

Dementia Caregiver Tips



Caring for someone who has dementia.



Providing Compassion and Care with Dignity since 1982



One of the most important things to know when caring for someone with dementia is that they have a brain disease. Their brain is slowly shutting down or dying like any sick organ in the body does when it is diseased. The ability to reason logically is impaired in the person who has dementia. Trying to reason with them may make the situation worse. Their reality is not the same as the person who does not have dementia. The person with the “well” brain needs to join in the demented person’s reality.

Disclaimer: Early in the illness, a person may still have the ability to be reoriented. Everyone is different and progresses differently throughout the illness. There are certain similarities in dementia but everyone is unique in the progression of the disease and how they react.

Some behaviors are not able to be “managed” with the following interventions. Sometimes the person may need medications to help with the extreme behaviors or they may need temporary placement in a behavioral health unit for medication management.

For those who are still able to safely interact in a home setting, the following tips may help the caregiver more effectively communicate with and care for someone with dementia.

Verbal Communication

- Approach from the front so you don't startle them.
- Get the attention of the person if they are not looking at you.
- Get permission to enter their room or approach them.
- Make eye contact, wave (visual cue), smile and look friendly.
- Call them by their name if you know it or say "Hi" – pause then start to approach or let them come to you.
- Move slowly and be calm.
- Move toward the right side of the person (stay at arm's length) and offer your hand, but give them time to reach for it, don't force it.
- Match the other person's level (sit if they are sitting).
- Once conversation is started allow time for the message to be heard and processed.
- Speak slowly, calmly, with a friendly tone, in an adult fashion.
- Be patient and supportive; Offer comfort and reassurance.
- Don't interrupt, avoid criticizing or correcting.
- Repeat what you don't understand: Offer a suggestion if they are struggling to find a word.
- Emphasize key words: Stress the words in a sentence you most want to draw attention to, like "Here is your coffee."
- Ask one question at a time.
- Use words that relate to the person's age and experience, avoid slang.
- Use familiar objects or actions to give a focus for the interaction (example: animal pictures).
- Offer your thanks and appreciation for their time or efforts.
- Use gestures, when appropriate, to help convey what you want done.
- Use memory aids or written information as needed (example: white board, bulletin boards).
- Limit distractions in the environment when communicating.
- Use touch when appropriate.
- Keep talking, even when a person may no longer be verbal.



- Never argue with them, instead validate their feelings - e.g., I see that you are (sad, upset, etc). Be genuine.
- Turn negatives into positives. For example say, “Let’s go here” instead of “Don’t go there”.
- Don’t say “remember”.

Tips To Keep In Mind

- Respect the fact that the person is an adult and treat them as such. Talk directly to the person, not to their caregiver or family member.
- Be aware of changes in senses (hearing, sight, touch). These changes impact how you communicate with that person.
- Allow the person to have a purpose. It is important to let people with dementia do as much for themselves as they can. Everyone needs a purpose for their day, no matter how big or small it is.
- Emphasize the “we” of activities. Let them know verbally that you are there, they are not alone and that everything will be all right. Do this constantly because it will lessen their fear of abandonment.
- Acknowledge requests and respond to them.
- Explain. Tell them what you are going to do before you do it, particularly if you are going to touch them. They need to know what is coming first so they don’t think that you are grabbing them.
- Give simple choices: too many choices can be overwhelming.

- Reassure. Let them know that you care about them. We all need to know that we matter and people care about us.
- Redirect attention and actions to something that is acceptable only after trying to understand what they want or need.
- Use humor whenever possible, though not at the individual's expense.
- Redirect attention and actions to something that is acceptable only after trying to understand what they want or need.
- Distract with activities you know they like and value. Be careful when using distraction with a person in an early stage of dementia because it can seem like you are discounting their feelings or needs.
- Body language: When it gets to the point where words and meaning of words start making less and less sense to them, use body language and/or draw pictures.
- We have to adapt. Because learning and retaining new information declines as the disease progresses, we have to focus on adapting the environment rather than re-teaching.
- In the early stages of the disease, gently offer 'orienting' information respecting what the person has said – NOT arguing reality.
- In the middle or later stages of the disease, figure out the meaning of confusing behaviors or words: repeat some of their words with a questioning tone to get started.
- If the individual repeatedly asks a question, keep in mind that he or she cannot remember the response that you have just given. Instead of answering the question after a second or third repetition, reassure the individual in the same way – everything is fine, you will be with him or her, you will help. Don't discount that they have something to say but reassure you are there.

*This is a brain disease.
You have the healthy brain.*

Aggression

Aggressive behaviors may be verbal (shouting, name calling) or physical (hitting, pushing). These behaviors can occur suddenly without an apparent reason, or result from a frustrating situation. Do not try to reason with the person. Try to identify the immediate cause. What happened right before the reaction? Did something trigger the behavior? Look for trigger patterns. Keep in mind you may not always be able to identify the reason.

- Focus on the feelings, not the facts. Try not to concentrate on specific details but consider the person's emotions and reassure them at all times. Validate their feelings and reassure them.
- Getting angry and upset will make the situation worse. Try to stay calm, be positive, reassuring, speak slowly with a soft tone, move slowly and use a gentle touch when appropriate.
- Try not to interpret anger from the person with dementia in the same way you would if it came from a well person. Anger from a confused person is often exaggerated or misdirected.
- Limit distractions in the environment if necessary.
- Is something in the environment a trigger?
- Try distracting the person by engaging them in an activity if possible but only after validating their feelings. Try different activities. Remove them from the stressful situation or place if needed.
- Try a relaxing activity like music, massage, or exercise to help soothe the person.
- Try to establish daily routines and schedule stressful activities when the person is most rested.
- Explain to those present that the person has an illness that causes the behaviors.
- If distraction and support do not work, try to ignore the angry behavior if the situation is safe. If the situation is threatening, try to make sure they are unlikely to harm themselves or others and stay clear but close until they calm down.

Verbal Outbursts

The person may forget social skills or respond on impulse especially when they are upset or agitated. Remember the person is not deliberately trying to upset you, but is affected by a disease that has compromised their behavior and impulse control. Verbal outbursts such as cursing, arguing and threats are expressions of anger, stress or even fear.

- React by staying calm and reassuring.
- Always validate their feelings.

Anxious or Agitated Feelings



Agitation and anxiety refers to a range of behaviors associated with dementia, including irritability, pacing, and verbal or physical aggression. Agitation may be triggered by a variety of things including environmental factors, fears, feelings of loss, tension and fatigue. Sometimes, anxiety and nervousness may be caused by changes in the brain.

Often, agitation is triggered when a person has “control” taken away from them. It could also be a sign of depression, boredom, pain and/or caused by medications or an unexplained part of the illness. Confronting a confused person may increase anxiety. A person with dementia may feel anxious or agitated at times. They may become restless and need to move around or pace.

They may become upset in certain places or focus obsessively on some thing or event. They may be attached to the caregiver and need constant attention or direction and become anxious if the caregiver is not available to them.

- Listen to their frustration and try to find out what may be triggering the anxiety and try to understand where they are coming from.
- Reassure them by staying calm, let them know you are there for them and that they are safe.
- Try involving or distracting them with activities like music, art, exercise, a car ride, or looking at a photo album. The person may need an outlet for their energy.
- Modify the environment if it is causing them anxiety. Try to decrease noise and distraction or move to another place.
- Reduce caffeine, sugar and junk food.
- Maintain structure by keeping routines. Keep household objects and furniture in the same places. Familiar objects and photographs offer a sense of security and can suggest pleasant memories.
- Keep dangerous objects out of reach.
- Allow the person to keep as much control as possible. Support their independence by allowing them to do as much for themselves as they can.

Suspicious Thoughts/Paranoia

Due to memory loss, confusion and loss of reality, the person with dementia may see things differently. They may become suspicious of those around them and accuse them of theft, infidelity, or other improper behavior. At times, they may also misinterpret what they see and hear. Remember, what the person is experiencing is very real to them. This is part of the dementia; try not to take it personally.

- Listen to what's troubling them and try to understand their reality, then be reassuring and let them know you care even if it does not make sense to you.

- Don't argue. Allow the person to express their opinions. Agree with their assumptions and acknowledge their thoughts. Arguing with them will make the situation worse. Offer a simple answer. Share your thoughts, but don't overwhelm them with lengthy explanations or reasons.
- Redirect their attention to another activity. Try to engage them in an activity or ask them to help with a chore.
- Duplicate items that are frequently lost. If they are looking for a specific item, have several available.
- Try to learn where the confused person's favorite hiding places are for storing objects.
- Try nonverbal reassurances. Respond to the feeling behind the accusation and then reassure the person, "I see this is upsetting to you, stay with me, I won't let anything happen to you."



Complaints and Insults

It helps to understand that the person may not always be tactful due to brain deterioration.

- Don't take it personally.
- Distract or redirect, but don't discount their feelings.
- It is pointless to argue, reason or contradict them.
- Ignore the complaints.
- Having to be cared for, feeling lost, losing possessions and loss of independence may seem to the confused person like cruel experiences. "You are cruel to me" may really mean "life is unfair".

Uncooperative and Resistant



People with dementia may become uncooperative and resistant to daily activities such as bathing, dressing and eating. Often this is a response to feeling out of control, rushed, afraid, or confused by what you are asking of them.

- Break each task into steps and in a reassuring voice, explain each step before you do it. Allow plenty of time.
- Find ways to have them assist to their ability in the process, or follow with an activity they can perform.

Demanding

Sometimes people with dementia can be demanding and appear to be self centered. This is especially hard to accept when the person does not appear to be significantly impaired.

- Step back and objectively evaluate the situation. Is the behavior part of the disease? If so, then it is not something they can control.

- Manipulative behavior requires the ability to use executive functioning skills, which the person with dementia is losing. It is probably the disease causing the behavior, rather than the person being purposefully manipulative.
- Some demanding behavior may reflect the impaired person's feelings of loneliness, fright, or loss.
- Remember they cannot control their behavior and have limited ability to learn anything new.

Sexually Inappropriate Behavior

Sexually inappropriate behavior, such as masturbating, undressing in public, lewd remarks, unreasonable sexual demands, sexually aggressive or violent behavior may occur during the course of the illness. This behavior is caused by the disease. Talk to the doctor about possible treatment plans. Develop an action plan to follow before the behavior occurs and how to respond. Try to identify what triggers the behavior.

- Respond calmly and firmly and do not overreact.
- They may undo their clothes or lift up a skirt because they need to use the toilet and have forgotten where the bathroom is. They may undress because they want to go to bed or a garment is uncomfortable. Urinary tract infections, itching, or discomfort may lead to handling of the genital area.
- Changing clothing type may help someone who undresses often.
- Masturbation and similar actions may be upsetting to families. Remember that this behavior is part of the brain deterioration. The person is only doing what feels good. They have forgotten their social manners. Gently lead the person to a private place, or distract them with another activity.

Hiding/Hoarding

A person may hoard food due to growing up poor and/or not having basic needs met. It may also be due to needing a sense of control in their lives. They may have had to give up their home and/or possessions and feel the need to protect things by hiding them.

- Limit the number of hiding places by locking drawers, cabinets, closets or extra rooms.
- Carefully check clothes baskets, hampers and trash cans before emptying.
- Lock up valuables when possible.
- Do not scold or accuse the person of hiding things. Do not try to reason with them. Instead, reassure them and help look for lost items. This may help you may become familiar with favorite hiding places.
- When possible, keep spares of frequently misplaced items, like glasses or keys.
- Try distracting or redirecting when possible.
- Do not become defensive if the person accuses you of taking things. This is a normal reaction to gaps in memory and increasing confusion. Try to remember that the person is not being purposely malicious.
- Buy them a special “safe” box to keep possessions in. This might make it easier to find missing items.



Shadowing

Shadowing is when a person with dementia imitates and/or follows the caregiver, or constantly talks, asks questions and interrupts. Like sundowning, this behavior often occurs late in the day and can be irritating for the caregivers. The behavior can be understood when we consider how strange the world must seem to a person who constantly forgets. The trusted caregiver becomes the only security in a world of confusion. When people cannot depend on themselves to remember the necessary things in life, one form of security is to stay close to someone who does know. For example, they cannot remember that when you go into the bathroom you will come back.

- Comfort the person with verbal and physical reassurance.
- Distraction or redirection might also help. Giving them a job such as folding laundry might help to make them feel needed and useful. It is still important for them to have a purpose.
- Set a timer and tell them “I will be back when the timer goes off.”

Recognition Difficulties

At times, the person with dementia may not recognize familiar people, places, or things. They may forget relationships, call family members by other names and become confused about where they live. They may also forget the purpose of common items such as a pen or a fork. These situations are extremely difficult for caregivers and require patience and understanding.

- Stay calm. Although being called by the wrong name or not being recognized is painful, try not to show you are hurt.
- Keep answers brief. Don't overwhelm the person with long statements and reasons. Instead, clarify with a simple explanation.
- Use photographs and other items to remind the person of important relationships and places.

Repetitive Actions

A person with dementia may repeat words or actions. In most cases, they may be looking for comfort, security and familiarity. It is usually harmless for the person, but can be stressful for the caregiver. It may be triggered by anxiety, boredom, fear or environmental factors. Dementia can cause the brain to become stuck on one activity and have difficulty shifting gears to a new activity.

- Look for a reason behind the repetition. Try to find out if there is a specific cause or trigger for the behavior and eliminate it.
- Respond to the emotions, not the behavior. Rather than focusing on what they are doing, think about how they are feeling. Reassure the person that everything is fine and that you will take care of things.
- Turn the action or behavior into an activity if possible.
- Stay calm and be patient. Reassure them with a calm voice and gentle touch.
- Answer even if you have to repeat yourself several times.
- Engage in an activity (redirect). They may be bored and need something to do.
- Use memory aids. If they ask the same questions repeatedly, remind the person with notes, clocks, calendars, white board, photographs, or a simple written message for those who can still read.
- Sometimes touch is a very good way to get messages to the brain and may stop the behavior.
- Consult a physician, as repetitive actions may be a side effect of medication.
- Don't discuss plans for activities or appointments until just prior to the event. This will help keep the person from asking about it days ahead of time.

Hallucinations/Delusions

Hallucinations (seeing or hearing things that others do not) and delusions (false beliefs, such as someone is trying to hurt or kill them) may occur as the dementia progresses. This is due to the deterioration in the brain. Sometimes delusions appear to come from misinterpreting reality. They can also be tied to past experiences. But remember, not all odd things people say are delusions.

- Remember that it is very real to the person experiencing it.
- State simply and calmly your perception and the situation, but avoid arguing or trying to convince the person their perceptions are wrong.
- Keep rooms well lit to decrease shadows. Reduce clutter, extraneous noises, or confusing aspects in the environment.
- Always reassure the person they are safe and you're there for them.

Wandering



People with dementia walk aimlessly for a variety of reasons, such as boredom, medication side effects,

anxiety, or to look for something or someone. They may be trying to fulfill a physical need like thirst or hunger. Discovering the triggers for wandering is not always easy.

- Make time for regular exercise. They may need to burn energy.
- Install locks that require a key. Position locks high or low on the door, keeping in mind fire and safety concerns for all persons.
- Try a barrier like a curtain or colored streamer to mask the door.
- Place a black mat or paint a black space on your front porch; this may appear to be an impassable hole to them.
- Add child safe plastic covers to doorknobs.

- Put away essential items such as the person's coat, purse or glasses. Some individuals will not leave without certain articles.
- Have them wear an identification bracelet and sew identification labels in their clothes. Always have a current photo available.
- Register with the local police department "Walk-away Program" or the Alzheimer's Association Safe Return program.
- Tell neighbors about the person's wandering behavior and give them your phone number.

Sundowning

Restlessness, agitation, disorientation and other troubling behaviors in people with dementia often become worse at the end of the day and sometimes continue through the night. Experts believe this behavior, commonly called sundowning, is caused by a combination of factors, such as exhaustion from the day's events, changes in the person's biological clock that confuse day and night, or a change in routine or environment.

- Plan for the afternoon and evening to be quiet and calm. Take a stroll outdoors, play a simple card game or listen to soothing music together. Try a warm bath/shower, warm milk/tea and comfortable blankets and pillows.
- Schedule more involved activities for earlier in the day.
- Turning on lights well before sunset and closing the curtains at dusk will minimize shadows and may help diminish confusion. At minimum, keep a nightlight in the person's room, hallway and bathroom.
- Make sure the house is safe by locking doors and cabinets, and putting away dangerous items.
- Secure all guns or remove them from the home.
- Be sure the person is getting adequate rest or "down time" during the day. Fatigue will increase the likelihood of late afternoon restlessness.

Sleeplessness

- Increase daytime activities and physical exercise. Discourage napping if possible.
- Avoid foods that may cause sleeplessness like sugar, caffeine and junk food. Plan smaller meals throughout the day and include a light meal before bedtime.
- Consider talking to their physician about medication to help sleeplessness. Be aware that sleeping pills and tranquilizers may solve one problem and create another, such as sleeping at night but being more confused the next day.
- If they become restless at night, reassure and coax them back to bed when possible. If restlessness continues, try putting them in a comfortable chair with the radio or television on softly. Some find a recliner more secure for sleep than a bed.

Fear

Fear is often the underlying feeling behind many challenging behaviors. When a person does not understand what is happening to them and they are dealing with many losses, it can cause fear.

- Reassure them, face them using eye contact, gentle touch or a hug and talk in a calm and soothing voice.
- Try to determine what the trigger might have been. Almost anything in the environment can be misconstrued as threatening.
- Try to avoid loud or confusing noises. Sometimes television shows can scare people who cannot separate them from real life.
- Let the person know that you will be there to protect and look after him.
- Some people with dementia find it reassuring to have a stuffed animal, baby doll or a security object.

Eating/Nutrition



Ensuring your loved one is eating enough nutritious foods and drinking enough fluids is a challenge. People with dementia literally begin to forget that they need to eat and drink. Complicating the issue may be dental problems or medications that decrease appetite or make food taste funny. The consequences of poor nutrition are many, including weight loss, irritability, sleeplessness, bladder or bowel problems and disorientation. Remember, weight loss can be a normal part of advanced dementia and not the sign of poor caregiving.

- Make meals and snacktime part of the daily routine. Try five or six smaller meals in place of three larger ones.
- Make mealtimes a special time. Play soft music and turn off loud radio or television programs.
- Eating independently should take precedence over eating neatly or with proper table manners. Finger foods support independence. Precut and season the food. Try using a straw or a sippy cup. Provide assistance only when necessary and allow plenty of time for meals.
- Sit down and eat with them. They will often mimic actions.
- Prepare meals they can eat. Use soft foods or cut food into bite-size pieces.
- Offer nutritious high-calorie snacks between meals if weight loss is a problem. If the problem is weight gain, keep high-calorie foods out of sight.

- Consider avoiding patterned placemats, plates and tablecloths.
- Serve only one food at a time. Set the table with only the utensils that are necessary.
- For some, bowls work better than plates.
- Watch chewing and swallowing carefully. Storing food in the mouth and swallowing difficulties can lead to choking.

Incontinence

The loss of bladder or bowel control often occurs as dementia progresses. Accidents may result from environmental factors. For example: someone can't remember where the bathroom is and/or can't get to it in time. If an accident occurs, be understanding and reassure the person. Always try to maintain their dignity and minimize embarrassment.

- Establish a routine. Remind them every two hours to use the bathroom.
- Schedule fluid intake to ensure that the person does not become dehydrated.
- Avoid drinks with a diuretic effect like coffee, tea, soda, or beer.
- Use signs with illustrations to indicate which door leads to the bathroom.
- A commode can be left in the bedroom at night.
- Use incontinence pads (washable or disposable).
- Use easy-to-remove clothing with elastic waistbands or Velcro closures, and provide clothes that are easily washable.
- If necessary, remove wastebaskets, flower pots and/or hampers from visible areas.
- Watch for nonverbal cues like restlessness, pacing or undressing.

Bathing

People with dementia often have difficulty remembering good hygiene, such as brushing teeth, toileting, bathing and regularly changing clothes. Being undressed and cleaned by another can feel frightening, humiliating and embarrassing. As a result, bathing often causes distress for both caregiver and the person with dementia.

- Try to follow as many of the person's old routines as possible. Do they prefer baths or showers? Mornings or nights? Do they use special products such as lotion, powder or sprays? Adopting as much as possible of their bathing routine may provide some comfort.
- It is not usually necessary to bathe every day – sometimes every other day or twice a week is sufficient.
- Allow as much independence as possible and respect the person's privacy and dignity.
- Be mindful of room and water temperature. Older adults are more sensitive to hot and cold. Pour a cup of water over their hands before they step in.
- Sometimes people with dementia become afraid of the water because they don't understand the feel or sound of the water, or what it looks like coming out of the shower head.
- Use safety features such as non skid bath mats, grab bars and bath/shower seats. A handheld shower head is helpful. Help people feel secure in the shower or tub, as falling is a common fear.
- Try to be as calm and gentle as possible. Try not to rush or force the person through the task and talk them through the process if needed.
- Never leave them alone.
- If hair washing is a struggle, make it a separate activity or use dry shampoo.
- If bathing in the tub or shower is consistently traumatic, a sponge bath may be a soothing alternative.

Dressing

Dressing becomes difficult for most dementia patients as the illness progresses. Choose loose-fitting comfortable clothes with easy zippers, snaps, elastic waistbands and minimal buttons. Reduce choices by removing seldom-worn clothes from the closet. To facilitate dressing and support independence, lay out one article of clothing at a time in the order it is to be worn. Remove soiled clothes from the room. Don't argue if the person insists on wearing the same thing.



Recap

Do:

1. Accept the behavior as a reality of the disease.
2. Be prepared for unexpected emotional shifts and outbursts.
3. Join their world or the past with them.
4. Be flexible and go with the flow.
5. Maintain structure and routines.
6. Be aware of your feelings and attitudes.
7. Get support. ASK FOR HELP.
8. Learn to let go. If the person is not doing anything to harm themselves or others, let them continue what they are doing.
9. Since learning and retaining new information declines, focus on adaptation of the environment rather than reteaching. Adapt yourself and the environment.
10. Focus on what you can control. Try to accommodate the behavior, not control it. You can change **your** behavior or sometimes the environment.
11. Learn to recognize triggers and signs of impending inappropriate behavior.
12. Be prepared to have the same conversation over and over.
13. Keep in mind, the person is doing the best they can.
14. Embrace change. The person with dementia can't change; therefore, you must change or change the environment.
15. Realize that not only do people with dementia have more difficulty expressing thoughts and emotions; they also have more trouble understanding others.
16. Always assume they can understand you.

Don't:

1. Reason, rationalize or expect logic to work.
2. Confront, argue, criticize, correct, patronize.
3. Underestimate OR overestimate what they can do.
4. **Take it personally.**

Resources

Books:

The 36-Hour Day, Nancy Mace & Peter Rabins

Dementia Caregiver Guide, Teepa Snow

Understanding Alzheimer's The Guide for Families and Professionals, Tam Cummings

Websites:

The Alzheimer's Association www.alz.org

Alzheimer's Foundation of America www.alzfdn.org

Caregiver Action Network www.caregiveraction.org

Teepa Snow www.teepasnow.com

Today's Caregiver Magazine www.caregiver.com

Caregiver Hotlines:

Caregiver Action Network 855-227-3640

Alzheimer's Association 800-272-3900

Alzheimer's Foundation of America 866-232-8484

Dementia Care/Evaluations:

Cleveland Clinic Lou Ruvo Las Vegas
www.clevelandclinic.org 702-483-6000

Banner Alzheimer's Institute bannerhealth.com
602-839-6900

Mayo Clinic 800-446-2279

Barrow Neurological Institute barrowneuro.org



Hospice of Havasu's Transitions Program is here to help those living with serious illnesses. The Transitions Program is offered at no charge, thanks to generous Hospice of Havasu donors.

Transitions can help if any of the following are present:

- Multiple serious medical conditions
- Increased ER visits or hospitalizations
- Unexpected weight loss
- Physical decline
- Frequent calls to primary care provider
- Missed medical appointments
- Recurring infections
- Transportation needs



The Transitions Team offers:

- Consultations with family/caregivers about “goals of care”
- Education about Home Health vs. Hospice care
- Caregiving options
- Caregiver and emotional support
- Long Term Care planning
- Referrals to local resources
- Health Care Powers of Attorney
- Communication with your healthcare provider
- Dementia Education

Call the Transitions Team at 928-453-2111.

**Lake Havasu City | Fort Mohave/Bullhead City
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