Guiding an Improved Dementia Experience (GUIDE)

EDUCATION AND SUPPORT RESOURCES

2

Common dementia behaviors

Strategies to make a difference

BAPTIST HEALTH

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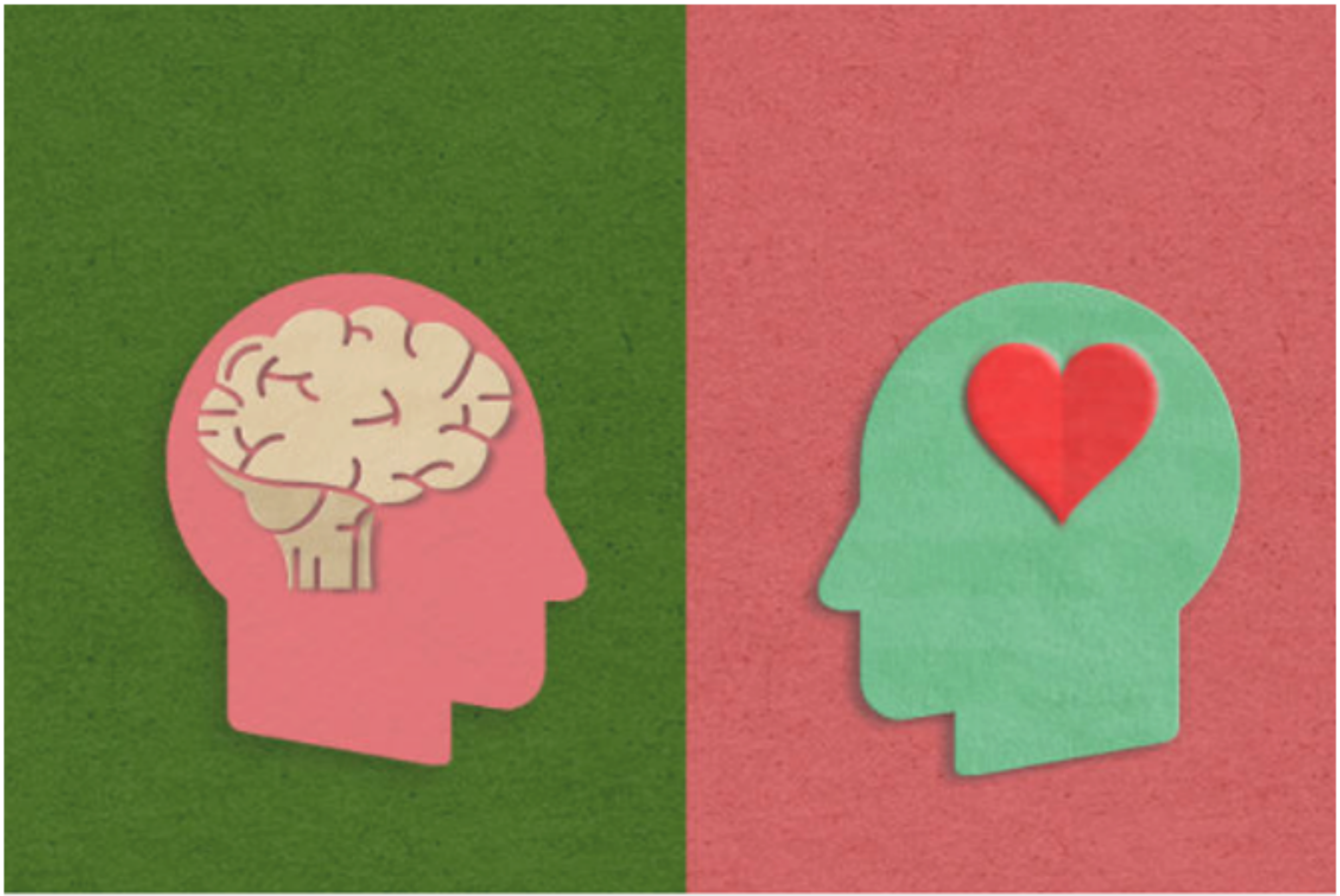


Common Dementia Behaviors

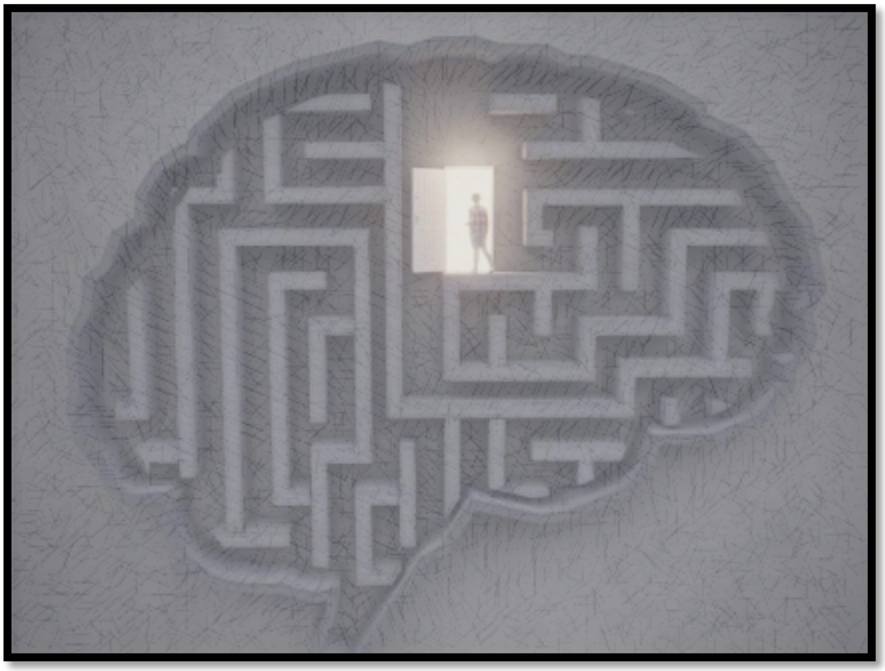
Dementia is a brain disease that can cause changes in personality, behavior and memory. Your loved one sees the world in a different way now. Your loved one does not intend to make things more difficult for you.

Dementia may also affect your loved one's ability to communicate. Your loved one's outbursts may be the only way to express needs or frustrations.

Even without a clear trigger, there may be great days and there may be bad days. Sometimes, the hardest part is not knowing what day (or night) you are going to get. But there are some common symptoms and skills you can learn to make the bad days better and help you reclaim a sense of control.

In the most difficult moments, remember that the changes of dementia are due to the disease and not the person with the disease. Sometimes, this reminder can help you from personalizing or internalizing your understandable anger, frustration and sadness.

Changes in personality and behaviors



Changes in the brain may cause changes in personality and behavior. They may cause anxiety and insecurity. Some types of changes in the brain cause confusion, hallucinations, delusions, paranoia, repetitive behavior and sundowning. Memory loss and changes in the ability to communicate magnify these conditions. These changes may occur at any stage but are more common in later stages. They may also be caused by other problems.

Rule out other possible causes of personality change or behaviors

- Sensory loss: hearing and vision, infections (especially urinary tract infections), medication side effects, lack of sleep, pain, poor nutrition, alcohol or drug withdrawal.
- Feelings of anxiety, fear, insecurity, stress, boredom, depression, social isolation, restlessness and loneliness.

Recognize changes in personality or behaviors caused by dementia

- Changes in the ability to focus
- Changes in the ability to communicate
- Changes in memory

- Fear of abandonment by caregiver
- Inability to unwind at the end of the day
- Anxiety with too many activities, sudden changes in routine or surroundings

Below are common symptoms of changes in behavior and personality

- Gets disoriented about the current place and time (day, year, season . . .)
- Repeats the same question, word or action
- Forgets recent actions, activities and events
- Becomes restless, agitated or confused more often in late afternoon and sometimes continuing through the night
- Unable to separate fact from fiction
- Hears frightening voices or noises, sees things or people that are not there
- Believes someone is "out to get me" or possesses superhuman power
- Feel the need to go somewhere to meet someone (or get away from someone)
- Feels anxious if the caregiver is not within the line of sight at all time
- Has trouble recognizing everyday items and what they are used for
- Has trouble recognizing surrounding surroundings that used to be familiar
- Looks for long deceased family members or friends
- Has trouble recognizing family members and friends
- No longer recognizes self in the mirror; may perceive the reflection as an intruder

Strategies to make a difference

Plan Ahead: **Identify prompting events or stressors**. Change what you can in terms of using signs for doors and items, keep vision and hearing assessments up to date (as long as you are able), de-clutter, work with your healthcare team to minimize medication side effects, cover mirrors if needed, address the environment to minimize noise and shadow and minimize changes to routines as much as possible.

Keep it simple. **Finding prompting events or stressors can be tough.** Try to think of what your loved one is attempting to say or is feeling, not what is actually said. Look for clues. Look at it from their perspective.

Example: Aunt Lani says bugs are running up and down her legs. You check her legs but do not see any bugs. Imagine tiny bugs running up people's legs. What would they look like? What would they feel like? Has she been sitting for a long time? Maybe she does not remember the word "numb" and can only describe what she feels. Tell her you will try to get rid of the bugs. Massage her legs. Refocus her attention on something else.

Respect your loved one. Your loved one may feel helpless about losing control over his or her life. Give back some of that control. Whenever a decision is needed, allow them to participate even if the role seems small. Give your loved one choice but limit the choice to two. Focus on finding the trigger and solving the problem.

Example: Aunt Lani often accuses you of stealing items, which are later found right where she left them. She no longer understands that memory loss – not you or anyone else – is the culprit. She firmly believes what makes the most sense to her: if she cannot find the item, someone has stolen it. Help her look for it. If you find it, don't scold her – she will not understand – simply say, "I found it".

Keep in mind your loved one's lifelong routines. They may take comfort and security in familiar things. Keep to their lifelong routines as much as possible even though current life is different. In the long run, it may save time and frustration.

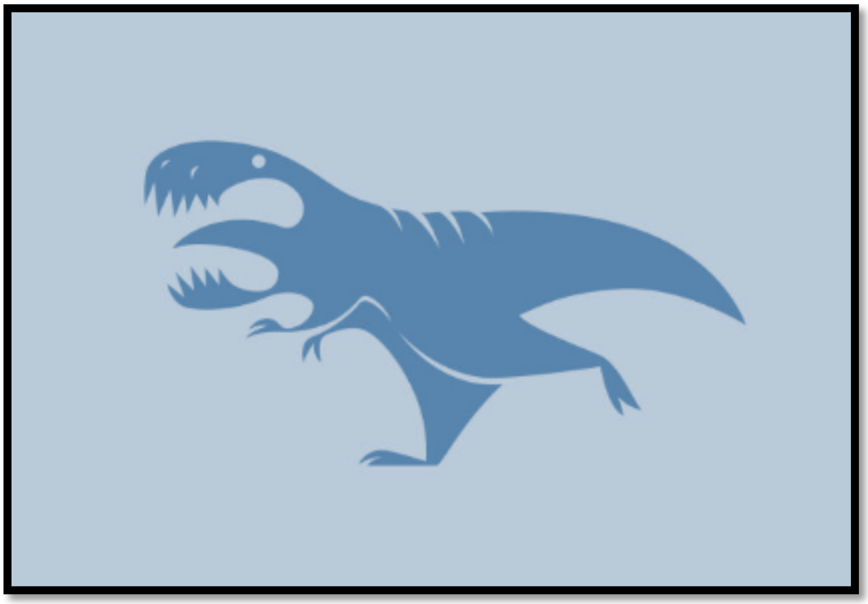
Example: At 5PM every day, Aunt Lani says she wants to go home. She may be remembering her lifelong "end of the workday" routine. Go along with it. Go through the motions of wrapping up the day's work. If able, take her for a ride around the block. Talk about the work she used to do. Come back inside and say, "We're home!". Refocus her attention on something else when you return inside.

Pick your battles. Drop the issue if no one is physically harmed by what he or she says. Decide how important it is that he or she lives in the current time. If it is important, hang a wall calendar that includes the day of the week and the year. Write something on the calendar that will help with orientation. Example: First day of spring – pick plumerias. If your loved one seems happier being in his or her time, join in.

Example: Aunt Lani keeps rummaging through all the closets in the house. You ask her what she is looking for. She replies, “My prom dress. I want to look nice when Aaron picks me up tonight.” Go along with it. Throw a pretend party for her if you can.

Think outside the box. Be creative. The answers do not have to be verbal or come from you directly. If your loved one often asks the time, put a clock where it can be easily seen. The next time they ask, point to the clock**. Tip:** Get a talking clock. Show which button to push if he or she wants to know the time. If they ask anyway, push the button yourself.

Anxiety and Agitation



A person with dementia may feel anxious or agitated. He or she may become restless, causing a need to move around or pace, or become upset in certain places or when focused on specific details.

Possible causes of agitation

Anxiety and agitation may be caused by a medical conditions, medication interactions or by **any** circumstance that worsens your loved one's person's ability to process information. Your loved one is – biologically – losing their ability to understand and process new information and stimulation. It is a direct result of the disease.

Situations that may lead to agitation include:

- Moving to a new home
- Changes in environment, such as travel, hospitalization or having houseguests
- Changes in caregiver arrangements
- Misperceived threats
- Fear and fatigue resulting from trying to make sense out of a confusing world

Strategies to Make a Difference

Do: Back off and ask permission; use calm, positive statements; reassure; slow down; add light; offer guided choices between two options; focus on pleasant events; offer simple exercise options, try to limit stimulation.

Listen to the frustration. Find out what may be causing the agitation, and try to understand.

Provide reassurance. Say: May I help you? Everything is under control. Use calming phrases such as: "You're safe here;" "I'm sorry that you are upset;" **“**I know it's hard;” and "I will stay until you feel better."

Check yourself. Do not raise your voice, show alarm or offense, or corner, crowd, restrain, criticize, ignore or argue with the person. Take care not to make sudden movements out of the person's view.

Strategies for preventing anxiety or agitation from escalating into aggression

Take Note: Pushing or shoving

- Does you loved one feel threatened by a recent change in surroundings?
- Do they feel threatened due to new/worsening hearing or vision loss?
- Are there too many people in the room? A recent change in people?
- Is there too much noise in the room or house?
- Does your loved one feel embarrassed because you or someone else is helping him or her in the bathroom?

Bounces or wiggles in the seat

- Is your loved one trying to get up?
- In need of the bathroom? Are they constipated? Or have a full bladder?
- Thirsty or hungry? In pain?
- Could this be a side effect of a medication?
- Are they frightened or upset by something?
- Are they drinking coffee or sodas with a lot of caffeine?

Fidgets with clothes

- Does your loved one need to use the bathroom?
- Feel too hot or cold? Feel itchy?

Paces around the house, opens and closes doors repeatedly.

- Are they looking for a bathroom?
- Looking for food or drink?
- Provide an opportunity for exercise. Go for a walk. Garden together. Put on music and dance.

Rummages or hoards items

- Is your loved on bored and looking for things to do?
- Confused by a recent change in surroundings?

Babbles or chatters loudly

- Are there too many people in the room or house?
- Is there too much noise in the room or house?

Shakes head repeatedly or rubs ears.

- Is your loved one confused about what they have been asked to do?
- Frightened by too much noise?
- Having ear problems?

Examples of triggers and solutions

Trigger: Physical discomfort
Solution: "What would make you feel more comfortable?" Offer a couple of solutions: "The doctor said you throat probably hurts a lot. Do you want a cup of tea or a fruit popsicle?" Gently massage hands or feet with scented cream or lotion. If possible, go for a walk outside. Try timed toileting to avoid the pain of a full bladder.

Trigger: A sudden change in surroundings that makes them seem lost/confused
Solution: Gently reassure that you are here to help.

Trigger: Even the quietest visitors may agitate your loved one.
Solution: Invite only 1-2 visitors at a time. If you cannot limit the number, be ready to take your loved one to a quiet room or outside.

Trigger: Something in the room is upsetting your loved one.
Solution: A common cause of stress is the television. You do not need to remove the TV. Just avoid certain programs – possibly those with physical violence, scenes of people falling, shouting at each other, close ups of flames . . .

Trigger: Your loved one will be visiting or moving to a new place
Solution: Show photos or videos of the new space. Talk about it every day for a few weeks. Pack a few familiar items that you can pull out right away: a favorite book, music, picture, game or blanket.

Trigger: Will a new person interact with your loved one a lot?
Solution: Introduce the person gradually. Try to arrange for the two to meet 15-20 minutes initially. Be present for that meeting. Explain that new person is helping you.

Trigger: Your loved one's loss of memory, judgement, independence or privacy.
Solution: Adjust your expectations. Is your loved one struggling with a particular task? Modify it so that it will be easier. Or take a break. Then, look for ways for you loved one to continue being helpful. Keep each task to 10-15 minutes. Make sure they take breaks. Consider a kitchen timer and say, "When you hear the timer beep it's break time!"
Trigger: A problem in communication, perception or understanding.
Solution: Your loved one may no longer understand or can no longer do what you have asked. Repeat yourself. Adjust your expectations. Adjust the tone of your voice. If necessary speak louder but keep the tone calm and soothing.

Solution: Communicate differently. Try using art, music or other activities to help engage the person and divert attention away from the anxiety. Use fidget blankets or Snoezelen carts.

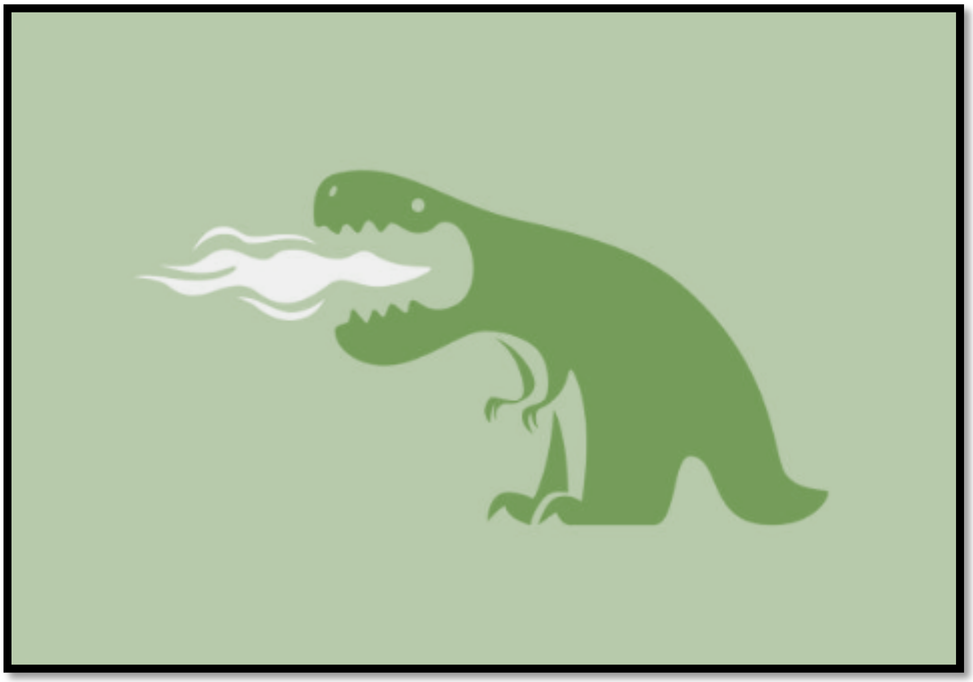
Treating Behavioral Symptoms

Sometimes, behavioral symptoms are related to an infection or change in health. Your loved one should receive a thorough medical checkup, especially when symptoms appear suddenly. Treatment depends on a careful diagnosis, determining possible causes and the types of behavior the person is experiencing.

Medications for agitation

Atypical antipsychotics are a group of medications that target certain chemicals in the brain, including serotonin and dopamine. They carry benefits and risks. All have side effects. The FDA requires that all atypical antipsychotics carry a safety warning that use is associated with an increased risk of death in older patients with dementia-related psychosis.

Aggression



Aggressive behaviors may be verbal or physical. They can occur suddenly, for no apparent reason, or result from a frustrating situation. While aggression can be hard to cope with, understanding that the person with dementia is not acting this way on purpose can help.

Due to their loss of cognitive function, they are unable to articulate or identify the cause of physical discomfort and, therefore, may express it through physical aggression.

Causes
Aggression can be caused by many factors including physical discomfort, environmental factors and poor communication. If a person with dementia is aggressive, consider what might be contributing to the change in behavior.

Rule out other possible causes

Physical discomfort: Pain, illness, disturbances of sleep, tiredness, hunger, thirst, effects of alcohol side effects of medication, temperature inside the home, outdoor temperature, vision or hearing impairment and other.

Sudden changes in routine, surroundings or people: loud noises, too many people, too many activities or tasks, unfamiliar surroundings, changes in lighting, troubling images on television, no longer recognizing themselves in the mirror and perceiving an intruder in the house and other.

Recognizing aggression

Common Symptoms

- Bites, hits, kicks, pinches, punches, pulling hair.
- Shouts, screams, shrieks, yells.
- Insults, swears, threatens.
- Injures self, destroys property.

Strategies to Make a Difference

Plan ahead

You may be able to prevent the outburst. Watch for symptoms of agitation: fidgeting, speaking loudly, resisting help. If needs or wants are not met, your loved one's behaviors may escalate to aggression.

Identify potential triggers of aggression

- Think of situations when your loved one became agitated or aggressive.
- What happened right before this behavior occurred? Could it be a trigger?
- How could you prevent this next time?
- Do they feel lost?
- Are your instructions simple and easy to understand?
- Are you asking too many questions or making too many statements at once?
- Is the person picking up on your own stress or irritability?
- Consider the time of day when making appointments or scheduling activities. Choosing a time when you know the person is less alert or best able to process new information or surroundings may be a trigger.

Keep in mind your loved one's lifelong routines

They may find comfort and security in familiar things and routines. Keep to the same routines as much as possible (meals, bath time, bedtime and other) to reduce the risk of aggression.

Pick Your Battles
Let it go of no one is physically harmed. Support your loved one even if your realities are different. Contradicting or criticizing may worsen the situation. Refer to the Best Friends approach in booklet one.

Think outside the box
Sometimes you should take your loved one's words literally.

Example I: ●If Nana rummages around the house and insists that her (long-deceased) brother Jim stole her favorite jacket, go along with it. Say "I'll call Jim right away." ●Then, call you own number, let it go to voicemail and say: "Jim, please return the jacket you've taken from my Nana."

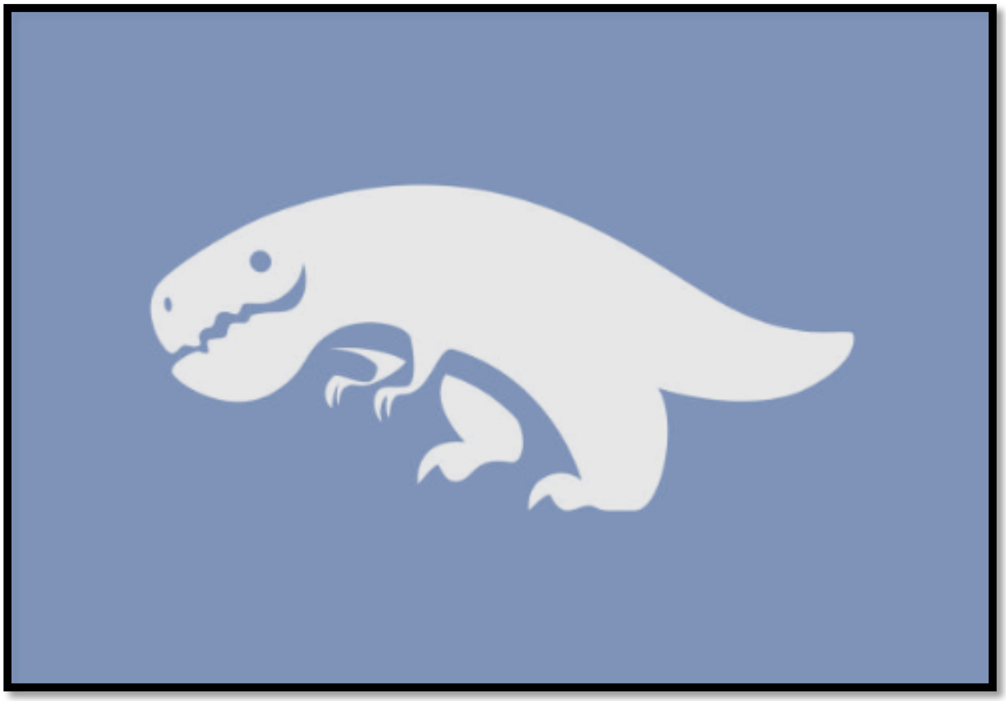
Example II: ●If your loved one keeps screaming, "I want to get out of here", take her words literally. She did not say where she wanted to go – just "out of here". ●Say, "Ok, Nana, I will help you get out of here." ●Take her outside for a walk. Encourage her to watch the birds, smell the flowers and wave to people. ●By then, she may have forgotten her outburst. Take her back inside.

Action Summary
- Take a breath. Relax your shoulders. Stay at eye level. Use your "indoor" voice.
- Do not restrain your loved one.
- Never scream or try to reason with your loved one.
- Get out of harm's way. If the situation has the potential to turn dangerous call other family members, friends or neighbors. If they cannot come right away, ask them to come as soon as they can.
- If you do call 911, make sure to tell responders the person has dementia, which causes them to act aggressively.
- Focus on calming your loved one: Do not approach from behind, Speak gently, If they would be safe, leave the room for 5-10 minutes.
- Once the initial outburst is over, continue helping. Refocus their attention on something else. Play their favorite music. Give your full undivided attention for 10-15 minutes.

Treating Behavioral Symptoms
Sometimes, behavioral symptoms are related to an infection or change in health. Your loved one should receive a thorough medical checkup, especially when

symptoms appear suddenly. Treatment depends on a careful diagnosis, determining possible causes and the types of behavior the person is experiencing.

Depression



Does your loved one refuse to leave the house these days? Do they often speak of dying? Has they been feeling extremely sad for more than two weeks? Your loved one may be experiencing depression. It can be difficult to tell if someone with dementia also has depression. Difficulty in finding the right words can make it harder to express feelings of sadness or hopelessness. Additionally, the symptoms of depression and dementia may overlap.

Depression is very common among people with dementia, especially during the early and middle stages. Treatment is available and can make a significant difference in quality of life.

Symptoms of depression

Experts estimate that up to 40 percent of people with dementia disease suffer from significant depression.

Examples of symptoms common to both depression and dementia include

- Apathy
- Loss of interest in activities and hobbies

- Social withdrawal or Isolation
- Trouble concentrating; feels tired, restless or irritable
- Impaired thinking
- Sleeps too little or too much
- Feels like crying; is sad, hopeless, discouraged, anxious or feels empty
- Experiences hallucinations or delusions
- Loses interest in sex
- Agitation or slowed behavior
- Fatigue or loss of energy
- Disruption in appetite that is not related to another medical condition
- Loses language skills, memory and the ability to reason/solve problems

Feelings of worthlessness, hopelessness and guilt as well as thinking about death or suicide, are more common in depression than dementia. However, depression in dementia doesn't always look like depression in people without the dementia. Here are some ways that depression in a person with dementia may be different:

- May be less severe
- May not last as long and symptoms may come and go
- The person with dementia may be less likely to talk about or attempt suicide

As a caregiver, if you see signs of depression, discuss them with the primary doctor of the person with dementia. Proper diagnosis and treatment can improve sense of well-being and function.

Diagnosing depression with dementia

There is no single test or questionnaire to detect depression. Diagnosis requires a thorough evaluation by a medical professional, especially since side effects of medications and some medical conditions can produce similar symptoms.

An evaluation for depression may include

- A review of the person's medical history
- A physical and mental examination
- Interviews with family members who know the person well

The most common treatment for depression in dementia involves a combination of medicine, counseling, and gradual reconnection to activities and people that bring happiness.

Simply telling the person with Alzheimer's or another dementia to "cheer up," "snap out of it" or "try harder" is seldom helpful. Depressed people with or without dementia are rarely able to make themselves better by sheer will, or without lots of support, reassurance and professional help.

Strategies to make a difference

Non-drug approaches

Support groups can be very helpful, particularly an early-stage group for people with dementia who are aware of their diagnosis and prefer to take an active role in seeking help or helping others; counseling is also an option, especially for those who aren't comfortable in groups

Schedule a predictable daily routine, taking advantage of the person's best time of day to undertake difficult tasks, such as bathing

Make a list of activities, people or places that the person enjoys and schedule these things more frequently

Help the person exercise regularly, particularly in the morning

Acknowledge the person's frustration or sadness, while continuing to express hope that he or she will feel better soon

Celebrate small successes and occasions

Find ways that the person can contribute to family life and be sure to recognize his or her contributions

Provide reassurance that the person is loved, respected and appreciated as part of the family, and not just for what she or he can do now

Nurture the person with offers of favorite foods or soothing or inspirational activities

Reassure the person that he or she will not be abandoned

Medication to treat depression in dementia

There are several types of antidepressants available to treat depression. Antidepressants called Selective Serotonin Reuptake Inhibitors (SSRIs) are often used for people with dementia and depression because they have a lower risk than some other antidepressants of causing interactions with other medications.

As with any medication, make sure to ask about risks and benefits, as well as what type of monitoring and follow-up will be needed.

Hallucinations

When a person with Alzheimer's or other dementia hallucinates, he or she may see, hear, smell, taste or feel something that isn't there. Some hallucinations may be frightening, while others may involve ordinary visions of people, situations or objects from the past.

Understanding hallucinations
Hallucinations are false perceptions of objects or events involving the senses. These false perceptions are caused by changes within the brain that result from dementia, usually in the later stages of the disease. Your loved one may see the face of a former friend in a curtain or may see insects crawling on his or her hand. In other cases, they may hear someone talking and may even engage in conversation with the imagined person.

Dementias are not the only cause of hallucinations. Other causes include:

- Schizophrenia
- Physical problems, such as kidney or bladder infections, dehydration, intense pain, or alcohol or drug abuse
- Eyesight or hearing problems

Medications
See the doctor. If a person with dementia begins hallucinating, it's important to have a medical evaluation to rule out other possible causes and to determine if medication is needed. It may also help to have the person's eyesight or hearing checked.

The first line of treatment is **non-drug approaches (see below)**. If these strategies fail and symptoms are severe, medication may be appropriate. While antipsychotic medications can be effective, they are associated with an increased risk of stroke and death in older adults with dementia. Work with a doctor to learn both the risks and benefits of medication before deciding.

Strategies to make a difference

When responding to hallucinations, be cautious. First, assess the situation and determine whether the hallucination is a problem for the person or for you. **Is the hallucination upsetting**? Is it leading the person to do something dangerous? Is the sight of an unfamiliar face causing the person to become frightened? If so, **react calmly and quickly** with reassuring words and a comforting touch. **Do not argue with the person about what he or she sees or hears.** If the behavior is not dangerous, there may not be a need to intervene.

Offer reassurance
- Respond in a calm, supportive manner. You may want to respond with, "Don't worry. I'm here. I'll protect you. I'll take care of you."
- Gentle patting may turn the person's attention toward you and reduce the hallucination.
- Acknowledge the feelings behind the hallucination and try to find out what the hallucination means to the individual. You might want to say, "It sounds as if you're worried" or "I know this is frightening for you."

Use distractions
Suggest a walk or move to another room. Frightening hallucinations often subside in **well-lit areas** where other people are present. Try to turn the person's attention to music, conversation or activities you enjoy together.

Respond honestly

If the person asks you about a hallucination or delusion, be honest. For example, if he or she asks, "Do you see him?" you may want to answer with, "I know you see something, but I don't see it." This way, you're not denying what the person sees or hears, but you avoid an argument.

Modify the environment

- Check for sounds that might be misinterpreted, such as noise from a television or an air conditioner.
- Look for lighting that casts shadows, reflections or distortions on the surfaces of floors, walls and furniture. Turn on lights to reduce shadows.
- Cover mirrors with a cloth or remove them if the person thinks that he or she is looking at a stranger.

Suspicions and Delusions

A person with dementia may become suspicious of those around them, even accusing others of theft, cheating or other improper behavior. While accusations can be hurtful, remember that the disease is causing these behaviors.

Help others understand changing behaviors
Make sure family members and caregivers understand that suspicions and false accusations are caused by the disease. They are not personal.

Delusions (firmly held beliefs in things that are not real) may occur in middle- to late-stage Alzheimer's and early, middle or late stage for other dementias.

Confusion and memory loss — such as the inability to remember certain people or objects — can contribute to these untrue beliefs. Someone with dementia may believe a family member is stealing his or her possessions or that he or she is being followed by the police. This kind of suspicious delusion is sometimes referred to as paranoia.

Although not grounded in reality, **the situation is very real to the person with dementia**. Keep in mind that your loved one is trying to make sense of his or her ever-changing world.

A delusion is not the same thing as a hallucination. Delusions involve false beliefs. Hallucinations are false perceptions of objects or events; your loved one may see, hear, smell, taste or even feel something that isn't really there.

See the doctor.
If you loved one is having severe delusions and there is a fear of self-harm or caregiver harm, or if the delusion is extremely troubling, it's important to have a medical evaluation to determine if medication is needed.

The first line of treatment for the behavioral symptoms of dementia is non-drug approaches, but if these strategies fail and symptoms are severe, medication may be appropriate.

While antipsychotic medications can be effective in some situations, they are associated with an increased risk of stroke and death in older adults with dementia. They are also contraindicated (should not be used) in some dementias. Work with the doctor to learn both the risks and benefits of medication before deciding.

Strategies to make a difference: How to respond

- Don't take offense. Listen to what is troubling the person, and try to understand that reality. Then be reassuring, and let the person know you care.

- Don't argue or try to convince. Allow the individual to express ideas. Acknowledge his or her opinions.

- Offer a simple answer. Share your thoughts with the individual, but keep it simple.

- Don't overwhelm the person with lengthy explanations or reasons.

- Switch the focus to another activity. Engage the individual in an activity, or ask for help with a chore.

- Duplicate any lost items. If the person is often searching for a specific item, have several copies or substitutes available. For example, if the individual is always looking for his or her wallet, purchase two of the same kind.

Memory Loss and Confusion

In the later stages of the disease, your loved one may not remember familiar people, places or things. Situations involving memory loss and confusion are extremely difficult for caregivers and families. They require much patience and understanding.

What to expect

In the earlier stages, memory loss and confusion may be mild. Your loved one may be aware of — **and frustrated by** — the changes taking place. They may have difficulty recalling recent events, making decisions or processing what was said by others.

In the later stages, memory loss becomes far more severe. A person may not recognize family members, may forget relationships, call family members by other names, or become confused about the location of home or the passage of time. He or she may forget the purpose of common items, such as a pen or a fork. These changes are some of the most painful for caregivers and families.

Causes

The main cause of memory loss and confusion is the progressive damage to the brain cells caused by dementia. While current medications cannot stop the damage dementia causes to brain cells, they may help lessen symptoms for a limited time. An evaluation can be done for interventions that may help.

Certain situations — such as a change in living arrangements, switch in routine or certain infections — can cause symptoms of memory loss and confusion to worsen. Any time there is a sudden change in behavior, it is important to have a medical evaluation to rule out other causes.

Strategies to make a difference: How to respond

Stay calm. Although being called by a different name or not being recognized can be painful, try not to make your hurt apparent.

Respond with a brief explanation. Don't overwhelm the person with lengthy statements or reasons. Instead, clarify with a simple explanation.

Show photos and other reminders. Use photographs and other thought-provoking items to remind the person of important relationships and places.

Travel with the person to where he or she is in time. If your loved one's memory is focused on a particular time in his or her life, engage in conversation about the memory with an understanding that this is his or her current reality.

Try not to take it personally. Dementia causes your loved one to forget, but your support and understanding will continue to be appreciated.

Repetition

A person with dementia may do or say something over and over — like repeating a word, question or activity — or undo something that has just been finished. In most cases, he or she is probably looking for comfort, security and familiarity.

Causes
The main cause of repetition in dementia is the deterioration of brain cells. In the case of repetition, your loved one may not remember that she or he has just asked a question or completed a task.

Environmental influences also can cause symptoms or make them worse. People with dementia ask questions repeatedly may be trying to express a specific concern, ask for help, or cope with frustration, anxiety or insecurity.

Strategies to make a difference: How to respond

Look for a reason behind the repetition. Does the repetition occur around certain people or surroundings, or at a certain time of day? Is the person trying to communicate something?

Focus on the emotion, not the behavior. Rather than reacting to what the person is doing, think about how he or she is feeling.
Turn the action or behavior into an activity. If the person is rubbing his or her hand across the table, provide a cloth and ask for help with dusting.

Stay calm, and be patient. Reassure the person with a calm voice and gentle touch. Don't argue or try to use logic; dementia affects memory, and the person may not remember he/she asked the question already.

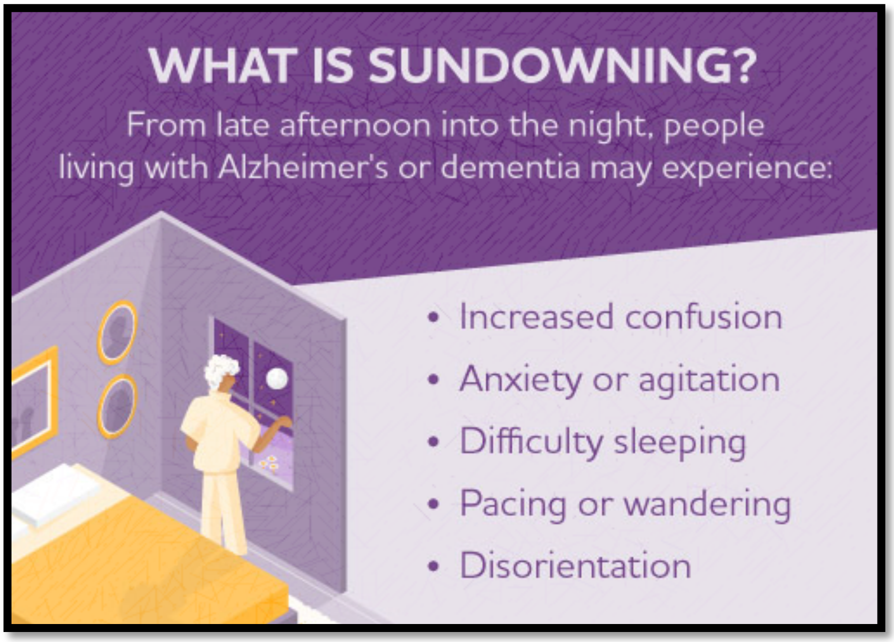
Provide an answer. Give the person the answer that he or she is looking for, even if you have to repeat it several times. If a person with dementia is still able to read and comprehend, it may help to write it down and post it in a prominent location.

Engage our loved one in an activity. The individual may simply be bored and need something to do. Provide structure and engage the person in a pleasant activity.

Use memory aids. If your loved one asks the same questions over and over again, offer reminders by using notes, clocks, calendars or photographs, if these items are still meaningful.

Accept the behavior, and work with it. If it isn't harmful, don't worry about it. Find ways to work with it.

Sleep Issues and Sundowning



WHAT IS SUNDOWNING?

From late afternoon into the night, people living with Alzheimer's or dementia may experience:

- Increased confusion
- Anxiety or agitation
- Difficulty sleeping
- Pacing or wandering
- Disorientation

Sundowning is the increased confusion that your loved one may experience from dusk through night. Also called "sundowner's syndrome," it is not a disease but a **set of symptoms or dementia-related behaviors that may include difficulty sleeping, anxiety, agitation, hallucinations, pacing and disorientation**.

Factors that may contribute to trouble sleeping and sundowning

- Mental and physical exhaustion from a full day of activities.
- Navigating a new or confusing environment.
- A mixed-up "internal body clock related to their dementia.
- Low lighting can increase shadows. This may cause confusion by what they see. They may experience hallucinations and become more agitated.
- Internalizing the stress or frustration in those around them.
- Dreaming while sleeping can cause disorientation, including confusion about what's a dream and what's real.
- Less need for sleep, which is common among older adults.

Strategies to make a difference

If the person is awake and upset

- Approach them in a calm manner.
- Find out if there is something they need.
- Gently remind them of the time.
- Avoid arguing. Offer reassurance that everything is all right.
- Don't use physical restraint. Allow the person to pace back and forth, as needed, with supervision.

Tips to share

- Share your experiences and find support
- Encourage your loved one to get plenty of rest.
- Schedule activities such as doctor appointments, trips and bathing in the morning or early afternoon hours.
- Encourage a regular routine of waking up, eating meals and going to bed.
- When possible, spend time outside in the sunlight during the day.
- Make notes of what happens before sundowning and try to identify triggers.
- Reduce stimulation during the evening hours. For example, avoid watching TV, doing chores or listening to loud music. These distractions may add to your loved one's confusion.
- Offer a larger meal at lunch and keep the evening meal lighter.
- Keep the home well-lit in the evening to help reduce the person's confusion.
- Try to identify activities that are soothing to the person, such as listening to calming music, looking at photographs or watching a favorite movie.
- Take a walk with the person to help reduce their restlessness.
- Talk to the person's doctor about the best times of day for taking medication.
- Try to limit daytime naps if the person has trouble sleeping at night.
- Reduce/avoid alcohol, caffeine + nicotine. These can affect the ability to sleep.

Talk to a doctor about sleep issues

Discuss sleep problems with a doctor to help identify causes and possible solutions. Physical ailments, such as urinary tract infections or incontinence problems, restless leg syndrome or sleep apnea, can cause or worsen sleep problems.

For sleep issues primarily due to dementia, most experts encourage the use of non-drug measures rather than medication. In some cases when non-drug approaches fail, medication may be prescribed. Work with the doctor to learn the risks and benefits of medication before deciding.

Getting Lost and Wandering

This section will discuss two separate issues: getting lost and wandering. At the early stages of dementia, your loved one typically begins a trip knowing where he or she is going. Your loved one **gets lost** and has a hard time finding the way back home. At later stages of the disease, your loved one may have a general destination in mind but seems **to wander** without knowing how to get there.

Getting Lost	Wandering
Changes in the ability to focus, pay attention	Changes in the ability to think/make decisions
Changes in memory	Changes in the ability to communicate
Depression, distress	Agitation, boredom, restlessness
	Confusion to time or place
	Physical discomfort or illness
	Too many distractions
	Changes in routine

Dementia causes people to lose their ability to recognize familiar places and faces. It's common for a person living with dementia to wander or become lost or confused about their location.

Six in 10 people living with dementia will wander at least once; many do so repeatedly. Although common, wandering can be dangerous — even life-threatening — and the stress of this risk weighs heavily on caregivers and family.

Who's at risk for wandering?
Everyone living with dementia is at risk for wandering.

Common signs a person may be at risk of getting lost or wandering include:

- Returning from a regular walk or drive later than usual.
- Has a hard time following directions; asks for directions several times
- Doesn't know how to turn back, turn left/right or follows roads or signs
- Forgetting how to get to familiar places.
- Talking about fulfilling former obligations, such as going to work
- Trying or wanting to "go home" even when at home.
- Becoming restless, pacing or making repetitive movements.
- Having difficulty locating familiar places, such as the bathroom, bedroom or dining room.
- Asking the whereabouts of past friends and family.
- Acting as if doing a hobby or chore, but nothing gets done.
- Appearing lost in a new or changed environment.
- Becoming nervous or anxious in crowds, such as markets or restaurants.
- Wears clothing outside the home that is inappropriate for the time of day or season.

Strategies to make a difference

Reduce the risk of wandering

The following tips may help reduce the risk of wandering and can bring peace of mind to caregivers and family members; however, these actions cannot guarantee that a person living with dementia won't wander.

Provide opportunities for your loved one to engage in structured, meaningful activities throughout the day.

Identify the time of day your loved one is most likely to wander (for those who experience "sundowning," this may be starting in the early evening.) Plan things to do during this time — activities and exercise may help reduce anxiety, agitation and restlessness.

Ensure all basic needs are met, including toileting, nutrition and hydration.

Consider reducing – but not eliminating – liquids up to two hours before bedtime to avoid (possibly) finding the bathroom during the night.

Involve your loved one in daily activities, such as folding laundry or preparing dinner. Create a daily plan.

Reassure if he or she feels lost, abandoned or disoriented.

If your loved one is still safely able to drive, consider using a GPS device to help if they get lost.

If they are no longer driving, remove access to car keys — a person living with dementia may not just wander by foot. They may forget that he or she can no longer drive.

Avoid busy places that are confusing and can cause disorientation, such as shopping malls.

Assess your loved one's response to new surroundings. Do not leave someone with dementia unsupervised if new surroundings may cause confusion, disorientation or agitation.

In the early stage of the disease and their care partners, the following strategies may also help reduce the risk of wandering or getting lost:

- Decide on a set time each day to check in with each other.
- Review scheduled activities and appointments for the day together.
- If the care partner is not available, identify a companion as needed.

- Consider alternative transportation options if getting lost or driving safely becomes a concern.
- Prepare your home

As the disease progresses and the risk for wandering increases, assess your individual situation to see which of the safety measures below may work best to help prevent wandering.

Home Safety Checklist
Place deadbolts out of the line of sight, either high or low, on exterior doors. (Do not leave your loved one unsupervised in new or changed surroundings, and never lock a person in at home.)

Use night lights throughout the home.

Cover doorknobs with cloth the same color as the door or use safety covers.

Camouflage doors by painting them the same color as the walls or covering them with removable curtains or screens.

Use black tape or paint to create a two-foot black threshold in front of the door. It may act as a visual stop barrier.

Install warning bells above doors or use a monitoring device that signals when a door is opened.

Place a pressure-sensitive mat in front of the door or at the person's bedside to alert you to movement.

Put hedges or a fence around the patio, yard or other outside common areas.

Use safety gates or brightly colored netting to prevent access to stairs or the outdoors.

Monitor noise levels to help reduce excessive stimulation.

Create indoor and outdoor common areas that can be safely explored.

Label all doors with signs or symbols to explain the purpose of each room.

Store items that may trigger an instinct to leave, such as coats, hats, pocketbooks, keys and wallets.

Do not leave the person alone in a car.

Plan ahead
The stress experienced by families and caregivers when a loved one gets lost or wanders is significant. Have a plan in place beforehand, so you know what to do in case of an emergency:

- Begin taking regular photos of your loved one – at least twice per year
- Consider registering with the Alzheimer's Association's Safe Return program
- Call the local police department. Ask if they have dementia registry.
- Ask neighbors, friends and family to call if they see the person wandering, lost or dressed inappropriately.
- Know the person's neighborhood. Identify potentially dangerous areas near the home, such as bodies of water, open stairwells, dense foliage, tunnels, bus stops and roads with heavy traffic.
- Create a list of places the person might wander to, such as past jobs, former homes, places of worship or a favorite restaurant.

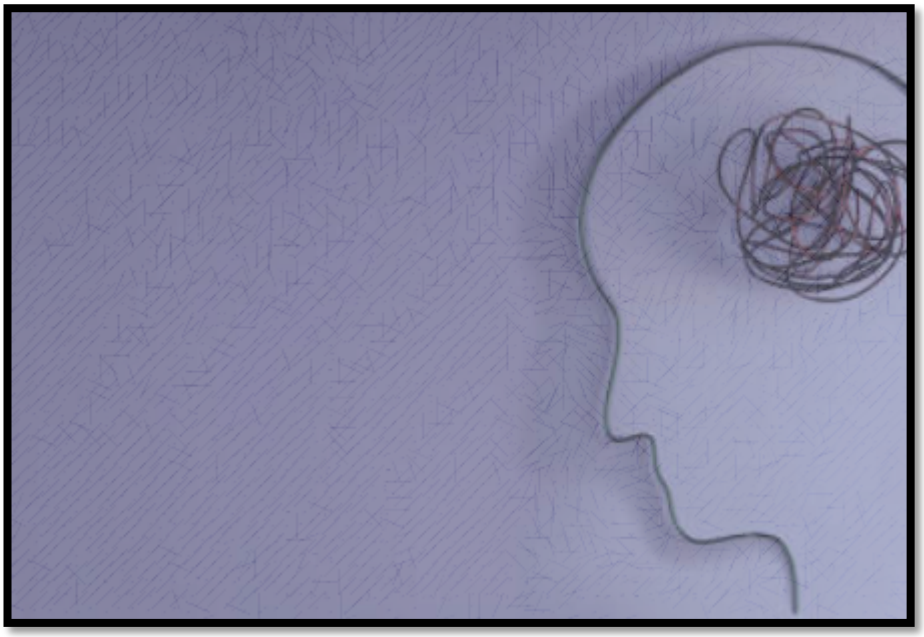
Act when wandering occurs
When someone with dementia is missing:

- Begin search-and-rescue efforts immediately. Many individuals who wander are found within **1.5 miles** of where they disappeared.
- Start search efforts immediately. When looking, consider whether the individual is right- or left-handed — wandering patterns generally follow the direction of the dominant hand.
- Check local landscapes, such as ponds, tree lines or fence lines — many individuals are found within brush or brier.
- If applicable, search areas the person has wandered to in the past.
- If the person is not found within 15 minutes, call 911 to file a missing person's report. Inform the authorities that the person has dementia.

Once your loved one is found

Never scold or show that you are scared. Your anger or fear may cause agitation. If your loved one seems upset, calmly reassure that they are safe now. Notify all other searchers. Go back to the day’s schedules and routines as soon as possible. Call someone on your care team to unwind and talk over the situation.

Inappropriate sexual behaviors



This section is about inappropriate sexual behaviors of people with dementia. Both men and women exhibit them equally – at any stage. For information about the need for intimacy and expression, see section: About Sex in the caregiver guide.

People with dementia have the same needs as everyone else, including the need to express sexual feelings. However, some types of sexual behaviors can make you, family members, friends and strangers uncomfortable.

Causes and common presentations
Rule out other causes: Physical discomfort or illness: delirium (this is a confusion and inattention that can come and go. It is often related to an underlying reversible cause), medication side effects or urinary tract infections. Their usual sexual partner is no longer present – death, hospitalization . . . Lifelong aggressive behavior. The use of alcohol.

The impact of dementia

- Unable to monitor and control the expression of sexual feelings
- Unable to understand social situations and how to act in them
- Unable to recognize that certain behaviors may offend others

- Unable to understand why certain behaviors are inappropriate
- Changes in inhibition (doing or saying things out of character)
- Memory loss, confusion, delusions, paranoias
- Incontinence, toileting difficulties
- Changes in communication skills
- Boredom or depression
- Changes in routine
- Misidentification and misinterpretation of the actions of others

Common symptoms of inappropriate sexual behavior

- Makes unwanted advances to familiar and unfamiliar people
- Accuses another of cheating; insults or attacks that person
- Tries to intimately kiss or touch someone who is not a spouse/partner
- Repeatedly asks someone to check/clean personal areas
- Tries to bully another person into having sex
- Gets into the bed of someone who is not a spouse/partner
- Makes inappropriate sexual remarks in public
- Engages in sexual activity in public including fondling personal parts

Each situation will be different. Each person with dementia is different. Each person who is the subject of the inappropriate behavior is different. Sexual behaviors typically involve mistaken identities, the need to toilet or misinterpretation of non-sexual acts. They are usually out of character and often do not involve sexual arousal.

It can be hard not to be shocked or offended by inappropriate sexual behaviors. Dealing with them becomes harder when the “actor” has dementia and no longer can understand or control behaviors.

Strategies to make a difference

Assess other possibilities

- Is this a sign that they need to toilet
- Do their clothes feel too warm, itchy, tight . . .
- Could it be an infection – such as jock itch
- Was there a sudden change that caused inappropriate touching

Plan ahead. Identify potential triggers of the behaviors. Think of a few situations and how you believe your loved one might behave. Is there a way to prevent the behavior? How would you handle the behavior if it occurs?

Be prepared. When your loved one behaves this way, they are likely unaware of the behavior's impact. Yelling or calling additional attention to the behavior – especially in public – won't stop the behavior and it may agitate your loved one.

- Stay calm
- Avoid screaming or hitting
- Quietly move to a private room; speak with your loved one if they can engage
- Focus on finding the trigger and resolving the problem if possible
- Find them some privacy if he or she is sexually stimulating themselves in public
- Look around and decide how quickly you can get to the nearest restroom
- In an emergency, use a newspaper or trash bag to cover the activity

Remember not to scold or humiliate. Example: Papa John, I know you miss Mama Elaine a lot. But it's not okay for you to stimulate yourself when other people are around. We need to find a restroom. Example: You took off your shirt, Papa John. It's not okay to take off your clothes when other people are around. Help me understand. Is the shirt scratchy? Did you feel itchy?

Consider a toileting schedule

Example I: **Upon waking:** Take to the bathroom immediately. **After breakfast:** Remind to use the bathroom. **Mid-morning (around 10:00am):** Take to the bathroom. **After lunch:** Remind to use the bathroom. **Mid-afternoon (around 3:00pm):** Take to the bathroom. **Before dinner:** Remind to use the bathroom. **Before bedtime:** Take to the bathroom.

Example II: Taking them to the bathroom upon waking up every 2 hours throughout the day, after meals, before bedtime, and potentially once during the night**,** depending on their needs. Use reminders and assistance as necessary to maintain a consistent routine and minimize accidents. This schedule can be and should be adjusted based on individual patterns of urination and bowel movements observed over time.

Think outside the box

If your loved one fondles him or herself or even another person, it may be a symptom of boredom, which they cannot express. Try these ideas for keeping hands and minds busy elsewhere.

- Bring along an art and craft
- Put on a barbeque apron with pockets. Add small items such as toys, keys, and coins to their pockets to keep their hands busy. Cover the lap with a cushion or a fidget blanket.

As a result of a delusion or misidentification, your loved one may get into the bed of someone who is not a partner or spouse. This person may represent comfort or warmth. Try tucking in a body pillow once they get back into their bed. Or wrap a hot water bottle in a bathrobe or large towel and tuck it into bed.

And remember, never scold or humiliate. Refocus their attention.

Example: Cousin Emma sure looks like Mama Elaine but there is only one Mama Elaine! Papa John, it’s not okay for you to get into Cousin Emma’s bed. I will help you find your own bed. Here’s a pillow to curl up with.

Dementia impacts all aspects of daily life. This booklet includes some of the most common behaviors and presentations. If you are interested in additional information please discuss with your GUIDE care team. This may include information in the Dementia-Friendly Lifestyle, Health and Nutrition, Cultural Diversity, Special Occasions and Grief.