

Caring For A Loved One With Dementia

a practical
guide
for family
caregivers
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Communicating with your Loved One



Introduction

“Communication is a two-way street.” This is a common phrase we learn very early on to aid in improved communication. It certainly can be helpful in a “normal” circumstance, but what if there is a deficit on one of the “streets?” And what if that deficit directly affects the outcome?

This book will be covering the topic of communication, specifically related to communication when caring for someone with dementia.

For purposes of this book, communication will be broken down into the following categories: Listening, verbal communication, nonverbal communication, emotional awareness, and written communication. Concrete examples will be provided with Do's and Don'ts of communicating with dementia and a list of tips will be provided organized by stages of impairment.



Before jumping into the different parts of communication it is important to stop and acknowledge a very key point: you are caring for someone who is memory impaired. The reason this is being mentioned now is that it is very easy and common that caregivers along the care journey “forget” to keep this in mind.

In relation to communication, this can really challenge and create more strain within communication as you might try to talk to your loved one as if they have no deficits and this further complicates the situation, essentially creating more stress and burden for you, the caregiver. Let’s get started and discuss the different aspects of communication and how those are further challenged by dementia.

Aphasia

A common condition that appears with Alzheimer’s disease and other dementias is an aphasia.

Aphasia means language disturbance. There are many different kinds of aphasias, but the most common are known as expressive aphasia, and receptive aphasia. A person with memory loss may have one or both of these types.

- **Expressive Aphasia**

The person has a partial or total inability to produce language, but their comprehension remains generally intact. They may be unable to express themselves verbally. Speech production is halted and difficult, writing is at least as impaired as speech. These patients are generally aware of their language deficits.

- **Receptive Aphasia**

The person is unable to process or comprehend information they are receiving from others. The ability to grasp the meaning of spoken words and sentences is impaired. While they do have the ability to speak and form sentences, they typically have trouble expressing themselves through speech, and may use inappropriate or garbled words. They are often unaware of how they are speaking and are not able to comprehend their own words.

Both of these aphasias severely impact a person’s ability to communicate, and to understand what others are saying to them. If your loved one is affected by an aphasia, other forms of communication may be helpful.

Nonverbal forms, including hand gestures, body language, and using pictures may help ease their frustrations and express their needs and wants.



Listening

As communication being a two-way street, listening is an important aspect of reaching successful communication. When you are communicating with your loved one with dementia this can be extremely challenged for various reasons:

- **Hearing**

Age related or environmental factors can challenge your loved one's ability to hear you, thus straining your communication. This can be very frustrating for you the caregiver and the individual with impairment. When running into a communication roadblock, our recommendation would be to stop and assess if your loved one is hearing you. If you have some concern about this, advocate for the physician to explore any physical signs and have a specialized hearing test as needed.

Hearing aids can be effectively used, even if your loved one has memory impairment, but there can also be challenges with this (i.e., person may forget to put them in, not remember that they are needed, or lose them). Have an honest discussion with your loved one's physician about this and the hearing specialists you are working with as well. Take the time to weigh your decision and the pros and cons of the situation.

- **Cognition vs. hearing**

"Is my loved one hearing me or are they not understanding what I'm saying?" The honest answer here is: We don't know. The challenge in answering this question is that the impaired person often times cannot be the most accurate reporter of what is happening inside their brain.

- **"Old" Patterns of communication**

One of the biggest challenges in communication occurs out of habit, not intention. This is the tendency to enter old patterns of communication even when our loved one has dementia. This can be especially challenging for spouses as their patterns of communication with their husband/wife have been developed through years of interactions.

In some situations, caregivers feel that they are betraying their loved ones by omitting information or keeping things simple, which is the recommended practice with dementia. Keeping things simple with someone who has memory impairments is one of the most practical ways to communicate. Short, simple sentences with simple messages will be easiest to comprehend and respond to.

The questions to ask yourself are:

- **Could they have expressive or receptive aphasia?**
- **Are there any physical deficits in hearing?**
- **Is my loved one having difficulty with comprehension more than hearing?**
- **What is happening around us that could distract them from listening?**
- **What were the patterns of communication like prior to the dementia?**

Verbal communication

There are various conditions or “by-products” that can challenge a person with dementia’s ability to verbally communicate. Among them are word finding issues, aphasia, and repetition.

Word finding issues are very common within cognitive impairment and can challenge a caregiver’s communication with their loved one as the caregiver then fills in and spends a lot of time focusing and guessing what their loved one is trying to communicate.

Some suggestions to overcome this challenge are to keep communication simple, try not to rush your loved one, and in some instances using a communication board may be helpful. This is a tool that is used when someone has difficulty verbally communicating, they can either point to words or emotions that are on the board to express themselves and their needs.

Key things to keep in mind when you, the caregiver, are communicating with your loved one is to keep it simple, make sure your loved one knows you are talking to them, and be mindful of how capable they are of communicating with you at the time.



Nonverbal communication

Nonverbal communication is a key with caring for someone with dementia. When your loved one cannot understand the words you are saying, they are going to be reading your body language. This can be related to infants/young children who rely on reading their parents facial expressions and body language, more than understanding the content.

An interesting example observed at an adult day care center: Two patients are having a conversation not realizing that one is speaking Vietnamese and the other Spanish. The non-verbal cues and set-up of the conversation carry this interaction so much so that the patients do not even realize that they were not speaking the same language.

As a caregiver, it is important to have awareness of what nonverbal cues you are giving off.

Some questions to ask yourself are:

- What are my facial expressions like right now?
- What kind of tone is my voice at?
- How is my body language within this situation?

Sundowning Syndrome



Sundowning is a phenomenon that may occur in patients with Alzheimer’s disease, and is often referred to as “late-day confusion.” Sundowning is most frequently present during the middle to late stages of the disease, but can happen at any stage. Sundowning is likely due to an interruption in the body’s “internal clock” leading to anxiety, disorientation, or aggression. Some people who experience sundowning may have difficulty separating reality from dreams, and difficulty interpreting shadows and light. This may lead to pacing or wandering behaviors, or the person may become restless or irritated.

The phenomenon of Sundowning is important to recognize as it may interfere with communicating with your loved one like you normally do. You may notice that later in the day, as the light is fading, they may have increased agitation, confusion, and be less receptive to respond to you or cooperate with a task. You may also notice a change in their sleep cycle in which they become sleepy or fatigued in the later afternoon, and may not sleep as well through the night.

To improve the chances of having positive and effective communications, avoid introducing stressful situations, new requests, tasks or concepts in the late afternoon. The morning is often the best time to communicate important information, as many individuals with memory loss tend to be clearer in the morning hours.

If your loved one is experiencing symptoms of Sundowning, try the following:

1. Stay active during the day to promote good sleep habits at night.
2. Brighten the lights when your loved one feels confused or agitated in the early afternoon or evening.
3. Avoid stressful activities and noisy or overstimulating environments during Sundowning episodes.
4. Use familiar items to comfort them- a familiar keepsake, blanket, or other item.
5. Keep a routine. A regular schedule of waking up, activities, and going to sleep will help promote a regulated sleep schedule for both caregivers and their loved ones.

Emotional awareness

Along the same lines as nonverbal communication, emotional awareness is key in any relationship, even more important to be aware of when communicating with your loved one with dementia.

Just as your cognitively impaired loved one is reading your nonverbal cues instead of focusing on your words, it is important for you to concentrate more on their emotions than words.

Many times the question comes up from caregivers in support group or counseling, how do I respond to my loved one when they are not making sense? The best approach is to respond to what they are feeling instead of what is being said.

Example: Your loved one may be asking for their parents. Instead of trying to orient and bring the person to reality stating that their parents have passed away, it is best to respond to emotion: “I haven’t seen them yet, but it seems like you might be worried about them.” This will allow your loved one to be listened to, heard, and their emotional state to be nurtured.

Written communication

Written communication can be a helpful tool with dementia. The reason being is that a person with dementia often has difficulty with their short-term memory, thus tend to repeat themselves. You can use written notes or pictures as reminders about what they will be doing today and other information they may be concerned about. Caregivers can use notes as reminders for tasks in the home or reminders of activities that day.

Interpreting Communication

<i>Behavior</i>	<i>Possible Interpretation</i>
Undressing	May need to use the bathroom. May be too warm or clothes are uncomfortable.
Hitting, Kicking or Biting	May have pain or discomfort, may be attempting to communicate pain or upset. May have a perceived threat or invasion into personal space, such as when personal care is attempted. May have frustration due to restriction, loss of control, and limited choices.
Crying, Fear, or Avoiding	May be related to an environmental fear. May be afraid of the bath because may believe that the water is deep. May be afraid of a black/dark rug as they may believe (and it may look to them) like a black hole in the ground.
Running Away	May be due to anxiety, or may have a plan or purpose of something they believe they need to do “I need to go to work!”.
Sexual Behaviors	May misunderstand the context or relationship. May misinterpret the purpose of personal care. May have a longing for intimacy.
Touching Face or Body Part	May have pain or discomfort. May have a dental issue.

Tips at Different Stages of Dementia

Mild (Early stage)

- Be aware of your communication patterns prior to Dementia
- Less is more- monitor how much information is shared and how complex it might be
- Use a white board to communicate reminders about schedule and appointments, put this in a prominent place to be seen by all
- Utilize notes and written reminders to allow for greater independence
- Helping person with dementia initiate/prompt conversations with others

Moderate (Middle stage)

- Make things like a headline- short but covers the extent of what you need or want from the person
- Looking at a photo book together may help jog memories or support conversation
- Therapeutic fibbing- also known as “love lies”; these are things that can be said to reassure people with dementia
- Don't reason, don't argue, don't confront!

Severe (Late stage)

- Use touch to communicate with your loved one (i.e., hold your loved one's hand or provide hugs to show your love)
- Pair challenging tasks with positive facial expressions (i.e., smiling at bath time)
- Communication board may be helpful at this stage when language may be very challenged
- Focus less on your words and utilize hand gestures



Effective Ways to Communicate with a Memory-Impaired Loved One

Verbal

Speak Slowly

Repeat As Needed

Short, Simple Sentence

Use Therapeutic Fibbing (Love Lies)

Write Down Information on Notes

Non-Verbal

Smile

Nod

Make Eye Contact

Reassuring Touch

Use a White Board or Pictures to Communicate

Conclusion

Communicating with a loved one with dementia can be challenging as the disease progresses. The good news is that there are many ways to reach an understanding of what your loved one is trying to say. By using pictures, written words, body language, touch, non-verbal clues and more, you can help comfort your loved one, keep them safe and convey emotions that go far beyond words.

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