Care Ecosystem
Navigating Patients and Families Through Stages of Care

Communication

Communication is the process that allows people to share information, feelings, and ideas. People with dementia experience many challenges with communication. They may have trouble remembering what someone said to them, or they may have trouble following a conversation. They may not understand the words being said, and they may also have trouble expressing themselves. Another common challenge people may have is finding the right word to use, so they sometimes substitute words that don't make sense. People with dementia often become quieter over time and don't take part in conversations. Older people with dementia may also have hearing loss that can affect their ability to follow a conversation.

It can be difficult for families to adjust to these changes

- It is hard to accept that the person with dementia cannot follow conversations the way they once did.
- It can feel lonely to lose the ability to have meaningful conversations with someone you have been close to.
- The ability to follow logic and reasoning often declines in dementia.
- It is hard to adjust to speaking in simpler terms.
- It can be difficult to figure out what the person needs or wants.
- People with dementia may feel frustrated and self-conscious about their difficulty with language and comprehension, and this can be hard for families to observe.

Things you can do to help

- Sometimes families find other ways to feel connected to the person with dementia, even in its advanced stages. Activities, such as listening to music, holding hands, or just sitting quietly together can feel meaningful.
- In many cases, the emotions being communicated are more important and more helpful than the content of what is being said. This is true for both the person with dementia and the caregiver. Pay attention to feelings rather than words. If you show feelings of being calm and comfortable, the message to the person with dementia is that they don't have to be worried.
- A person's behavior can be a good way to gauge how well they understand what is going on.
- For example, if the person is becoming irritated or anxious, that may be a sign that the conversation is too difficult or overwhelming.
- Do not use reasoning and logic if it leads to frustration and irritability.
- Tips for managing caregiver frustration include: counting to 10, taking a deep breath, taking a break, getting some help, attending a support group, and finding out how other caregivers are dealing with these same concerns.

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Common Problems and Strategies

Symptom	Result	Strategy
Trouble with speech and language	-Mixing up words -Frustration with trying to express themselves -Difficulty understanding what is being said	-Help the person find the word by guessing, asking them to describe it, or saying what they do with it -Apologize for not understanding -Be patient and give the person time to say what they need to say
	-Avoiding conversations	-If they don't understand what you have said, repeat it using the same words -Offer limited choices -Ask "yes" or "no" questions rather than open-ended questions -Tell the person what you want them to do instead of telling them what you don't want them to do -Pay attention to the underlying emotion the person is expressing -Go along with nonsensical speech—show interest and use the tone of voice/rhythm that mimics a typical conversation
Visual problems	-Difficulty reading notes, calendars, or written signs	-Use simple sentences to give instructions -Try commonly recognized icons; for example, place a stop sign on doors that you don't want the person to open -Show the person where to go or what you want them to do with gesture and gentle touch; for example, use gentle pressure on the lower back to offer guidance on where to walk

Forgetfulness	-Forgetting what was said -Repeating themselves frequently -Forgetting names and relationships -Worrying about forgetting something important -Denying being forgetful	-Greet the person by name and introduce yourself in case they cannot remember who you are -Do not give the person information too far in advance if they might worry about it -Do not test their memory or remind them that they forgot -Offer a reassuring response to frequently asked questions -Redirect the person to something pleasant -Apologize even if it's not your fault
Inattention	-Difficulty following conversations -Getting distracted easily	-Try to engage the person in one-on-one conversation instead of group discussion -Make sure the environment is quiet; turn off the TV or radio -Keep eye contact and respond with enthusiasm
Poor judgment	-Saying rude or offensive things -Not noticing or not responding to other people's feelings	-Try to understand that this behavior is caused by the disease, not the person -Try not to take things personally -Try to find other ways to feel connected such as through humor -In public, you may want to apologize to others for the person's inappropriate comments -Avoid opportunities for trouble; plan public outings carefully -Try using distraction with a snack or activity

Loss of reasoning skills	-Inability to follow complex explanations -Inability to understand "why" like they used to -Difficulty making good decisions	-Note that this can be difficult for both of you -Try to let go of being right -Honor the person's grief over loss of independence -Offer alternatives when available
Inability to problem solve	-Overreacting or worrying about little things	-Respond to the feelings, not the words -Increase support to meet the person's needs without taking over -Limit information if sharing it will only cause worry -Apologize even if it's not your fault
Slowed thinking	-Difficulty understanding what was said -Difficulty coming up with an answer to an open-ended question	-Speak slowly and use simple sentences -Give the person time to process what you are saying -Repeat yourself as needed using the same words you used the first time

Types of conversations

Person with dementia	Less helpful response	Strategy	Better response
"I don't know why that doctor took away my driver's license. I am a good driver."	*"Don't you remember? The doctor says you can't drive with a diagnosis of dementia."* *"You ran through the stop light, and I had to tell your doctor that it's not safe for you to drive."*	Avoid defending the decision that the person stops driving; it may lead to an argument between the two of you. It's OK to acknowledge their frustration and anger about not being able to drive.	*"You have always been a good driver. I know this is difficult. Shall we go have lunch now?"*

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"This is not my home. I want to go home."	*"Of course this is your home. We have lived here for 30 years. Don't you remember?"*	Pay attention to the emotion and the feeling being expressed. The person isn't recognizing their home. Try to elicit positive memories.	*"You have a lovely home. Tell me something you love about your home."* *"Tell me something about the town you grew up in."*
"You didn't tell me I have a doctor's appointment today."	*"I told you this morning, but you don't remember."*	While difficult to do, it's sometimes easier to accept blame even when you know you are right.	*"I'm sorry, it must have slipped my mind. I thought we could have lunch after the doctor's appointment."*
"What are we doing today? Where are we going?"	*"I just told you that we are having lunch with our friends."* *"What do you want to do today?"*	The person isn't deliberately forgetting: they really cannot remember. Yes/no questions may be easier to answer than open-ended questions.	*"It is time for breakfast now. Let's listen to the birds and drink our coffee. Would you like eggs or yogurt?"* *"Shall we go to the park or to our friend's house?"*
"Where am I? Why am I here?"	*"Why do you keep asking me? You come to this day program every day."*	Dementia often affects visual perception, so places may not seem familiar.	*"This is the Senior Club. I am glad you came for class. Can you help us move those chairs over here?"*

"Leave me alone—get out of here! I don't need your help!"	*"But you can't do this by yourself."*	Avoid arguing. Maybe take a break and try again later. With some distraction, the person may be willing to accept assistance.	*"I am sorry, this is a tough time. Let's make the best of it together. Did you see the blossoms on the trees out front? They made me sneeze all morning! Would you please get me a tissue?"*
"I don't want to go to that program!"	*"You always go on Wednesdays, and they are expecting you."* *"I need you to go to your program, so please hurry and get ready."*	Avoid arguing or reasoning. Distraction may help. Check with the program staff and make sure the person is enjoying the program once they get there.	*"I'm sorry you are feeling this way today. Let's get ready for breakfast now. Do you want your blue shirt or your red shirt?"*
"I don't care what you want! I'm getting away from here!"	*"Don't go out the door! It's a busy street and it's not safe!"*	Telling a person to not do something when they are agitated can make them even more upset. Tell the person what you **want** them to do instead of telling them what you **don't** want them to do.	*"I'm getting a snack. Let's go to the kitchen."* *"I'll walk with you."*