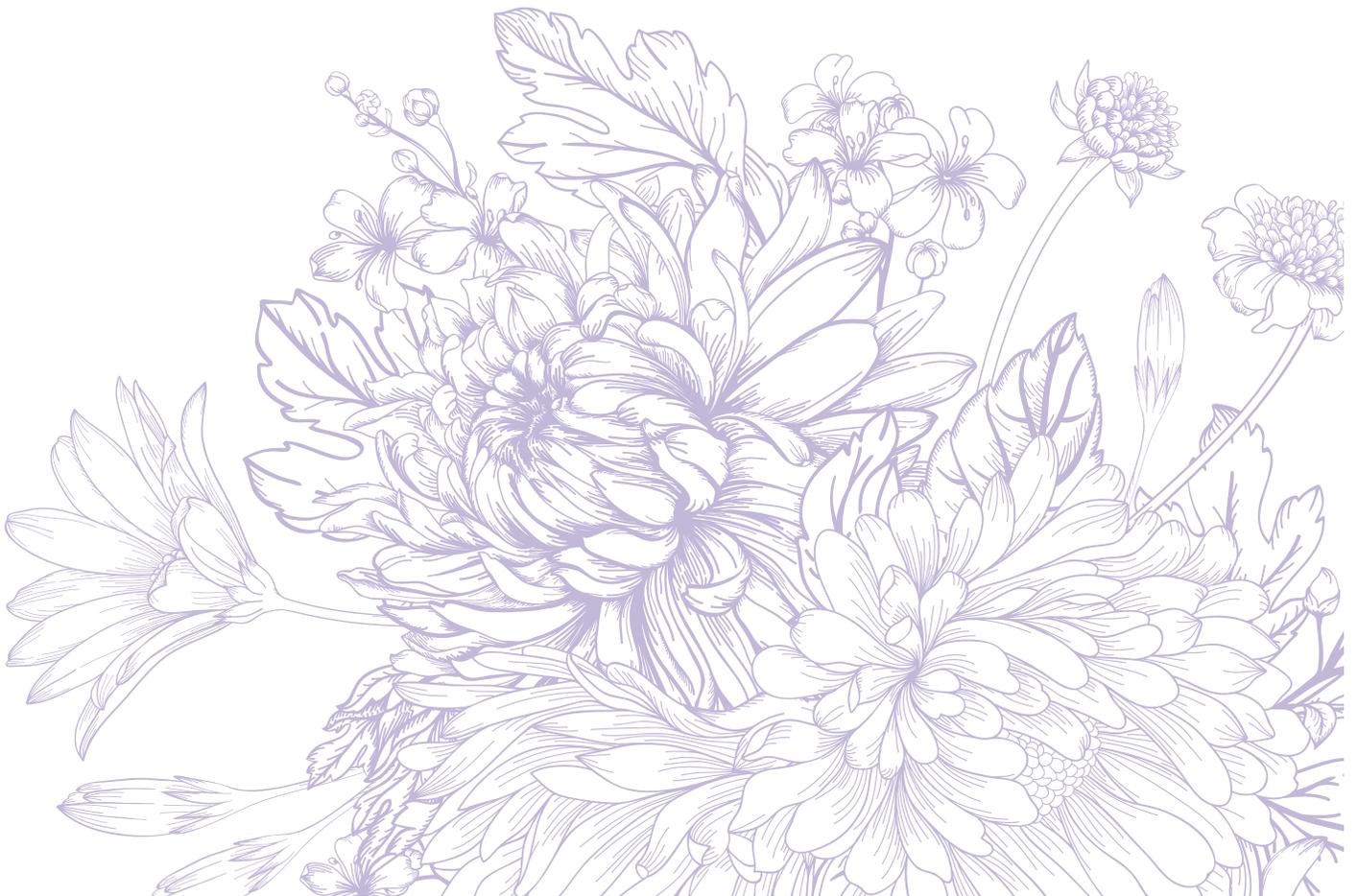


*Dear Health Care Professional
taking care of my mom
with Alzheimer's disease*

by CHRISTINE DiLEONE MSN, RN



No matter who you are, what you've accomplished, what your financial situation is—when you're dealing with a parent with Alzheimer's, you yourself feel helpless. The parent can't work, can't live alone, and is totally dependent, like a toddler. As the disease unfolds, you don't know what to expect.

MARIA SHRIVER

Dear Health Care Professional
taking care of my mom with Alzheimer's disease,

Let me start by simply saying thank you! Thank you for your tireless work in the medical field. Whether you are handing her medication and checking for side effects, or prescribing said medication. Maybe you are the nurse's aide who helps her get dressed in the morning and reminds her where to find the dining room. Are you the social worker who takes my concerned calls? Or the lab technician who draws her routine blood work? Maybe you are the technician who did her chest x-ray when she had that horrible cough. Whatever role you play in the care of patients with Alzheimer's disease please know that I see and hear you when you interact with my mom. I see how you care about and even love her. I hear you lovingly call her honey and sweetie and laugh with her when she is confusingly silly. You are so important in the life of a patient with Alzheimer's disease.

I am a healthcare professional myself, a nurse, but first I am human. I am the daughter of an amazing woman who has been stricken with a horrible disease.

This letter I write to you, as a fellow healthcare professional, is with the intent that you might better see beyond the blank eyes of Alzheimer's disease. Maybe you already do and if so, many many thanks to you! You Rock!

I would like you to get to know the person my mom was, not the person she now is. The God and family first person, not the confused, unable to make a decision woman you only see now. This is her story, the story behind the blank eyes. This is also my family's story. We are walking this journey right beside her.

Everyone with Alzheimer's disease has a life story behind them. I would like you to hear Mom's. She had a life before this disease took her away from us and into your care.

My mother is one of fifteen children, and was raised on a farm in upstate New York. Of those fifteen children, seven of them have died from, or currently have, Alzheimer's disease. I know, crazy, right? Our family suffers continually as we watch our dear mother fade farther and farther away from us. I hope you realize that you are not only taking care of my mom, but you are taking care of her family as well. Sometimes, your words comfort us and sometimes they anger us. We're really doing the best we can with this very important loss in our life.

Mom was a Real Estate Broker all her life; the best one in town (I'm her daughter, I'm allowed to be a little bit biased!). She worked from sun up 'til sun down helping people get into a home where they could raise their families. She helped them obtain the mortgages they would need to make their dream of being a homeowner come true.

After being raised on a farm, she married young and had her first child at eighteen years of age, with three more to follow. She divorced an abusive husband and moved to Florida when I was sixteen. While there, she was a member of the million-dollar club for real estate sales. That was a big deal in the 80's. After a brief stint as the owner of a waterbed company, she later returned to upstate NY in order to be closer to her family, and continued her real estate business for the next twenty years.

This is just a brief synopsis of the amazing person that was my mom. I can't begin to talk about the hundreds of people, family and friends she helped before she got sick. She truly put others before herself and I swear her heart really was made of gold.

THE EARLY STAGES

I think the earlier stages of Alzheimer's are the hardest. Particularly because the person knows that they are losing awareness. They're aware that they're losing awareness, and you see them struggling.

PATTI DAVIS

Here we are. Life has stopped, the status quo is gone. It feels like the lightening before the thunder strikes. You wait for the boom. You hope it doesn't come because it's loud and kind of scary.

The early stages began when my brother, who lived with Mom at the time, received calls that Mom had a real estate appointment she didn't show up for. She was with her sister cleaning out their brother's home because he was recently admitted to a nursing home with dementia. Any appointments she had were gone from her head. I received phone calls from her sales agents, "Chrissie, something is wrong with Mom, she isn't remembering items on contracts." What was I supposed to do with this information? My gut knew what was going on, but thought, let's just see how it plays out. Please don't force me to make decisions about Mom, I pray. She is the one that makes decisions about her life. She has been divorced for years, always independent. She always told me to get my own career so I wouldn't have to rely on a man. It's not my place to tell her what to do. She knows what to do, doesn't she? Can't she see she is forgetting things? No, she cannot.

And then her many trips to CT to visit me and my children began to leave her lost and confused about how to get to our home. She once called me from a church in town asking me to come get her, as she couldn't remember how to drive to our house after she got off the highway. We knew we couldn't avoid it anymore when she became confused about how to get home from a church convention that she attended every year her whole life. We had to get out of our denial and help her. We knew the Alzheimer's that afflicted her older sister first, was now creeping in on her.

I was heavily relied on as the medical person in the family to figure this all out. How could I do that when I was grieving along with everyone else, and just wanted this to go away?

I was able to convince Mom to sell her real estate business and work part time for another realtor. What was I thinking? How unfair of me to think she might still be able to function. As you can imagine, that was a disaster. She hated everyone. My sweet, never forgot to say I love you when our phone conversations were done Mom, hated everyone she worked with, and they knew it, trust me.

Can you imagine how hard it was to watch her forget to pay her bills or forget to eat? Or how painful the early stage personality changes were to watch? She believed her sister was going through her checkbook and taking her money. This once sweet woman now "decided" she didn't like my brother's fiancé and was not sweet to her anymore. The early stages brought so much anger, some paranoia and delusions. Now I wonder, did part of her know what was happening?

I struggled with her primary care doctor to find something else in a diagnosis. Maybe a thyroid or vitamin B12 deficiency was the cause. I had a list of things I wanted him to check so I could stay in the denial stage of facing my mom's prognosis. Please don't say the word; please don't say she has it. Please. And then he said it: your mother has





Alzheimer's disease. And then my brother told me how she cried when she knew what she had. She knew what her end would be, just like her sister, who was in long term care with Alzheimer's. How painful this must have been for her to hear. I can't imagine. Can you imagine the fear inside of her and her family, with the realization of what her end would be, knowing there is no cure and no treatment for this disease?

So imagine for a minute, being in my shoes, having to make the decision in your late 30's to move your mom out of her home. Her home that was called "the museum" because it was so clean that you could eat off the floors. A daughter in her 30's going to grad school, with children ages 10 and 15 and a full time job, driving a U-Haul truck across two states with all your mother's belongings to have her move in with you. I was too young to be having these experiences. Too young to be losing my best friend, the first one my children called when something exciting happened to them or when it was time for a trip to Disney with Gram. My kids? Way too young to "lose" their gram. This was especially not fair to them. Yes, I was angry. Maybe, as you read this, you are thinking, please, there are worse things in life than what you went through. I know that. I know there is suffering in this world much greater than my own. But to me, this was the most significant loss in my life.

We turned an office into a bedroom for Mom. I wondered how that felt to her. She was leaving all she knew, her home, her business, and her family, to live in one room in her daughter's home. Did she really realize what was happening?

We managed okay for a few months. I was able to get her on Medicaid after prepaying her funeral (picking out a casket with my mother was not on my bucket list) with the profit she made from selling her house, and obtained a companion to come once a week to bring her to the mall or go for a walk. Mom actually liked this woman. I took Mom to see both independent living and assisted living facilities, as she frequently told me she wanted her own place, but she always hated each one. When I look back, I don't know what I was thinking bringing her to independent living facilities. Why did I think she would be ok there? She would still have to remember to eat. Funny how denial and avoidance follows you. It doesn't want to let go.

When her paranoia was at its best, she would call her brother and tell him my neighbor didn't want her living with me or my father-in-law didn't think she should be at our home. My husband, who works from home, heard her talking on the phone and no one was on the other line. I clearly remember being in the kitchen with Mom discussing alternate housing. I was trying to explain to her that she had Alzheimer's so we needed to look at places that had medical professionals on staff. The blank look in her eyes felt like a slap on my face. I remember thinking she can't process this, she wants to, but she can't. At that point I realized my mom was clearly ill. I was able to have her seen by a psychiatrist that specializes in Alzheimer's disease and my mother was medicated appropriately to offset both the depression that so frequently accompanies the disease, as well as the paranoia and delusions.

Mom lived with me for five months. I was the nurse in the family, and the closest one to her. I thought I could take care of her and I should, that's what she would want. I was wrong. I was a walking anxiety attack. The monthly visits to NY where she would stay with my aunt for the weekend weren't enough. I had to come to the realization that I was not able to give her what she needed. She needed socialization and people her own age to talk to. A very painful decision was made to move her back to NY into assisted living. We were fortunate to find one that was income-based. Assisted living is so expensive.

Onward we went on a very cold February day with Mom's stuff in yet another U-Haul. Onward we went to the middle stages of this disease.

THE MIDDLE STAGES

If you learn to listen for clues as to how I feel instead of what I say, you will be able to understand me much better.

MARA BOTONIS

Maybe I am wrong, but it feels like the move to assisted living jump-started the disease progression for her. She lived in a very small studio apartment, and had a hard time adjusting to a different environment. While she was constantly saying she was bored, I constantly doubted myself as to whether I made the right decision. I was frequently on the phone with her making sure she was ok. I felt helpless. This feeling of helplessness has followed me quite a lot through her illness.

About a year and a half after her move to assisted living, Mom started wandering outside the perimeter of the facility. On one occasion a staff member found her on the street with some of her belongings saying she needed to get home. It was time for us to cry uncle; she was not safe there anymore. Thankfully, my brothers were with her when the homecare nurse did her evaluation and confirmed that she needed long-term care.

It's easy to say you would never put your parent in a nursing home. So easy. I said it myself. I used to joke with Mom that when she was old I would "stick" her in a nursing home and she would say "you better not." Wrong again.

The move into long-term care was without a doubt the hardest part for me. She lost a lot when that move was made. She had to now give up her primary care doctor and become a patient of the doctor assigned to the nursing home. I did not know that. Her room, though private, was much smaller than the one in assisted living. How in the world was I ever going to explain to my mother that she was moving? How could I uproot her world yet again? My aunt took Mom out for a drive, to visit her brother. Meanwhile, my brothers, my husband and my kids moved her belongings to her new room on the other side (she was in a facility that had assisted living on one side and long term care on the other). When she returned, I told her she had a new room. I said, "It's really nice, let's go see it." I took her hand and walked her to the elevator and up we went to the third floor. I was pleasantly surprised at how happy she was with her new space. This was too easy, the heavens must be on my side. I stayed with Mom for three days to ensure she was adjusting to her new place. I signed paper after paper, I spoke with the nurse manager and social worker to make sure she knew Mom's hymns on the CD should be played for her. "We will add it to the care plan," she said (blind faith). I spoke to the Nurse Practitioner to ensure she knew Mom was a DNR, and that I was her health care proxy and wanted to be notified of any changes.

About six months into her stay I received a call from the nurse manager that Mom was having "behaviors" that they were watching. She was found in a room with a male patient and kissed a lot of the men in the hallway. I'm sorry, this one made me laugh. If they only knew my mother who had been asked out so many times after her divorce and always said, "no," the same woman who always said, "I don't need a man," was the "kisser" on the floor, they would laugh too. This behavior was managed for a few months with an alarm on her door and every 15-minute checks by the staff. Then on Christmas Eve, the same year she was admitted to the nursing home, I received an abrupt call from the administrator that Mom was somehow now a danger to other patients and she was being moved from the third to the fifth floor, in about thirty



minutes. HUH? I am three hours away; it's Christmas Eve. I attempted to rationalize with the administrator about the abrupt move and was told, "your mom is being moved whether you like it not, Merry Christmas," and the phone was hung up on me. This was a very tough move on Mom, as she was taken away from a sister on the same floor. They would sit in each other's rooms and talk about the old days. It was an ideal situation, as far as ideal nursing home situations go. She was moved into the same room as her older sister, the one first stricken, who was non-verbal and had the disease for nearly twenty years.

As a nurse, the Department of Public Health coming into your facility always puts a bad taste in your mouth and knots in your stomach, as you rush around to make sure everything is as it should be before "the State" gets here. The only thing I will say about this experience is, as a family member, "the State" was my advocate, my voice, the ones who knew the rules like the back of their hands; my helper.

THE END

I don't know why Alzheimer's was allowed to steal so much of my father before releasing him into the arms of death. But I know that at his last moment, when he opened his eyes, eyes that had not opened for many, many days, and looked at my mother, he showed us that neither disease nor death can conquer love.

PATTI DAVIS

The final stages of Alzheimer's. The stage you know will come eventually because it's part of the disease progression, but it comes too quickly. The stage you see your aunt in and hope maybe it won't happen to Mom.

Interestingly, at a recent visit to see Mom, we were in her room, her hymns were playing and she was lying on her bed while I was sitting in a chair. I sat there for a good twenty minutes and no words were spoken. Mom was in a zone listening to the music and I felt like she didn't even know I was there. It was then that I realized the Alzheimer's was getting bigger and I was getting smaller.

We were told at her last bi-yearly appointment with her neurologist, that my mom had begun the advanced stages of the disease and that she does not need to see the neurologist any longer. There is nothing else the neurologist can do for her. Imagine what that feels like when you hear there is nothing else that can be done, that it is not necessary to come anymore. You can't be in denial anymore. The knots in your stomach grow. You knew it would come to this, but when you are told, well, I don't need to say anymore.

On my way to work one morning, my cell phone rang. It was the nursing home. A call from the nursing home at 7:20 in the morning always puts a knot in my stomach. The nurse said to me, "I'm calling to let you know, the aide was getting your mom dressed and your mom screamed and fell to the floor, and appears to have had a seizure, her pupils are fixed, she is not responding and she is not with us." Moments like this are when I have to say, dear Health Care Professional, please watch your words to family members. Why was it ok to tell me my mom's pupils were fixed and she was not with us? The answer: it wasn't. After speaking to her neurologist about this incident, I learned it is not uncommon for patients in the advanced stage of the disease to have seizures. I didn't know that.

Mom had only made three trips to the hospital in the three years she had been in both the assisted living and the nursing home, and was never before admitted. This time she was. She managed to pull out four IVs and was made to stay in bed, which she was not accustomed to. She walked the floor of the nursing home at her leisure. So it's no wonder she was constantly saying she wanted to go home. Home means comfort; what she was really saying was, "someone help me, I am so confused and I don't know where I am or why I'm here." Shortly after my brother left her room, I got a call from the hospital that the nurses wanted to restrain Mom. That's when I realized it was time to stop any further hospital visits. The trips were simply torture for her and unnecessary. If Mom was going to pass on, it would be in a place she was familiar with and surrounded by people who loved her, not in a confusing hospital. Mom now has comfort care only.

Now we wait. We wait for all those things we know will happen that shut down her body. The inability to eat or walk or talk. The moment she looks at me and does not know my

name anymore. This disease is how her story ends, but it's not how it started and it doesn't define who she was or is, not by a long shot.

I was given a calendar for Christmas with daily Bible verses on it. "I have fought the good fight, I have finished the race, I have kept the faith" (2 Tim. 4:7). This is what I will share with family and friends at Mom's funeral.

Thank you Mom for fighting the good fight, you certainly kept the faith and now your course is finished. Thank you for being such a loving, kind person.

Until we are together again.

* * *

In closing, dear Health Care Professional taking care of my mom, thank you for listening to her story. Thank you for taking a step back as you care for her every day, to see who she was. I encourage you to take some time to get to know the stories of all the patients in your care with this disease. I'm sure their families would be happy to share them with you. You will find they led interesting lives. You will see they certainly wouldn't have wanted this to happen to them, nor would you. But it did. Please find the joy in them. They need you so much. They need you to see them, to see they are just as human as you are. They need to be treated with the kindness and respect we all like to be treated with. They need you to help maneuver their very confusing days. They need dignity. They need silliness and smiles, compassion and love, patience and hugs. They need you. Their families need you, need to know you love and care for their loved ones like they were your mother, father, grandmother, grandfather, aunt or uncle.

Sincerely,

Christine

Life lessons my mother continues to teach me with her disease:

- People you thought would support you do not, and you become pleasantly surprised at who does. Be thankful for the handful of people who become your support system.
- Being angry at family and friends for not taking the time to visit Mom in the nursing home/assisted living is not beneficial to anyone. Everyone is doing the best they can. Maybe they won't know what to say when they visit, maybe nursing homes make them uncomfortable and they don't know what to do with that feeling. It doesn't mean they don't love her, they do. Forgive, and let your expectations of them go.
- Things that seem so important to us in our everyday life just aren't. Mom thought it was important that she follow the strict rules of her religion. She had to wear a skirt every day, as well as have her long hair in a bun. Mom never ever wore jewelry and rarely watched TV. Guess what? The aides put her hair in a ponytail, and she wears the Mardi Gras beads that she wins at bingo!
- Alzheimer's does not take away love. Love is too big. Mom loved her God a lot. Alzheimer's hasn't taken away that love either. She suffers from chronic back pain and when I ask her how her back is, she tells me it hurts, and then says God is good to me.
- All that matters is our moments. That's how Mom lives now, in the moment. All the things we worry about for tomorrow, so much energy spent on pointless worries. All we have is this moment, this day. Stay there.
- There is some joy in Alzheimer's. Yep, I said it. Mom did not have to deal with the pain of losing a niece and nephew that passed in their forties, whom she was close to. She doesn't think about who is paying her phone bill and when she needs new clothes. She doesn't know her ex-husband passed away, or that a sister in California died from the same disease she has. She doesn't know that another sister is the one in the bed right next to her. Or that yet another sister is on the third floor of the same facility with the same disease. She does not know that a fourth sister is now in the assisted living next door with a form of dementia. That is a lot of pain she didn't have to face.
- As horrible as this disease is, she really is okay. All is well.
- We will be together again one day. Her mind will be clear, and she will see how much she taught all of us by having Alzheimer's.
- It's ok to be wrong. It doesn't matter who is wrong and who is right anyway.
- You will have people along the way that will come into your journey simply to help you and then move on (Power of Attorney and Health Care Proxy were not the first things on my brain).
- Alzheimer's disease is a family disease, not an individual disease.
- I'm stronger than I thought I was. You were right, Mom!



In my opinion, and it's only my opinion based on my experiences with this disease, our therapeutic communication is probably the single most effective thing we can give these patients and their families. Our communication, our reaction, helps them maintain their dignity when their words aren't making sense to us.

Mom has a lot of difficulty with language and finding the right words. For example, I was having lunch with her on a cold winter day and we were sitting near a door that, when opened, brought a cool breeze with it. When the breeze hit her and she felt the cold air she said, "Oh that water is cold." When we talk on the phone every night and all she can muster up for words are "I'm so tired," I say, "you must have had a busy day." She will say, "yes, I was here, there, and everywhere." That's when I say, "you have been working hard all day, you need to rest now," She agrees. And I wonder how many things her poor diseased brain has tried to process that have happened during her day without success. That must be exhausting.

We must go into their world. Their world is what makes sense to them, not ours.

One thing she clearly says at the end of our conversations every night is: "I love you a whole bunch." Sometimes, she even still calls me "tootsie." This is what I hold on to now. The never-fading love between a mother and a daughter.

What follows are some great tips from the Alzheimer's Association on effective communication. You can find them at Alz.org.



1. COMMUNICATION IN THE EARLY STAGES

In the early stage of Alzheimer's disease, an individual is still able to participate in give-and-take dialogue, have meaningful conversations and engage in social activities. However, he or she may repeat stories, have difficulty finding the right word or feel overwhelmed by excessive stimulations.

Tips for successful communication:

- Don't make assumptions about a person's ability to communicate because of an Alzheimer's diagnosis. The disease affects each person differently.
- Don't exclude the person from conversations with family and friends.
- Speak directly to the person if you want to know how he or she is doing.
- Take time to listen to how the person is feeling, what he or she is thinking or may need.
- Give the person time to respond. Don't interrupt or finish sentences unless the person asks for help finding a word or finishing a sentence.
- Communication is how we relate to one another. It is an important part of our relationships. How we express our needs, desires, perceptions, knowledge and feelings. The exchange of thoughts, messages and information. It is more about listening than talking. About attitude, tone of voice, facial expressions and body language.
- Talk with the person about what he or she is still comfortable doing and what they may need help with.
- Explore which method of communication is most comfortable for the person. This could include email, phone calls or in-person conversations.
- It's okay to laugh. Sometimes humor lightens the mood and makes communication easier.
- Be honest and frank about your feelings. Don't pull away; your friendship and support are important to the person with dementia.



2. COMMUNICATION IN THE MIDDLE STAGE

The middle stage of Alzheimer's is typically the longest and can last for many years. As the disease progresses, the person will have greater difficulty communicating and will require more direct care.

Tips for successful communication:

- Allow time for response so the person can think about what he or she wants to say.
- Engage the person in one-on-one conversation in a quiet space with minimal distractions.
- Be patient and supportive. Offering comfort and reassurance can encourage the person to explain his or her thoughts.
- Maintain good eye contact. It shows you care about what he or she is saying.
- Avoid criticizing or correcting. Instead, listen and try to find the meaning in what is being said. Repeat what was said to clarify.
- Avoid arguing. If the person says something you don't agree with, let it be.
- Don't overwhelm the person with lengthy requests that require complex thinking. Instead break down tasks with clear, step-by-step instructions.
- Speak slowly and clearly.
- Ask one question at a time. Multiple questions can be overwhelming.
- Ask questions that require a "yes" or "no" answer. For example, "Would you like some coffee?" rather than "What would you like to drink?"
- Give visual cues. To help demonstrate the task, point or touch the item you want the individual to use. Or, begin the task for the person.
- Written notes can be helpful when a spoken word seems confusing.

3. COMMUNICATION IN THE LATE STAGE

The late stage of Alzheimer's disease may last from several weeks to several years. As the disease advances, the person with Alzheimer's may rely on nonverbal communication such as facial expressions or vocal sounds. Around-the-clock care is usually required in this stage.

Tips for successful communication:

- Treat the person with dignity and respect. Avoid talking down to the person or as if he or she isn't there.
- Approach the person from the front and identify yourself.
- Encourage nonverbal communication. If you don't understand what is being said, ask the person to point or gesture.
- Sometimes the emotions being expressed are more important than what is being said. Look for the feelings behind words or sounds.
- Use touch, sights, sounds, smells and tastes as a form of communication with the person.
- It's OK if you don't know what to do or say; your presence and friendship are most important.

ABOUT THE AUTHOR

Christine DiLeone MSN, RN is an Assistant Clinical Professor at the University of Connecticut School of Nursing. She utilizes the resources of the Alzheimer's Association in her teaching, specifically on communication techniques with dementia patients to maintain dignity. She is a PhD nursing student at the University of Connecticut, and plans to continue research with those afflicted with this disease. She serves her faith community as a parish nurse by assisting pastors in the care of the mind, body and soul of the congregation members. DiLeone is a champion in the "Fight Against Alzheimer's Women's Campaign", coordinates a monthly Alzheimer's support group and is actively involved in yearly walks to end Alzheimer's.



Mom in the beginning of the early stages, on one of our last trips to Disney World.



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