

Tami Anastasia

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Michael Miller, whose mother had Alzheimer's, introduced Tami with the following quote: "Communication is the life of the relationship".

Tami's talk today will provide tips on communication since it affects both sides of the relationship (the caregiver and the person being cared for).

Tami is a dementia consultant, educator, and the author of Essential Strategies for the Dementia Caregiver. She has a private practice and provides dementia guidance, emotional support, caregiver strategies, and assessments for families caring for a loved one living with dementia and she provides physical and cognitive stimulation for people living with dementia.

Her book Essential Strategies for the Dementia Caregiver walks the caregiver through the journey from the beginning to end of life.

What is dementia?

Dementia is a general category that describes any type of cognitive impairment that interferes with the ability to perform instrumental activities of daily living (i.e. balancing a check book, cooking, paying bills) and activities of daily living (the ability to take care of themselves – i.e. bathing, dressing, eating).

Alzheimer's is the most common type of dementia.

Dementia affects our thoughts, memory, behaviors, language, mobility, judgment, processing, and visual spatial perception. It causes brain damage and functional impairment, resulting in being less able to function and do daily activities and tasks.

All behavior is a form of communication. For example, irritability and frustration may arise when the person doesn't have the verbal capacity to explain what their needs are or they are having difficulty understanding what you're saying. This requires the caregiver to read their body language in order to better understand what the person is trying to communicate. It's important to acknowledge and make eye contact with the person living with dementia.

Short term memory loss can cause a person to keep repeating things – often that's because they can't remember asking the question or remember the answer to their question. They don't have control over what they say and do. They are not trying to test your patience or get on your nerves.

As dementia progresses, people with dementia will often ask to go "home." "Home" is often a metaphor for feeling safe, secure, comfort, and familiarity. People living with dementia have no control over what they say and do. They will confabulate: they will take pieces of the past and present and mix them. Some may be true and some made

up. If you argue with the person living with dementia they will argue back because they are defending their thinking. If you point out that what they are saying is incorrect or wrong, they are likely to get upset. They truly believe what their brain tells them - they are not making things up intentionally.

As dementia progresses, they will lose the ability to think rationally and process information logically. They can become argumentative if you argue. They may become accusatory due to the damage that is happening to their brain. Some communication pitfalls to avoid:

1. Do not argue. They have firm beliefs. They will defend their thinking. Don't challenge them.
2. Don't be forceful or insistent. Don't rush them. Caring takes patience. You will feel sad and a sense of loss. This is a learning process. Don't blame yourself.
3. Don't ask them why they did something. They can't tell you why. They don't know why.
4. Don't test their memory. E.g., Remember when I told you? Remember John? .
5. Don't ask open-ended questions. Most times they are going to say no so that they have some control. That's their default. Simplify the decision making process. E.g., give two choices. Do you want cereal or toast? This gives them some control and allows them to feel independent.
6. Try not to tell them no they can't do something. They often interpret this as trying to control them or you're treating them like a child. Instead, come up with other ways to distract them rather than telling them "no" – you could say "that's a great idea but I could use your help over here or I could use your help with this." instead of saying "no".
7. Don't try to use reason or logic. Information can get misconstrued. Keep your questions and answers short and simple. The less you say, the better. Don't give long explanations that may cause them to get overwhelmed, agitated or frustrated.

What do we do instead?

1. Be mindful of your body language as the caregiver. They hone in on it. Smile and lose your temper/patience in another room.
2. Instead of saying "you", say "we" and "us". E.g., let's go put on our pajamas. It's time for us to have breakfast. This is more inviting and welcoming and increases cooperation.
3. If you were in their shoes, how would you want to be approached? Provide a reassuring and comforting response. Validate what they say. This makes them feel heard and understood. Repeat what they say. You don't need to agree or disagree. Don't challenge or dismiss them.
4. Keep questions and answers short and simple. Sometimes sequential memory gets lost. E.g., take a shower. They can't remember what the steps are. Create success at each step. Break things down, one step at a time. Or use visual cues, like a picture. Doors can be labelled with the name of the person who uses the room.

5. Find other ways to connect, so that you can connect with their soul. E.g., a smile, kiss, gesture. There are many non-verbal ways to connect. These are invaluable forms of communication
6. Compliments go a long way. Changing clothes example: That is such a pretty color on you....uh oh....I notice you have a spot on your shirt. Let me try to get it out (as you hand them another top) vs telling them you stink or your clothes are so dirty. As dementia progresses, they may forget how to dress and undress themselves.
7. Invite them. Try to make it hard to say no. E.g., I would love to have you join me to have a hamburger. I would love your company. This is better than telling them to do something. If you ask an open-ended question like do you want to do {name the activity} they may be fearful of what you are trying to tell them to do so inviting them makes them feel important and it's a gentle way of motivating them to do something. Tap into making them feel special, important, helpful etc.
8. Demonstrate what needs to be done. Or we do it together. You will mourn the loss of what they can no longer do so you may try to interact with them the same way you always did but they are going to need more guidance to do simple and normal things. You have to adapt to their limitations and meet them where they're at.
9. As they lose their abilities, capitalize on the abilities that they still have. Give them something to do that you know they can still do. WE (the caregivers) have to adapt and change. This is a lot on the caregiver. It is emotionally and physically exhausting. You are as important as the person you are caring for. Remember to take breaks and take care of yourself. Dementia demands more care than one person can provide. You are not failing your loved one. As dementia progresses, their needs increase. Know that you are doing the best you can under the circumstances.
10. It's a huge loss to see them decline. Give yourself permission to trial and error as their needs constantly change. There is not a one size fits all – you learn by doing. Take your cues from them. Tell them whatever won't upset them. E.g., if telling them someone died causes tremendous despair and angst then you're not going to want to tell them so and so died. Spare them emotional distress. In the dementia literature this is referred to as therapeutic fibbing but I call it therapeutic acts of kindness. You're not withholding information or lying with the intent to deceive them – instead your withholding information to spare them from getting upset or distraught and from them accusing you of lying to them. It's all about sparing the person from anguish. They believe what their brain tells them. Change the story if your loved one gets upset. Join their world and meet them where they're at.
11. If they say "I want to go home" and they're already at home, it's likely your loved one is thinking of the home from their past – when they were a child
12. It can be heartbreaking if your loved one doesn't recognize you. You may have to leave the room and walk back in and introduce who you are – i.e. "Hi Joe, it's your wife Betty."

Questions:

1. What do you do when you visit them and they are happy? When you leave, they are sad and try to follow you.

Say I'll be back soon. Try to avoid saying "I'm leaving or goodbye." Don't say where you're going and when you will be back. They don't understand when you say "I'm leaving" or "I'm going to work" – this doesn't reassure them that you'll be coming back. Reassure them that "I will see you soon – or I'll be back soon". This is more comforting. And, if they ask....can I go with you? Instead of saying "no" – acknowledge that they would like to go with you but make up a reason why they can't – for example you might say..."I would love for you to go with me but I have to go to a hair appointment. I look forward to seeing you soon and spending more time together." If they ask "When?" Reply "As soon as I can - I'll see you soon". They need to know that you are not abandoning them. Fear is an underlying feeling in behavior. We need to provide reassurance. Try to make them feel important and special. Tap into their sense of purpose with something they know and can do. They want to feel like they are contributing and are still important. Everyone wants to feel valued and important through the end of life.

2. For a parent with suspected dementia, write a note to the primary care doctor what you're observing. E.g., My mom's memory is declining. I've noticed in the last 3 weeks that she's not remembering our phone conversations. Give details of what you're seeing happening or are observing. Let the doctors know privately what you're noticing – what their limitations are – try not to do this in front of your loved one. It's important to keep in mind that people living with dementia are not in denial – they may have anosognosia – if there is damage in the part of the brain where "self-awareness" is stored they are not going to be capable of being aware of their limitations so trying to convince them about their limitations will be hitting your head against a wall – they aren't refusing to see what you want them to see – they truly aren't capable because of damage being done to their brain. And, pointing out their limitations will most likely cause friction in your relationship.

3. Mom says she is worried about memory loss, but she seems normal.

Ask mom what she thinks is wrong. What frustrates her? What is happening that concerns her about her memory? See if you can get her to describe what is happening and why that worries her. Then, gently open the door to see if she would like to run it by her doctor because maybe there is something they can do to make it better. Get as many details that you can from your mother. Get specifics. And, you also want to start writing down your own observations, as well as what your mother says. Keep in mind, short term memory loss isn't the only symptom of dementia - language, reasoning, speech and judgement may go before memory.

Other factors that mimic dementia are hearing loss, vision problems, vitamin B12 deficiency, UTI (urinary tract infection) dehydration, thyroid imbalance, sleep apnea are other health issues that can contribute to increased confusion.

The bottom line - If something feels off, trust your gut. It may be dementia, but it could also be something else that is treatable so it's always good to discuss any changes in cognition and behaviors with a doctor.

Other side notes:

- We need to change how we interact with people living with dementia and enter into their world.
- Find out more about them and what makes them happy.
- Join the person's reality, versus trying to keep them in our reality.
- Dementia will progress and your loved one will decline as time goes on.
- And, remind yourself that....You are as important as the person you're taking care of. Be as loving, kind, nurturing and compassionate with yourself as you are to those you love.
- Thank you for all of the love, support and care you provide.
- You are the backbone to caregiving and you're a blessing to the person you're caring for and to those who know you.