DEMENTIA COMMUNICATION TIPS

from Jo Huey's Ten Absolutes of Alzheimer's Care

Never argue – instead, agree

Never reason – instead, divert

Never shame – instead, distract

Never lecture – instead, reassure

Never say "remember" – instead reminisce

Never say "I told you" – instead, repeat/regroup

Never say "you can't" – instead, do what they can

Never command/demand – instead, ask/model

Never condescend – instead, encourage

Never force – instead, reinforce

(source: Jo Huey, Alzheimer's Caregiver Institute, 1996)

#1: Never Argue, Instead Agree

Especially in the early stages of Alzheimer's or dementia, caregivers often report their loved ones become very argumentative. Many describe a situation in which their loved one "says things that are inaccurate, then becomes very defensive/angry when someone tries to correct or clarify the inaccuracy."

In these types of situations, it's important to remember the person with Alzheimer's is experiencing a progressive cognitive decline beginning with short-term memory loss. In their minds, what they're saying is what they know to be true.

Below are two common scenarios in which the "never argue, instead agree" tool makes for more positive interactions:

The person with Alzheimer's is looking for someone who has died: Depending on one's stage of Alzheimer's, they could be 95 years old and searching for their "Momma" who passed away decades ago. Instead of telling them the person is dead, tell them, "I haven't seen them today." It's the truth, and you avoid telling them the person for whom they are searching is dead. Remember, in their mind (due to memory loss) this might be the first time they have heard this devastating news.

The person with Alzheimer's says, "I want to go home." It is believed they are truly looking for a better place in time, and "home" describes such a place in one's heart. Instead of saying, "This is your home," try saying, "So do I." This provides an opportunity for both of you to approach something together rather than being in a state of disagreement.

#2: Never reason, instead divert.

As a caregiver, it's important to remember the disease progressively attacks different parts of the brain that control:

- Short-term memories (i.e., difficulty remembering things from a few hours or days ago)
- Language (i.e., difficulty finding the right word)
- Logical thought (i.e., problem-solving, grasping concepts, making plans)

What you and I consider "mindless" routine tasks (e.g., eating, bathing, dressing), may be difficult concepts to grasp for someone with Alzheimer's. They lack the ability to understand the significance of completing these daily tasks in a timely manner.

Trying to reason with them is a futile effort because the part of their brain that controls logical thinking has been hindered. It also seems to imply, "I am right, and you are wrong."

A much better approach is to change the subject to an agreeable topic.

For example, if you're trying to get the person to eat breakfast, say something like: "The sunrise was spectacular this morning! It was so relaxing to sit back and watch it while I enjoyed my morning coffee. Speaking of which, I think I'll get some more. Would you like some coffee or something to eat?"

This is a great way to "guide" someone into eating breakfast, rather than demanding they do so. I'll save the bathing for another absolute, but keep it in mind.

#3: Never shame, instead distract.

If I hadn't already copyrighted these Ten Absolutes, I would change the word "shame" to "embarrass." The meaning is essentially the same, but the term seems better.

We’ve all had “Duh!” moments, when we were truly embarrassed, perhaps even ashamed, of something we said or did. Imagine how much worse this would be if it were witnessed and pointed out to everyone around. How would you feel?

When caring for someone with Alzheimer’s or dementia, it’s important to remember that the parts of their brain that control short-term memories, language and logical thinking have been impaired. They most likely don’t realize what they’re saying or doing could be viewed as inappropriate.

For example, if you run into a friend at a restaurant, and the person with Alzheimer’s takes a sip of their water, avoid accusing them of doing something wrong.

Keep in mind that the person with Alzheimer’s may not remember drinking the water just seconds ago. Even if they do remember, they may not be aware it was someone else’s. They were thirsty, and the water was there. In their mind, it seemed appropriate to take a sip to quench their thirst.

A kinder approach would be to change the subject as quickly as possible. Ask if you can pull up a chair, and hand the water to the person with Alzheimer’s. Motion to the waiter and ask for two fresh waters (one “replacement” and the other for yourself).

If there isn’t time, just tell your friend, “I’ll catch up with you later.” Move along without mentioning the water, and even suggest to the person with Alzheimer’s that you stop for ice cream on the way home.

If your friend wasn’t already aware of your loved one’s situation, call them later to “catch up” and use the water incident to segue into a conversation about the challenges you’ve been facing.

#4: Never lecture, instead reassure.

We’ve all had days when it seems the world is working against us. First, you oversleep. Then, you spill coffee on yourself. By this point, you’re so flustered that you can’t remember where you put your keys.

The last thing you want is for someone to lecture you on how you should’ve gotten to bed earlier and should always put your keys in the same place.

Imagine how much better if would feel if someone just smiled and reassured you, “I did the same thing just yesterday! I’m so glad we’re able to laugh at ourselves! This will be our little secret.”

When someone has Alzheimer’s, it can be difficult for them to remember what to do in certain situations, even if you provide simple instructions.

Let’s say you drive them to the doctor’s office and drop them off at the front door while you find a parking spot. Even if you tell them to, “Stay right here,” they may wander off in the few minutes it takes you to park the car – not because they’re purposing disobeying you, but because they simply can’t recall the instructions you just gave them.

Not only is it frustrating and scary for you, but it's also frustrating and scary for them. Imagine how confused they must feel not knowing why they're standing outside of an unfamiliar building.

As a caregiver, your first instinct is probably to lecture them about how worried you were, but keep in mind, this will only aggravate the situation. Due to the disease destroying the part of the brain that houses short-term memory and logical thought, they really don't remember what you told them or why they're there.

Instead, offer reassurance. Next time, plan better so you don't have to leave them alone, even for a few minutes.

#5: Never say, "remember," instead reminisce.

As I've mentioned in previous posts, Alzheimer's disease progressively impairs the parts of the brain that house short-term memories, language and logical thought.

The disease then moves on to the parts of the brain that control emotions and processing of the senses (i.e., sight, smell, touch, etc.). Eventually, the disease attacks the part of the brain that stores one's most precious memories (e.g., wedding day, birth of a child, etc.).

Keeping this in mind, try to avoid asking someone with Alzheimer's or dementia if they "remember" something or someone. Just as you wouldn't ask a blind person if they'd just seen a new movie or read a recent book, you shouldn't ask someone with memory impairment, "Remember when … ?"

I understand this can be a difficult habit to break, given we are so inclined to start conversations this way. Even when doctors are trying to diagnose the illness, they commonly ask Alzheimer's patients to recall/remember things.

The problem with this is that the person with Alzheimer's really can't remember, even if they try. Not only is this frustrating and embarrassing for them, but it can lead to social withdrawal. It's not uncommon for them to refuse to respond or even walk away.

Instead of asking them if they "remember," try starting the conversation with a statement.

For example, if you're looking through a photo album, don't point at a photo and say, "Remember Bob and Sue's wedding?" Instead, point to the photo and say, "This looks like it was taken at Bob and Sue's wedding."

This way, you're not putting them on the spot. If they remember, great! They will feel a part of the conversation and enjoy reminiscing with you. If not, they can simply enjoy looking through the photos with you as you tell them the story of Bob and Sue's wedding day.

#6: Never say, “I told you,” instead repeat/regroup.

In today’s fast-paced society, it’s easy to get so caught up in “keeping up” that we lose sight of when we’ve lost control – the moment when we are no longer dealing with a situation to the best of our ability.

These “breakdowns” are our mind’s way of telling us that we need to take a break, a vacation or, at the very least, ask for help with our workload.

As a family caregiver, this “breakdown” is the moment when you find yourself losing patience with your loved one who has Alzheimer’s or dementia. Instead of reacting with compassion, you say things like, “I told you. I just told you! How many times do I have to tell you?”

This reaction is a serious “wake-up call” that you, as the caregiver, need to regroup. If you allow yourself to continue down this stressful path, you are more likely to say or do things that will further aggravate the situation. Additionally, loved one will pick up on this stress, resulting in a difficult time for you both.

The easiest way to regroup is to take at least three deep breaths and try to refocus. Something this simple can help you decompress and start the conversation fresh.

Often, because of the situation, you can’t just take some time off without some preparation, but you may also consider enlisting the services of family, friends or a professional caregiver to allow you some time to relax and rejuvenate your spirits.

Remember, as the caregiver, your first priority must be your own health and wellbeing! Without it, you won’t be able to care for your loved one to the best of your ability.

#7: Never say, “You can’t,” instead do what they can.

No one likes to be told they can’t do something; however, for someone with Alzheimer’s, this scenario is all too familiar.

As the disease progresses, it is increasingly difficult for them to discern what they can and can’t do safely.

What may seem rational to them could actually be detrimental to their health. Simple things like, “You can’t go outside; it’s raining,” “You can’t go to the bank; it’s midnight,” or “You can’t wear shorts; it’s freezing outside!”

Although you have their best interest at heart, it’s just another reminder to them that they are losing their independence and freedom.

As the caregiver, you’re tasked with the responsibility to search for the things that the person with Alzheimer’s can do successfully.

It’s important to focus on those activities that offer them a choice. For example, get an umbrella so you can go out in the rain with them; go to a bank with a drive-thru ATM; or pair shorts with a warm sweater so it’s more comfortable to go out in the cold, etc.

These small and easy changes will have a positive impact on your loved one’s confidence and self-esteem, resulting in a win-win for you both.

It’s also important to avoid “yes/no” questions if “no” will not be an acceptable answer. For example, instead of asking, “Do you want to go to breakfast?” offer an invitation, “Come with me! They have the best smelling food for breakfast.”

#8: Never command/demand, instead ask/model.

These days, it feels like we’re always on the go. Everything is done with such urgency, there never seems to be enough time!

In our “hurry-up” world, years of life can be lost in the blink of an eye.

If you’re caring for someone with Alzheimer’s or a related disorder, you’re probably feeling overwhelmed with the amount of “stuff” you need to get done; however, due to the disease’s progressive nature, your loved one has likely lost all sense of urgency and time.

Understandably, this sense of time conflict can cause tension between you and your loved one. As your patience wanes, your frustration may cause you to take a demanding tone, to which your loved one responds poorly.

One of the best-known books about Alzheimer’s, “The 36-Hour Day,” sheds light on this topic and offers suggestions on how to best handle these situations.

Remember, actions speak louder than words, and often produce amazing results when dealing with Alzheimer’s.

If you need to go somewhere, try linking arms. This usually works wonders.

If your loved one needs to eat, sit across from them and take a few bites. They’ll be more likely to mimic your actions than heed your words.

If you’d like for them to sit down in the car or on the toilet, try patting the chair. Make eye contact and lean back as if to sit. This will often result in their sitting down.

You’ll quickly find these methods work much better than verbally encouraging, saving both you and your loved one unnecessary frustration.

#9: Never Condescend, Instead Encourage/Praise.

When caring for someone with Alzheimer’s or dementia, you may find yourself excluding them from conversations concerning their health and wellbeing, as if they’re not there.

We tend to think the only way to explain the situation to family, friends and/or physicians is to talk about the person with Alzheimer’s as though they are invisible.

Not only can this hurt your loved one’s feelings, but it can result in aggression toward the provider of care.

Rather than excluding your loved one from the conversation, make a conscious effort to include them. Stand or sit next to them, and allow them to be a clear part of the conversation. It’s often helpful to link arms or hold their hand when you speak to the other person.

For example, say, “Dr. Brown, John said he’s feeling fine and doing well, but he asked me to make sure I mentioned to you that he has been having a lot of trouble sleeping lately.” Or when talking to family or friends, “Jane, John said he really enjoys your company, and he asked that we wait for you to eat breakfast. He’d also like you to help him with his medications and getting ready for the day.”

#10: Never force, instead reinforce.

No one likes to be told they’re doing something wrong. A better approach is to start by telling them what they’re doing well. Then, gently approach what they could be doing better.

One of the most common challenges for an Alzheimer’s caregiver is addressing a loved one’s obvious neglect of self-care.

This is often the first indicator to friends and family that something is wrong – when a loved one forgets to change their clothes or shower. Despite the best intentions, this observance is often met with defensiveness or withdrawal.

At this point, it’s common for family to turn to healthcare professionals for advice. Statements like, “My Mom has probably not had a real shower in months, but she insists she took a shower this morning,” are quite common. These statements are also followed with, “Why is the bath such a problem?”

My response is that I truly don’t see how ‘the bath’ cannot be a problem. Think about it from your loved one’s perspective. Would you feel comfortable letting a friend, family member or stranger watch and/or assist you with removing your clothes to take a shower/bath?

A much better approach is to provide everything your loved one will need to take a shower at the regular time.

Gather a change of clothes so they can get dressed in the bathroom when they’re finished. Run their bath water or get it the right temperature and ask them if it feels comfortable.

If your loved one is not physically capable of bathing/showering on his/her own, you may need to gently guide them through the process while explaining each step (e.g., foot bath, neck massage with warm towels, etc.).

With patience and understanding, what was once a struggle can become a completed task.