

# Understanding Dementia Behaviors

Alzheimer's and other forms of dementia have a profound impact on the lives of people throughout the world. Worldwide, an estimated 55 million people had some form of dementia in 2022. In 2019, there were roughly 6 million cases of Alzheimer's dementia just within the United States. As the proportion of the US population that is seniors grows thanks to longer life spans and a large, aging Baby Boomer generation, cases of dementia are projected to increase dramatically.

Those with dementia use extensive caregiving services since they often require 24-hour supervision for several years at the end of their lives. Currently, over 11 million people, such as spouses and adult children, provide full- or part-time unpaid care to someone with dementia. This means that nearly 4 out of every 100 Americans are caring for someone with dementia without pay.

Too often, dementia caregivers feel lost and overwhelmed as they witness their loved ones adopting new and troubling behaviors that they don't know how to handle. To demystify the caregiving experience and make it more manageable, we've created a guide that will cover how to respond to many common dementia behaviors, how to improve your communication with those who have dementia, and where to look for more information on dementia.

## **The Basics of Dementia**

If your loved one has recently been diagnosed with dementia, you may struggle to understand the basics of what dementia is and what causes it. Remember that dementia is a general term referring to cognitive impairment, especially memory loss, that significantly changes daily life. Under this umbrella term, there are many kinds of dementia. Below we'll explore some of the most common types and some factors that increase a person's risk of developing dementia.

## **Types of Dementia**

The overlap of symptoms between different types of dementia is quite extensive. Below we've included brief explanations of the most common kinds of dementia and resources that delve into the specific symptoms of each dementia.

### **Alzheimer's Disease**

Alzheimer's symptoms start with minor lapses in memory that grow more severe over time and may include symptoms like hallucinations, vision problems, mood swings, etc., leading to loss of independence. However, not every patient will experience all possible symptoms. A hallmark of Alzheimer's is the plaques and tangles that form in brain tissue and are thought to kill brain cells. This disease accounts for 60%-80% of the cases of dementia in the United States. While there's no universal test for Alzheimer's, diagnosis involves medical history, physical examination, special written and verbal tests, brain imaging and blood tests to rule out other conditions.

### **Vascular Dementia**

Vascular dementia is the second most form of dementia. In this case, the brain impairments are caused by reduced blood flow and damaged blood vessels within the brain. Studies suggest an association between this form of dementia and cardiovascular disease. The symptoms depend on which areas of the brain are affected. Patients may have problems with short-term memory, reasoning and problem-solving, muscle control, attention, mood, etc. Diagnosing vascular dementia is challenging because it shares similar symptoms as Alzheimer's.

## Lewy Body Dementia

The exact cause of Lewy Body dementia (LBD) is unknown, but the disease is known for its accumulation of abnormal deposits of a protein called alpha-synuclein within the brain. Symptoms may include hallucinations, memory decline, and confusion about time and place. Movement problems such as tremors, falls, and fainting are also common. This disease is sometimes associated with Parkinson's Disease. The National Institute on Aging (NIA) estimates that about one million Americans have LBD.

## Reversible Dementias

While dementias are typically considered irreversible, some can be partially or fully treated with surgery, a lifestyle change, or doctor-prescribed supplements or drugs. Examples of things that cause these "reversible dementias" include brain tumors, hormonal deficiencies, Korsakoff syndrome (a severe B-vitamin deficiency usually related to alcohol abuse), substance abuse, and improper nutrition. Diagnosing dementias such as Alzheimer's often involves questions aimed at ruling out these reversible dementias.

## Mixed Dementias

Sometimes elderly adults will develop multiple kinds of dementia simultaneously, a condition called "mixed dementia." For example, a patient with Alzheimer's may suffer a stroke and experience additional or worsened symptoms from vascular dementia's damage to the brain's specific region. Mixed dementia can be difficult to detect since different dementia types share the same signs despite their differing causes. The Alzheimer's Society in the United Kingdom estimates that about one in every ten people with dementia has mixed dementia.

## Other Dementias

According to the World Health Organization (WHO), there are many types of rare dementia, and their differences are often difficult to define. Nearly all follow a progression of early, late, and middle stages as described in the WHO article above, but the symptoms' causes may differ. Creutzfeldt-Jakob Disease, Huntington's Disease, frontotemporal dementia, and HIV-Associated Dementia are some of the rarer types of dementia.

## Dementia Risk Factors

Below are some of the most common risk factors associated with different types of dementia. Remember that this information reflects statistical risk, it does not mean that a person will necessarily develop the condition.

**Heart Disease and Diabetes:** Some chronic diseases, such as cardiovascular disease and diabetes, which are frequently linked, are considered risk factors for dementia. The CDC provides more information on the connection between heart and brain health. Diabetes, especially Type 2, is recognized as a major contributor to dementia and cognitive decline because it can damage the blood vessels within the brain.

**Genetics:** Some forms of dementia, including rare early-onset Alzheimer's, Huntington's Disease, vascular dementia, and others, have a genetic component. However, genes play a complex role in developing the disease, involving multiple genes. Having a relative with dementia does not guarantee a diagnosis. Usually, the genetic risk factor may be reduced by lifestyle changes. Predisposition does not mean predestination, as the doctors say. Please read Alzheimer's Society's in-depth review to learn how genetics affect the risk of developing the condition.

**Traumatic Brain Injury:** Numerous studies show relationships between a history of Traumatic Brain Injury (TBI) and dementia. Studies of veterans' long-term health outcomes suggest that TBI can increase the risk of developing dementia by twice as much as someone without a history. Moreover, some studies suggest that repetitive mild brain injury, common in contact sports such as boxing, is also linked to an increased risk of dementia.

**Lifestyle:** Inactivity, isolation, untreated mental health problems, poor nutrition, and substance abuse all contribute to the risk of developing dementia. According to the Alzheimer's Association's 10 Ways to Love Your Brain, a healthier and more active lifestyle decreases your risk factors, but it doesn't have to be complicated.

## Understanding and Responding Appropriately to Dementia Behaviors

Dementia causes a series of unique personality and behavioral changes in each patient and diagnosis. It's common for some behaviors to change with specific circumstances, ranging from increased irritability to aggression.

It's crucial to inform the senior's medical team of any behavioral changes. The appearance of a new behavior may warrant a physical exam to rule out undetected physical problems or the need for a medication adjustment. Below are the practical solutions and compassionate practices for responding to troubling behaviors.

### Sundowning

Sundowning, also called late-day confusion, is the phenomenon of dementia patients becoming more active, confused, and agitated in the afternoon and into the night. They may be unable to sleep, wander, look for something to do, and experience emotional distress. Sundowning causes more caregiver burden due to sleep deprivation if it continues late into the night.

#### How to Respond to Sundowning:

- **Reduce Sedentary Daytime Behaviors:** Get the senior on a better evening routine by limiting daytime napping, adding exercise, introducing a hobby, and adding social time during the day. Consistent schedules and calm evening activities can help since dementia can make it difficult to handle changes in activity.
- **Change the Lighting:** Some theories suggest that using special light therapy boxes in the morning hours can help seniors' circadian rhythms normalize, leading to better nighttime hours later. Getting morning sunlight within reason while being careful of over-exposure may have a similar effect.
- **Get Help:** Contact your loved one's doctor and ask if they have any suggestions. Recognize that your loved one may simply need less sleep than before. Hire a nighttime helper so you don't get too tired and unable to cope with your duties.

### Wandering

Wandering may be an early sign of dementia and involves roaming aimlessly, wandering outside the house, or losing direction while driving. As memory loss progresses, landmarks and directions lose meaning for a dementia patient. While interior wandering may not pose a problem, outdoor wandering can endanger a cognitively impaired senior.

## Causes of Wandering:

- Looking for a room, person, item, or activity
- Trying to get away from a stressful situation, including a noisy room or an unfamiliar person
- Feeling physically uncomfortable due to hunger or the need to use the restroom
- Trying to return to something remembered from the past such as a job

## How to Respond to Wandering:

- **Invest in Security and Accessories:** Door alarms, specialized “child proof” locks, or GPS-enabled accessories can restrict and monitor the movements of seniors who tend to wander. You can also make them wear a medical bracelet engraved with their identification and emergency contact numbers to identify them quickly if they wander.
- **Limit Access to Vehicles:** If there’s a car in the garage at the senior’s residence, it may be wise to keep the car keys out of reach. Seniors with dementia won’t remember that their doctors don’t want them to drive anymore.
- **Ask If They Need Something:** When the senior is wandering, you can ask what they need. Whether or not they were looking for something specific, the question may help direct their attention toward you.
- **Alleviate Boredom:** Minimize the senior’s urge to wander by providing meaningful and fun activities. Gardening, light exercise, a simple art or craft project, a puzzle, cooking- any safe activities they can enjoy. Such activities can help them to feel fulfilled and less restless.

## Withdrawal from Social Settings

Seniors with dementia may struggle in social situations, forgetting names and becoming overwhelmed by social situations. They may feel tired, shy, or embarrassed, and this could lead to anger or worry. They may struggle to be outgoing with people they now view as strangers. Depression is also common, which may be something to discuss further with their doctor.

## How to Respond to Social Withdrawal:

- **Modify Social Time:** Reduce stress by limiting the number of people in any social situation, shortening the interaction length, checking in with them to see how they feel, or choosing less noisy locations for socializing. Comfort items like a knitting project, prayer beads, or a fidget device may also help.
- **Help Others Understand:** Warn family and friends of things that may cause distress to the senior. Explain to them the nature of dementia and the patient's current stage to remove any stigma and prevent misunderstandings while communicating with your loved one.

## Incontinence and Related Issues

Incontinence and loss of bowel control occur more often in the middle and late stages of dementia. Relieving oneself in unconventional places or not wiping adequately can also occur. This can lead to caregiver frustration as they must clean up the mess and be patient with their loved ones.

## Common Causes of Incontinence and Bathroom-Related Issues:

- Forgetting how to find the bathroom
- Having obstacles in the path to the bathroom
- Forgetting what the appropriate response to the feeling of needing to go is
- Being dehydrated, constipated, or having a urinary tract infection
- Being unable to express the need for help with bathroom tasks

## How to Respond to Incontinence:

There may not always be a fix for dementia-related incontinence, but there are many ways to improve seniors' ability to use the restroom more regularly.

- **Speak with the Doctor:** The senior's doctor can check for a medical problem causing bladder or bowel control loss. They may suggest switching medications, testing for infections, or giving guidance on using incontinence products like adult diapers.
- **Provide Cues and Clear Obstacles:** Bathroom cues can include scheduled reminders from you (every one or two hours, for example), a label with a toilet picture on the bathroom door, or an offer to walk the senior to the bathroom from time to time. Ensure the path to the toilet is clutter-free and leave the bathroom door open and the seat covers up so the patient can find and use the restroom easily.
- **Don't Infantilize or Scold:** For some, it may seem natural to revert to childish words or even scolding when dealing with incontinence. However, these actions can be embarrassing to the senior. Stick to adult words for biological functions, provide help without taking over more than necessary, and refrain from shaming the patient.

## Agitation and Anxiety

Agitation and anxiety can manifest as pacing, shouting, unkind words, physical violence, crying, panicking, fearfulness about once-familiar things, and more. This behavior may be a complete change from the person the dementia patient used to be.

## Common Causes of Agitation and Anxiety in Dementia Patients:

- Untreated pain such as an undetected infection, sore, rash, toothache, or headache
- Hunger or thirst that the senior cannot verbalize
- Hallucinations that are scaring the patient
- Frustration from feeling rushed or talked down to
- Feeling disconnected from people and reality, feeling lost and alone

## How to Respond to Agitation and Anxiety:

- **Remain Calm and Respectful:** Give the senior some physical space and be calm before engaging. Ask permission to help, make eye contact, and speak calmly. Remember that their actions aren't personal or truly reflect how they feel about you. If you walk away momentarily, ensure the senior is safe first.
- **Meet Needs:** The inability to communicate what they need may be the root cause of agitation for a senior. Find out if the patient is hungry, thirsty, tired, needs the bathroom, or something else. Encourage them to point, mime, make a sound, or describe their needs. Turning down music or TV and altering the light can help
- **Provide Medication:** While medications can lead to side effects, they may be prescribed by a doctor and useful in these situations. Antipsychotic drugs, for example, may be needed when hallucinations are consistent and frightening. Some medications may not work as intended, so communicate this with the doctor when necessary.

## Perseveration

Perseveration is a repetitive speech or action arising from changes to the brain. A senior who has problems with perseveration might try to eat all the apples in the fridge, not realizing they've already had a few. They might also repeatedly say a word or phrase or voice the same worry or question. Caregivers may become irritated or distressed by the repetition and may have concerns if the person is doing something that could lead to health problems.

## **How to Respond to Perseveration:**

- **Be Patient:** Recognize that the impulse to repeat an action or question is probably entirely beyond the person's control. If you notice that specific topics or items trigger perseveration, avoid discussing them or having them around unless necessary.
- **Limit Access:** If a particular object, such as a noisemaker or food, causes perseveration and is deemed harmful, unhealthy, or too disruptive, consider putting the item away. It's often vital to keep sweets, alcohol, and supplements out of reach to avoid overuse.
- **Distract:** Steer the senior towards an alternative subject, action, or item. Engage the patient in enjoyable activities like taking them out for a walk or bringing up an old, fondly-remembered story from their past.

## **Paranoia, Accusations, and Hallucinations**

Some seniors will experience hallucinations which may or may not be accompanied by paranoia. With or without hallucinations, paranoia is common. Confusion and changes in the brain can lead to mistrust. For instance, when items are misplaced, seniors may become convinced that someone is stealing from them. Throwing accusations at family, friends, and even strangers is quite common. Make sure you keep your loved one's doctor updated on these symptoms.

## **How to Respond to Paranoia, Accusations, and Hallucinations:**

- **Be Compassionate:** When dealing with a hallucination, you can state that you don't see what they see but avoid trying to convince them that it's not there. Don't argue; reassure them that they are safe. Turning on lights, closing curtains, or moving to another room may diminish hallucinations. When dealing with paranoia, accusations, or hallucinations, acknowledge their feelings of frustration. Realize that accusations are just a symptom of the disease and not intended to hurt anyone's feelings.
- **Help Them Look:** If the senior has lost something and starts the accusations, help them look for the item rather than focusing on the accusation. Provide distraction if it's unlikely that you'll find the object, and consider a replacement if it's something that the senior will repeatedly miss.

## **Nutrition-Related Problems**

Seniors with dementia have nutrition-related problems for several reasons. Changes in their brains may dull their taste and smell, making food seem flavorless and bland. Sometimes vision and brain function issues also make seniors have difficulty distinguishing food from the plate or table. Muscle control and coordination loss can also occur, making simple dining tasks like holding utensils or getting food into the mouth nearly impossible.

## **How to Address Eating and Nutrition Problems:**

- **Focus on Favorites:** Providing favorite foods may help seniors be more enthusiastic about eating. Having them help you with simple cooking tasks may also help them be more interested in the final result.
- **Snacks:** If the patient is so stressed about eating that they can't finish meals, add small, healthy snacks throughout the day. You could place snack packs at the front of the refrigerator for seniors prone to rummaging through the fridge.
- **Simplification:** For problems with fine motor skills or vision, a simplified meal seniors can easily eat with their hands is ideal. Additionally, use high-contrast tableware and placemats (compared with food and drinks) to help low-vision patients.

## Bathing and Grooming-Related Problems

Seniors with dementia often forget to take care of themselves or are physically unable to bathe, change clothes, and do other personal care activities. In addition, some seniors may become angry, embarrassed, or frustrated when reminded to do these things. Seniors may forget about personal care and hygiene and their importance or lose their train of thought while doing self-care activities.

### How to Address Bathing & Grooming Problems:

- **Provide Simple Direction:** Provide simple instructions for personal care activities like hair combing and toothbrushing. Streamline the process and remove excess items to avoid visually overwhelming them.
- **Make Self-Care Comfortable and Fun:** Pay attention to things that interest your loved one, like specific colors, patterns, or fabric textures. More importantly, make it comfortable. Provide loose, stretchy options, and use easy buttons, Velcro, or anything elastic. Avoid pullover shirts and other garment styles that require more coordination.
- **Schedule Appointments:** Many seniors can't reach their feet and may develop painful overgrown nails or calluses. Thus, scheduling pedicures to maintain proper foot care is highly recommended. While not strictly a health concern, regular haircuts may help your loved one to feel confident. Hire a professional for in-home visits if possible, as going into a noisy shop agitates the senior too much.

## Loss of Inhibitions

Those with dementia may lose some inhibitions due to several factors. Seniors with frontotemporal dementia have a significantly decreased capacity to reason and decide whether something is appropriate. Even for those with other types of dementia, awareness of learned social norms fades, resulting in more impulsiveness. Dementia may also potentially increase sexual drive, but sometimes the opposite is true.

### Common Signs that Loss of Inhibitions Is Happening Include:

- Generally rude or discriminatory comments to or about others
- Using uncharacteristic explicit language or profanity
- Talking with strangers in a very trusting or open manner
- Sexual comments, undressing, or inappropriate touch to self or others

### How to Respond to A Loss of Inhibitions:

- **Taking the Situation into Account:** How you respond to a loss of inhibitions depends on the senior's action and how harmful it is to others or themselves. In the case of rude comments, you probably won't convince them to stop, so it's best to provide distractions. Later, explain to others that the senior doesn't understand how hurtful they were. Meanwhile, if your loved one is having a friendly conversation with a stranger, you don't have to intervene unless they give out too much personal information.
- **Dealing with Sexual Behaviors:** A loss of sexual inhibitions may be nothing more than an occasional off-color comment. In this case, it's best to steer the topic elsewhere, provide a distraction, and apologize to anyone offended later. However, if the behaviors are physically or verbally aggressive, it's best to supervise the senior, especially around children or anyone who might be offended. For caregivers dealing with inappropriate behaviors and unsure how to handle them, speak with a doctor or psychologist specializing in elder care. Speaking with a professional can help you formulate a better plan on how to respond in the future and keep everyone safe and happy.

# **Ten Tips For Communicating With A Person With Dementia**

## **1: Use Tone of Voice and Facial Expression to Convey Calmness**

Sometimes nonverbal cues are the most important ways for the patient to feel loved or reassured. Smile and look kind as you comfort your loved one when they get confused. You may even find that staying emotionally engaged and putting in the effort to present a loving demeanor leads to caring nonverbal responses from those who no longer speak much.

## **2: Laugh Together**

They say “laughter is the best medicine,” and research seems to back that claim regarding stress relief. Laughter has short- and long-term benefits for blood pressure, the immune system, and other parts of the body. Although being a caregiver is stressful, remember that suffering from cognitive decline is just as stressful, so be intentional about bringing gentle humor into both of your lives.

## **3: Use Reassuring Touch**

One powerful, healing way to reconnect with a loved one with dementia is through touch. According to UC Berkeley, touch is crucial to human health, so massage therapy can help reduce stress in Alzheimer’s patients. Massages, hand-holding, arm-touching or a gentle knee tap, can distract a person’s focus away from a stressful situation and toward connection. Of course, be mindful of your loved one’s personal, physical boundaries.

## **4: Provide Names and Relationships Cues**

Casually and frequently feeding information, such as people’s names and relationships, can help dementia patients. This can make them feel more comfortable and avoid embarrassment when you ask for such information. If the patient indicates that they don’t need the help, don’t offer it. During late-stage dementia, you will need to identify yourself before interacting. Most experts recommend approaching from the front to avoid startling a dementia patient. This helps put your loved one at ease.

## **5: Don’t Argue About Reality**

Your loved one will have an alternate version of reality as the disease progresses. Paranoia, time confusion, hallucinations, and problems keeping track of people and events will likely cloud their perceptions. They may forget they’ve already done or said something and feel offended if you contradict them. Feel free to explain your side, but providing a distraction is better than arguing about the facts. It’s implausible that you can eradicate a delusion since the nature of the disease will prevent the retention of new facts.

## **6: Keep Questions, Choices, and Instructions Simple**

Keeping dementia patients involved in their own lives preserves their dignity, promotes mental sharpness, and increases their sense of control. Making choices, expressing opinions, and preparing for their day can positively impact their mood. However, bringing in too many choices will have the opposite effect. For instance, presenting multiple options for clothing and meals will confuse and overwhelm many seniors with dementia. Also, complex instructions with too many steps will have a negative effect. Start with two options and one step at a time, provide visuals, or perform the activities alongside them so they can follow you.

## **7: Avoid Talking Down To or Over the Senior**

Don't assume your loved one doesn't understand when you're talking about or down to them. Never assume their level of understanding. Speak slower and clearer and make eye contact, but be careful with using patronizing language. Moreover, teach others that talking in a condescending manner will upset and embarrass the senior.

## **8: Look for an Underlying Cause**

Behavior is often just an expression of some kind of need or mood. However, dementia patients will often act or behave irrationally. Below is a list of potential triggers for difficult behavior in people with dementia:

### **Common Triggers For Difficult Behaviors:**

- Untreated pain or new health problems
- Feelings of isolation and boredom
- Feelings of overstimulation from noise, crowds, television, clutter, or other sources
- Fear of falling and feeling unsafe
- Tiredness
- Hallucinations
- Declining muscle strength, leading to frustration
- Hunger, thirst, or even malnutrition due to difficulty with eating
- Needing to use the restroom
- Medication side effects

These issues are resolvable and could reduce symptoms of problematic behaviors. However, remember that you cannot fully eliminate difficult behaviors, but monitoring these potential triggers will improve the senior's quality of life.

## **9: Encourage Your Loved One to Use Gestures**

If your loved one finds it difficult to talk, you can use gestures to communicate. For immobile patients, offer choices that they can reach and touch. Even if communication is challenging, your loved one will still appreciate the attention, interaction, and sense of control over daily choices.

### **10: Foster Connection Through Positive Sensory Experiences**

Positive sensory experiences may include listening to music, taking an art class, scrapbooking, singing, dancing, nature walks, etc. If you can participate in activities you both enjoy, you'll deepen your bond and make you both happier. Try a few different activities, and don't be discouraged if certain ones aren't a good fit.

## **10: Foster Connection Through Positive Sensory Experiences**

Positive sensory experiences may include listening to music, taking an art class, scrapbooking, singing, dancing, nature walks, etc. If you can participate in activities you both enjoy, you'll deepen your bond and make you both happier. Try a few different activities, and don't be discouraged if certain ones aren't a good fit.

## Dementia Resources

If you have more questions about dementia care, we've compiled a list of well-researched resources and websites below: If you still have questions about dementia care, consider looking at the collection of resources below. We've pulled together some of the most well-researched and user-friendly websites available so that you can view articles, videos, and more on the topic of dementia.

RESOURCE PAGE	SOURCE	TYPE OF RESOURCE	TOPIC
<a href="#">Caring for Yourself When Caring for Another</a>	Center for Disease Control	Article	Caregiving Help
<a href="#">How Alzheimer's Changes the Brain</a>	National Institute on Aging	Video	Understanding the Brain
<a href="#">Common Questions About Participating in Alzheimer's and Related Dementias Research</a>	National Institute on Aging	Article	Research and Clinical Trials
<a href="#">Dementia</a>	Medline Plus	Master List of Online Dementia Resources	Virtually All Dementia Topics
<a href="#">Dementia Care (including Alzheimer's Disease)</a>	U.S. Department of Veterans Affairs	Article & Resource Lists	Tips and Resources for Veterans with Dementia
<a href="#">Forgetfulness: Normal or Not?</a>	National Institute on Aging	Article & Infographic	Information for Distinguishing Between Typical and Atypical Forgetfulness