

Caring For A Loved One With Dementia

a practical
guide
for family
caregivers
2

Managing Behaviors



Introduction

The behaviors that caregivers encounter when caring for someone with dementia can be challenging at times. Rather than seeing them as challenges or difficulties, this may be an opportunity to see them as unmet needs, either physical or psychological.

Behaviors are a way of communicating, and caregivers need to listen with all their senses to interpret what their loved one is trying to say.

Many common challenges and opportunities to communicate and understand come from the behaviors listed in this book.



1. Resistance

One of the most common behaviors in individuals with dementia is resistance. Your loved one may refuse to eat, groom, or even get out of bed. Below is a break down of why they may be resistant, and ways to manage it. Here are a few of the commonly resisted tasks:

a. Personal Care and Hygiene

Your loved one may not understand why you want to assist and think that they do not need any assistance at all. They may also feel embarrassed about being assisted in the shower or in the bathroom and losing their independence. The fear of being controlled can also affect how they will react to you wanting to assist them.



Helping your loved one maintain their hygiene is a challenge, and your ability to communicate the positive and fun opportunities that exist when we brush our teeth may contribute to the success of completing the task. In the early stages, resistance may present itself in the form of wanting continued privacy and independence. They may not want, or may not “need” your assistance or supervision. In the mild/moderate stage, the person may be resistant because they are focused on maintaining control of this, and any situation that they can.

In moderate to late stages, the person may not understand what a toothbrush is used for, and why you are putting it in their mouth. All scenarios require positive approaches to accomplishing the task.

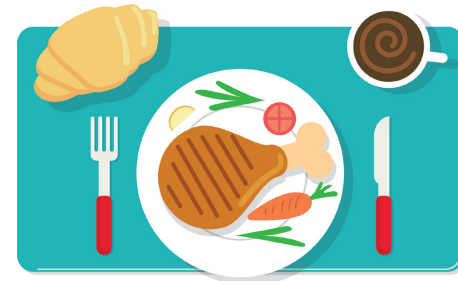
When your loved one senses your frustration and distress, it is likely to contribute to their resistance. Approach tasks with a smile, a happy tone, and a positive approach “It’s time to relax with a bath!”.

Caregiver Tip

If your loved one refuses to take showers, give them a bed bath. Wipes can be very useful. Gently wipe one part of the body at a time. Try to distract them while you do so by singing to them, playing relaxing music or telling them a story.

b. Eating

Your loved one may show resistance at meal time for a number of reasons. They may think that they already ate, they may be confused, or they may not understand why one has to eat in the first place. It is common for patients with dementia to lose interest in food. Some medications may also reduce their appetite or make them fatigued. Here are a few tips for a positive meal time experience.



Caregiver Tips

- **Create an inviting environment.**

Making eating a pleasant experience. Using colored plates (a different color from the food so they can differentiate and see the food) encourages more eating. Dining in a simple, quiet environment will help them relax while eating. Loud music, lights, crowds, or conversations may be too overstimulating or confusing for your loved one to focus on eating.

- **Watch for swallowing & chewing trouble.**

It's important to keep an eye out for any chewing or swallowing difficulties. If you notice this, talk to your loved one's doctor right away. Certain changes can be made to the food or beverage texture, such as thickening agents or pureeing food. These assist with minimizing the risk of choking if swallowing becomes more difficult.

- **Make eating easier.**

You may find that simplifying the menu to finger foods in place of traditional meals may prolong a person's independence and increase their satisfaction and consumption. Cut some fruit or veggies like apples, carrots, cucumbers or celery. Serve two-bite sided sandwiches or cheese cubes on crackers.

- **Be good company.**

Smile during meal time. Show that you are relaxed and make eye contact with your loved one.

c. What to do about resistance?

First, start by explaining calmly to your loved one why you want to assist them and what you are about to do. Let them do as much as they can on their own, and then try to assist them again.

Then, you may redirect or distract them with other subjects. Always stay positive and provide encouragement.

Caregiver Tip

Always be positive. One caregiver gives the following example:

I would always start the conversation with my mom by saying something positive first, such as: 'Mom, we are going to go out to lunch! Does that sound good? Yes! Ok, first, let's take a shower'. This would put her in a good and happy mood and she was more willing to cooperate to get ready.

Ask for help, no one can do it alone. If your loved one refuses your help, ask a family member to provide assistance and take turns assisting.

Last but not least, respect their right to refuse! Then, try again later. This is key to successful caregiving. If an attempt doesn't work the first time, wait a few minutes and try again.

2. Repetition

Every dementia caregiver knows what repetition means. Whether it is a particular question, story, or behavior, this is one of the symptoms of the disease.

Questions that may repeatedly be asked by a person with dementia include: “When is lunch?”, “What time do I go home?” (Sometimes even when they are in their own home), or “When is my spouse picking me up?” (Their spouse may even be deceased).

Repetitions can also mean returning to the bathroom again and again, or looking for an object or a person.

They may also be repeating a story, something that happened a long time ago and that they are remembering, or believe is current.

The reason for these repetitions is that short-term memory is the first thing to be affected in a person with dementia. They do not recall that they just told this story, or asked this question. They are not doing it intentionally or to be difficult.



What to do about repetition?

For any type of repetition, a good way to handle it is to change the subject. If you notice that your loved one repeats a certain question at a particular time of day, try to keep them occupied with activities during that time.

If it's about returning to the bathroom repeatedly, gently inform your loved one that they already went and redirect them to an activity. Engage them by asking simple questions like "Will you help me with

Caregiver Tip

Kim attends an Adult Day Health Care Center. After 2 pm, she repeats the same question approximately every 10 minutes. “What time is my daughter coming to pick me up?”. Staff respond by telling her that her daughter is coming at 4 pm, or giving her a note that reads “Lisa is picking you up at 4 pm”. The questions become more frequent in the afternoon, so a special activity is scheduled for her during that time to keep her occupied and interested. This lowers her anxiety and allows her to enjoy the time at the Center.

Try to find ways to soothe your loved one's anxiety by telling your relatives and friends how to respond to their questions. If you are alone with your loved one, listen to what your loved one has to say and find a way to distract or redirect them when listening to the same story.

3. Fearfulness

Common fears among individuals with dementia may include: fear that someone wants to hurt them or kidnap them, fear that others are stealing from them, fear of other people, fear of abandonment, or fear of unknown places.

Why are they fearful?

Dementia distorts a person's ability to separate reality from fiction. It is also common for patients to lack insight into their deficits, and blame others for events, such as losing money and accusing others of stealing from them. In the early stages, this may happen as a way for them to draw attention away from their memory changes, or explain events they are confused about.

What to do?

First, try to understand your loved one and meet them in their reality. Let them know you care and that you will not let anyone hurt them. Reassure them by saying that they are safe.

Explain each situation as much as you can. If they will be spending the day with a friend, a caregiver, or at the day care center, repeat why they are going there and that everything is going to be fine. Be reassuring, but firm.

Therapeutic items like dolls or robotic pets may help quiet your loved one's fearfulness and provide them tactile comfort.



Use positive affect. Smile, and use a comforting voice, volume, and tone. They will respond to your energy and mood. Be positive and they are more likely to be agreeable and cooperative.

4. Wandering

Wandering is very common for people living with Alzheimer's disease or another dementia. Patients wander from room to room, walking around the house or looking for something. They may also wander into the bathroom, talking to their own reflection in the mirror. In more serious cases of wandering, some patients may leave, or attempt to leave the house, day or night. This may result in panicked caregivers, friends, and neighbors attempting to locate the patient and bring them home safely.

Why does your loved one wander?

They may fear they will be abandoned or forget where they were going. They may feel that they have a place they are supposed to be; at work, for instance. They may be looking for a vehicle they once had or feel that they have an important task to do.

What to do?

If your loved one wanders, let them walk around but make sure they are completely safe in their environment. Ask for support. If you can't walk with them, ask a friend or a relative to support you and accompany your loved one.

Redirecting is key. To avoid your loved one wandering in the bathroom or any area, try to distract them with an activity they enjoy doing. This may include coloring, painting, singing/listening to music, folding towels, or looking through photo albums.

- **Secure the doors².**

If your loved one has ever tried to leave the house unsupervised, has been lost, or left after dark, you may want to consider an interior door locking mechanism. Medical supply companies offer diverse types of locks to secure the doors safely. The locking device may require several steps to open it and secure access to the outside, generally out of the scope of abilities for patients with compromised memory or reasoning skills.



Alarms can also be used as a deterrent and safety measure to be alerted if your loved one attempts to leave the house. Note that this can happen anytime, to anyone, at any time of the day. Prepare your home by using products that will make it harder for your loved one to wander off, such as a bed alarm, a door lock that locks access only from inside.

Put notes around your house.

Communicating with your loved one through notes, messages, or other written formats may solve some problems. In some cases, simple messages can reassure them and keep them from repeating the same questions. Write messages on post-it note,

write down their schedule for the day on paper, or use an iPad with every piece of information they need to know, i.e. their address, the date, etc. It also gives them some independence to get the information they want without having to ask.

Although my Mom was living with me, she would always say she wanted to go “home”. It was so frustrating for her that she would try to leave the house constantly. So I placed notes on each door of the house that said “Wait for Gloria”, and she would immediately stop trying to get out.

5. Aggression and Anger

Your loved one may become aggressive, angry, and frustrated. These feelings may be originated by a number of reasons that we have mentioned before, such as fear of abandonment or resistance to something you’d like them to do. If your loved one is interacting with someone who does not speak their language, the language barrier may cause frustration as well.

What to do?

When your loved one becomes aggressive, step away, stay calm, and try to deescalate the situation. Ask for help! If you are not successful at calming them down and reassuring them one day, maybe a relative or friend will. Maintain safe distance and continue to speak calmly and redirect them.

- **Try Therapeutic Fibbing**

What is therapeutic fibbing, you ask? It’s meeting the patient in their reality.

An example of effective therapeutic fibbing is in the case of Bob, a former executive who traveled extensively in his career. Bob became very upset and aggressive while at the Doctor's office. Bob began to yell that he had been here, at the airport for four whole days waiting for his flight! It was unacceptable to be waiting so long for take-off! The nurse responded to Bob by replying that she was very sorry for the delay. The flight would be leaving soon, and could she get him a glass of water while he was waiting? Bob responded that yes, thank you, a glass of water would be nice.

A therapeutic fib does not attempt to correct the person, re-orient them, or convince them of anything that is not their current reality. While you may feel tempted to try and correct your loved one and re-orient them, the best thing is to “go along with it” and keep them calm, happy, and reassured.

- **Explore Medication**

Being in a state of anger and aggression is not only difficult for the caregiver, it is also distressing for the patient. When they are upset and unable to express it appropriately, communicate their needs, or get attention to a matter that is disturbing them (such as pain or an infection), it is a top priority to help them calm down.

The first thing to rule out is a physical ailment. Could they be experiencing pain? Might they be uncomfortable, or need attention to a condition or infection? Are they hungry, thirsty, or have another unmet need?

If all physical needs have been ruled out and the anger and aggression persists, it may be time to talk with their neurologist about medications to help them calm down. Medications come with pros and cons. They frequently have side effects. The side effects may include increased risk for falls, weight gain, dry mouth, incontinence, and more.

You may decide that minor irritation can be managed without medication, but ongoing anger and physical aggression may require a medication intervention for the safety of the patient and the caregiver. Talk with their doctor about medications that are options, side effects, and the ways that it might improve your loved one's quality of life.

Checklist:

- Observe if your loved one is rubbing a part of their body before they get aggressive. It could be a sign that they are in pain but would not know how to express it. For example, if your loved one rubs their cheek, they may have a dental issue.
- Try to limit changes in their environment as much as possible: you may want to avoid moving furniture around or using objects that are too modern and may confuse them.
- Write down each one of your loved one's behaviors and share them with their neurologist.

6. Impulsive and Disinhibited

Impulsive and disinhibited behaviors are common with individuals in the moderate stage of Alzheimer's disease, and those affected by certain types of dementia, such as Frontotemporal dementia, a type of dementia that specifically attacks the frontal lobe of the brain, which houses inhibition, judgement, and impulse control.

People who are desinhibited may have inappropriate behaviors in public, such as impulsively stealing from a store, or singly loudly in restaurants, or they may get impatient with others. Some also tend to vocalize their thoughts, or want to touch young children, which can become very stressful for the caregiver.

These behaviors can be difficult to manage as a caregiver because they are embarrassing. The fear of embarrassment can cause caregivers to isolate themselves in order to avoid these types of situations.

What you have to realize is that if your loved one behaves that way, they are never doing it intentionally or maliciously, but rather because their social filters are gone. Their ability to judge a situation is different because of the disease. Try to be mindful about what may trigger their behaviors and learn how to read their cues.

What to do?

- **“My loved one is vocalizing all of his thoughts, or fixates on things that he will repeat over and over again.”**

This behavior can be quite common among people with dementia. As a result, a caregiver may decide to avoid going to a play, the movies, or other public place because they are worried their loved one will disturb other people.

Nadia could not stop humming. It would annoy everyone around her and the other people at the Senior Center started complaining about her behavior.

The staff found a simple solution: they had her chew on chewing gum, which prevented her from humming and eased the situation.

- **“My loved one undresses and urinates in public.”**

People with dementia may undress unexpectedly in public, or in the middle of the living room with young children around. The behavior is not intentional and they may not realize why it is inappropriate or that it is inappropriate.

More than likely, your loved one is trying to tell you something. Very often, they may undress because they need to use the restroom. If possible, try to understand what is going to trigger their urge to undress or urinate.

Caregiver tips

Solutions to this problem can be as simple as being on a schedule: guide them towards the restrooms every 2 to 3 hours. Prompt them use the restroom before they go out.

You can also dress your loved one with overalls or one piece outfits, or use incontinence supplies. Some clothing websites¹ sell one piece outfits that may deter them from undressing in inappropriate places.

- **“My loved one makes inappropriate sexual comments and has inappropriate sexual behaviors.”**

If your loved one has inappropriate sexual behaviors towards people other than his/her spouse, try to see if there is anything that triggers them. Is it when they get hugged or touched? A person with dementia still has a body, and their sexual needs may still be very intact. What we would suggest is to always tell them very directly when their behavior is inappropriate and to remove them from the situation.

Some patients will masturbate in public. In that case, it's important to keep their hands busy: give them a magazine to flip through, occupy them with another task like puzzles, busy them or distract them.

- **“My loved one is stealing.”**

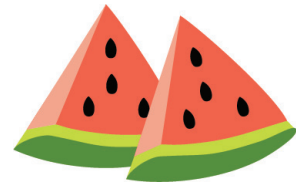
What we have realized at the center is that, for patients who steal, there is a reason behind their behavior. Often these patients either grew up poor or used to struggle financially.

People with dementia still have their long-term memory intact, and it's interesting to see that a stealing behavior can stem from a purposeful place.

Louise was stuffing things under her shirt all the time. When the staff at the day care center realized that she was stealing, they encouraged her daughter to have the patient bring a bag with her. The patient would then use the bag to take the items away and bring it back home at night. The daughter then emptied the bag and brought the items back to the center the next day.

- **“My loved one eats all the time.”**

Impulsive eating is common among people with dementia because they forget that they already ate, so they keep eating. Sometimes, they'll want to eat only sweets because their sense of smell is lost. Using child locks on the fridge and cabinets may be a way of keeping them away from eating constantly. If you prefer, you can also make sure that only healthy foods are available. For example, you may leave a bowl of fruit or a platter of vegetables out instead of a jar of cookies. It will help prevent them from gaining too much weight. Make sure you feed them adequately during meals with healthy and hearty foods, which may help them feel full longer.



If your loved one keeps asking for alcohol, substitute grape juice or nonalcoholic beverages for them to have and fulfill this need.

If you eat out and your loved one has trouble deciding what to order, look at the menu ahead of time. When you arrive, giving a heads up to the server about your situation (“I am caring for my husband with special needs”) should ease the ability to have a nice meal.

Caregiver Tip

Create a name badge that says “Please excuse my behavior, I have dementia.” And place it on your loved one's shirt. A lot of caregivers say it helps people understand. You may also handout cards that say "This person has Alzheimer's. Please be patient. Thank you."³

Resources

¹**Clothing for Undressing Problem**

Some clothing websites sell one piece outfits that may help deter your loved one from undressing in inappropriate place:

www.buckandbuck.com

www.silverts.com

²**Confounding Safety Door Locks**

www.alzstore.com

www.agingcare.com

³**Dementia Explanation Card**

www.alzstore.com

www.dementiaassistancecard.com

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