Bob's LAST MARATHON Living the Alzheimer's Journey

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Communication and Activities Tips and Techniques

Felicia Greenfield: Communicating with a person with dementia is a common question or concern that caregivers ask about. The way we communicate with people with dementia can affect behavioral outcomes. Take Amy and Joel, for example. In a caregiver class, Amy shared that it takes her about an hour to get her husband ready for bed each night and it's always a fight and leaves her feeling exhausted. When asked what a typical night looks like, she tells us that her husband, Joel, watches the news downstairs in the living room on full volume. She stands at the top of the stairs yelling for him to come up and get ready for bed. The other night, he did not respond to her yelling, and, full of anger, she went downstairs and yelled at him, accusing him of not listening to her and being difficult. She turned off the TV and he responded in anger, telling her that he can go to bed whenever he darn well pleases. Amy stormed out of the room feeling defeated and Joel proceeded to pace around the house until Amy was able to calm herself down and finally cajole him upstairs to bed.

Stefanie Bonigut: Effective communication is the foundation for all your caregiving skills. If it's done well, it can decrease arguments, reduce frustration, increase the self-esteem of the person living with dementia, reduce difficult behaviors, and actually increase feelings of connection with your loved one. Communicating with somebody living with dementia can be challenging, though. The cognitive impairment affects the person's ability to understand what you say, it limits their ability to express what they want to say, it limits their ability to remember their own thoughts from moment to moment, and it can prevent them from finding the right words or sometimes words at all. So what this means is the person living with dementia can't fix their communication challenges; we have to find other ways to communicate with them. So here are some things to consider when communicating with your loved one.

Pay attention to your nonverbal communication. What's your overall attitude? What's your tone of voice and

your volume of voice? What are your facial and body expressions and body language? In our example that you heard, it's always a fight, so Amy was already expecting a fight. That was her attitude. She started off by yelling her request. That was her volume of voice, and she was full of anger, which was likely apparent on her face and in her body language.

How you approach a person living with dementia is also important for effective communication. You want to make sure you have their attention, approach them calmly and from the front so you don't startle them. Make eye contact or use gentle touch to get their attention. And sometimes it helps to call them by name. Again, in our situation, Amy wasn't in the same room as Joel, so he didn't acknowledge her. She didn't have his attention. People living with dementia mirror or mimic the people around them. So if you're frustrated, angry, or sad, the person living with dementia is going to pick up on those feelings and mimic them. It can go the other way, too. I was getting really frustrated with my own mom because I couldn't get her to change her shirt. I was trying so hard to convince her she needed to do it. I should have known better. I'm a social worker in the field and I finally realized that. I started laughing at myself, and within seconds, my mom started laughing too. I still didn't get her to change her shirt right then, but we were definitely both in better moods. And again, we see this in our case. Amy was angry and Joel became angry. Amy stormed out of the room and Joel began pacing the room.

What you say to your person living with dementia should be clear and concise. They are not going to be able to follow long explanations or multi-step directions. You may have heard the communication acronym KISS, but in dementia communication, we call it "Keep It Simple and Slow." And one caregiver of mine used to call it Western Union communication: You pay by the word, so keep it short.

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A few more tips: If you need to repeat something, repeat it exactly as you said it the first time so they don't have to process a new statement or question. Avoid trigger words. Trigger words are words that trigger a behavior or a symptom, so something that the person living with dementia doesn't like. So maybe they don't like to shower, you have trouble getting them showered, so don't use the word shower. Don't say, "Let's go take a shower." Maybe you say, "Let's go get cleaned up," so avoiding a word. Rephrase a question into a statement or a gentle command. Limit the choices you give them. Break down complex tasks into one simple step at a time and avoid using idioms or slang.

In our case, Amy shouted at Joel to come up and get ready. This was not clear or specific. What was Joel supposed to get ready for? And try not to reason, argue, or convince somebody living with dementia about something. It's not going to be successful. The disease affects these cognitive processes, so those interactions are just going to result in frustration.

Remember, too, that they are also living in a reality which is different from ours, so our rules of logic and reason don't apply. If you feel that you can't do that yet, I suggest this trick. Say "I think" before the correction you're trying to make. An example, they say, "Today is Monday," but it's not. So you say, "I think today is Thursday." Using "I think" is a great first step to not reasoning or arguing. You're conveying a fact, but you make it sound like an opinion. Better yet, try focusing on the feelings and not the facts, the words, or the behavior. We call this validation. We can usually figure out the emotion behind some of these words or actions even when we don't know what they are saying. It might not be so clear to us, so keep it simple and short. "You seem angry," "You seem frustrated," "You seem happy." Notice how I didn't say why they were angry, frustrated, or happy, I just acknowledged their emotion. That is often enough to make a person feel heard and understood.

And often as caregivers, we have to take the blame

even though we haven't done anything wrong. A simple "I'm sorry" can defuse a situation. Or try "I'm sorry" with validation. "I'm sorry you're upset. I'm sorry I upset you," even if you don't know what you've done to upset them. It's important not to ignore your person. You can acknowledge what they say without agreeing to it. Some useful phrases are "That's interesting," "You might be right," "That's an idea," or just use exclamations like "Huh," "Uh-huh," "Hmmm."

And lastly, consider using a fiblet, also known as a loving lie, a therapeutic fib, creative storytelling, many names. But this can be difficult since we're so used to being honest with the people we care for. But a fiblet is meant to keep the person living with dementia from experiencing distress.

So going back to our case, once Amy was downstairs with Joel's attention, she could have said any one of these things: "I'm sorry to interrupt your news show. I'm really tired. Let's go to bed." Here she's taking the blame and offering a simple direction. Or she could have said, "I think the news is over. Let's go upstairs." It may have been a fiblet and she was avoiding trigger words. Or she could have said, "I think the news is over. Let's turn off the TV and go to bed." A fiblet and a gentle command. Hopefully by preparing herself and by changing her approach and wording, she can avoid this nightly battle.

Katie Brandt: So now, I'd like to turn it back to Felicia to talk to us more about activities and meaningful engagement.

Felicia: Meaningful engagement for someone with memory loss has a number of benefits, so it can decrease agitation in challenging behaviors such as wandering or aggression. It decreases anxiety and depression when somebody is meaningfully engaged. It also improves sleep. It helps maintain brain health, and after an initial investment, it frees up caregiver on-duty time. It increases the bond between caregiver and care recipient and can help balance out some of the less pleasant interactions. Most importantly,

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the innate human need to participate in meaningful occupation or activity doesn't disappear in the context of dementia. However, it may be more difficult for your loved one to fill this need themselves and they may need your assistance getting started.

So sometimes it's difficult to know where to begin. This can be the most daunting part of setting up an engaged day. Consider the following questions when thinking about meaningful engagement: Did your loved one work? If so, what did they do? What were their hobbies? What did they like to do for fun? What did you like to do for fun together? And what was your loved one's role in the family or what were their responsibilities around the house? If you don't have answers to those questions right now, don't worry. You can still introduce new activities to your loved one even if they've never expressed an interest in them before. Remember, dementia can change personality including likes and dislikes, so never say never.

Many people with memory loss who had no prior interest in arts and crafts actually love using adult coloring books, so it's worth giving it a try. Sometimes activities need to be adapted so that they are more accessible to your loved one. Sometimes the activities that you come up with aren't practical on a day-to-day basis, but you can use them as a jumping-off point and modify using the following methods. First, scale down the activity. For example, if you and your loved one used to go on long walks together, can you maybe cut the walking time in half or take a walk in a new environment? Next, break the activity into smaller, more manageable chunks. For example, if your loved one used to throw elaborate dinner parties, try giving them small, discrete tasks one at a time like, "Please chop this onion," or "How about we look through this cookbook together and choose a menu?" Finally, focus on roles and feelings. If your loved one worked as a nurse but had to retire, think about what they may have gotten out of their work. They probably enjoy helping and nurturing people during a difficult time, so you may give them a case and ask them for advice.

And now I have just a few useful general tips. Think about placing the focus on the process and not the results. So if your loved one spends an hour sorting items and they're more jumbled than they were to begin with, that's okay. The most important thing is that they're engaged. Choose activities that can be done in short bursts. People with memory loss often have shorter attention spans and difficulty concentrating. Try having a few activities available so if your loved one tires of one, you can move on to another one quickly. Try to have the materials set up in advance and keep the surrounding environment as distractionfree as possible. You might also change your approach. Instead of asking, "Would you like to color?" try, "Now it's time to color," or "I would like to color and I'd love for you to join me." Or instead of using words at all, just sit down next to your loved one and quietly start doing the activity yourself. They may want to join you. Another tip is to make activities social. Involve family and friends. And finally, if your loved one refuses an activity, don't force them to participate. You can always try again later or tomorrow or next week.

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Activity Suggestions

Listen to or play music or go see a concert	Listen to a book or short stories on tape	Watch a YouTube train ride video	Sort collections, coins, silverware, etc.
Dance	Read poetry out loud	Spend time with friends, children, and grandchildren	Fold laundry
Look through photo albums or watch family videos	Paint, draw, or collage	Volunteer together	Wash dishes
Take down an oral history or simply share old family stories	Go for a walk in nature	Go to a Memory Café	Dust and vacuum
Cook a simple meal together or bake cookies from a mix	Do a relaxed exercise video, like chair yoga	Spend time with pets or other animals	Go "shopping" for items in a magazine
Do a jigsaw puzzle or word search	Plant and tend to house or yard plants	Go to a museum during off-hours	Use a rummage box or twiddle muff