





# understanding and responding to dementia-related behavior



**workbook**

## A General Guide to Understanding and Addressing Behavior

This workbook is a companion piece to the Understanding and Responding to Dementia-Related Behavior program. It provides general tips for each of the four steps presented in the program, applies these to five common types of behavior, and includes an Intervention Worksheets for you to use as you sort through the needed steps to take with any behavior. Although the tips will generally apply throughout the course of the disease, the behaviors you encounter can change many times as the disease advances.

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|---|--|
|  <b>Step 1: Detect and connect</b> <ul style="list-style-type: none"><li>• Join the person in his or her reality</li><li>• Understand the person’s reality in context before intervening: Who? What? Where? When? How?</li><li>• Approach the person calmly and respectfully.</li></ul>  |  <b>Step 2: Address physical issues first</b> <ul style="list-style-type: none"><li>• Look at medical issues, starting with pain</li><li>• Address physical problems, such as hunger, thirst, need to use the bathroom, medication reactions, etc.</li><li>• Address environmental triggers for discomfort, such as restrictive clothing, room temperature, lighting, glare or sounds</li></ul>                       |
|  <b>Step 3: Then address emotional needs</b> <ul style="list-style-type: none"><li>• Think about how the situation feels to the person.</li><li>• Focus on the feelings, not facts.</li><li>• Reinforce that you are there to help.</li><li>• Use your knowledge of the person’s preferences.</li><li>• Redirect the energy into a more soothing activity.</li></ul> |  <b>Step 4: Reassess and plan for next time</b> <ul style="list-style-type: none"><li>• Go back to detecting and connecting.</li><li>• What went well and what didn’t?</li><li>• How can you make adjustments?</li><li>• Create an intervention plan that includes who can help with assessment and intervention, what to try and in what order, and what to do if the situation escalates or your inter-</li></ul> |

## Anxiety or agitation

Restlessness or pacing, distress, or over-reliance on caregivers.

### **Vignette**

*Ann, a 75-year-old woman with Alzheimer's disease was pacing the hallways in her house in the evenings, saying, "I need to go, I need to go." She would not stop walking, even for meals. Her family would give her sandwiches to eat while she was walking. Though she used a cane, she was getting blisters on her feet and had lost weight from not eating. Her family would ask Ann to sit down, but as soon as she sat, she would immediately get up and start pacing again. Ann had worked for 40 years as a nurse on the night shift, and her agitation began every evening. Her shoes were worn and she appeared to be in pain as she walked.*

### **Step 1: Detect and connect**

- Listen to the frustration and try to understand the feeling.
- Try to identify any triggers for the behavior by asking yourself who, what, where, when and how questions.
- Check for sundowning: difficulty in the late afternoon and early evening.



### **Step 2: Address physical issues first**

- Assess for pain, infection, medication interaction or other medical issues. Intervene as needed.
- Abrupt surges in agitation can result from urinary tract infections, which occur frequently in older people. If the shift occurs suddenly, check with a doctor.
- Be sure the person gets enough exercise during the day. This can help to discharge energy and help the person feel tired at the end of the day.
- See if the person is hungry, thirsty or lacking social interaction. Provide the person with healthy snacks and beverages, and offer them periodically.
- Because constipation may trigger agitation, make sure his or her diet includes plenty of fruit and fiber, fluids and sufficient exercise.
- Explore the area surrounding the person and try to see anything that may have triggered physical discomfort or distress.



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## Step 3: Then address emotional needs



- Again, acknowledge that you understand that the person is feeling frustrated or upset, and that you want to help him or her feel more comfortable.
- Check to see if something has happened to upset the person and trigger hurt feelings, anger, worry, frustration, loneliness or other distress.
- Join the person physically, matching his or her pace of movement, volume or speech, etc., but keep your voice calm and reassuring.
- Once the level of agitation is reduced a bit, offer to engage in a soothing activity that the person enjoys.
- If the person is fearful, lonely or sad, providing reassurance and companionship can help.

## Step 4: Reassess and plan for next time



- Did your new responses help?
- Do you need to explore other potential causes and solutions? If so, what can you do differently?
- Assume that the person will feel anxious or agitated again in the future, and make a plan for addressing those feelings. Be sure to include what to do if the situation escalates or your interventions are ineffective.

**Resolution:** \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## Confusion or suspicion

The person may not recognize familiar people, places or things; he or she may also forget relationships or names for people and common items. Sometimes this confusion results in the person suspecting others or theft, infidelity or other improper behavior. It can be very difficult for caregivers when the person cannot remember who that caregiver is or what the caregiver's character is like.

### **Vignette**

*When Ann's family comes to visit and evening begins, she becomes very suspicious that people are trying to get into her house and are watching her through the big picture windows. She becomes suspicious of her family for not making the people "go away" and that they all must "be in cahoots" with each other.*

### **Step 1: Detect and Connect**

- Try to stay calm as you explore.
- What is the confused or suspicious behavior? When is it happening? With whom? Where? How does it manifest?
- Check the environment for potential sources of confusion.
- Try to discern whether the person is reacting to something in the present or is instead reacting to something imagined or in the past. What is the meaning for the person?



### **Step 2: Address physical issues first**

- Rule out a medical explanation such as infection, low blood sugar level or delirium.
- If the person is experiencing pain, intervene to increase the person's comfort.
- If the person is being given pain medication, consult with his or her doctor right away about possible side effects.
- Assess for physical discomfort due to environment, overstimulation, fatigue, etc.
- Modify the environment if needed (take down mirrors, upgrade lighting, etc.)
- Respond with a brief and accurate explanation, but avoid arguing.
- Offer corrections as gentle suggestions or answers, and show photos and other reminders to trigger the person's recognition of what may have happened.
- If items are lost and no one can find them, see if you can provide a solution by duplicating them, or providing multiples of often-used items.





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- Remember that this is about defusing the situation, not convincing the person of the truth.

## Step 3: Then address emotional needs



- Briefly let the person know that you understand he or she is upset and in what ways.
- Let the person know that you will take care of the situation. Repeat this message to the person as he or she begins to calm down.
- Remember that you have entered the person's reality. Let him or her know that you are here to help and are on his or her side. Agree, validate and apologize as needed. For example: "I'm so sorry this is happening, Mom. Let's see what we can do to fix it."
- Try not to take the person's confusion or behavior personally. This is difficult when you are the target of accusations, but remember it is the disease causing the accusations and they are not a reflection of the person's trust in you.

## Step 4: Reassess and plan for next time



- Ask yourself whether your new response helped.
- Do you need to explore other potential causes and solutions? If so, what can you do differently? If you can identify other approaches, try them out and continue to reassess throughout the process.
- Assume that the person will feel confused or suspicious again in the future and make a plan to address that.

**Resolution:** \_\_\_\_\_  
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\_\_\_\_\_  
\_\_\_\_\_

## Aggression

Aggressive behavior may be verbal or physical. It may occur suddenly for no apparent reason, or may emerge following a trigger.

### Vignette

*Ann's husband, Bill, is standing at the back of the room, leaning against the wall with his arms crossed, watching television. Ann, walks in and tells him, sharply, "You aren't the boss here!" Bill ignores the comment and continues to watch television. Ann comes closer, raises her voice, and says, "You can't tell me what to do!" When Bill doesn't respond, Ann comes up to Bill and hits him on the arm with her balled fist. Prior to her dementia symptoms, Ann was quite calm by nature, and would never have exhibited this behavior. Lately, her outbursts are becoming more frequent. She continues to come at Bill, who retreats from her and locks himself in the bathroom to avoid further conflict. He does not have a cell phone with him. Since both had been avid hunters when they were younger, there are guns in the house, but Bill has removed all of the ammunition.*

### Step 1: Detect and connect

- Try to identify the immediate trigger for the aggression. Did something frighten or alarm the person? This may not be a logical response.
- Ask yourself the who, what, when, where and how questions to explore the situation.
- Gently say the person's name and let him or her know you are there, you understand the feelings and you want to help before attempting to intervene.
- Apologize when it seems that it would help calm the person. You may be apologizing for something you didn't do, but this apology is a reflection of the person's reality, not yours.



### Step 2: Address physical issues first

- Rule out medical causes. Some people lash out when they are in pain.
- Limit or remove any distractions.
- Screen the environment for any obvious triggers, such as excess noise, changes to the usual schedule or something the person may have perceived as a threat. Safely make any needed adjustments.



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- When in doubt, check with a doctor.
- Be sure to protect everyone involved so no one gets hurt.

## Step 3: Then address emotional needs



- Screen for emotional triggers. People act aggressively when they perceive danger or are scared, surprised, alarmed or in pain. Some triggers may not be directly clear to you.
- Adjust the environment to avoid situations that may cause emotional distress. situations. This may mean asking someone to leave the room while the person calms down, reducing the volume on a television or radio, asking family members only speak one at a time, or making alternate plans for bathing.
- Focus on feelings, not facts.
- Be positive and reassuring.

## Step 4: Reassess and plan for next time



- Once you have settled on interventions that are effective in calming the person and reducing aggression, recognize that this type of behavior will probably return and may even increase in degree.
- Make a plan so you can avoid being taken by surprise. Particularly with aggressive behavior, having a plan in place is crucial. Be sure to include what to do if the behavior escalates dramatically.
- Make sure that some neighbors are aware of the person's diagnosis.
- Remove guns and ammunition from the home.
- Be sure to have a plan for protecting everyone in case the aggression becomes dangerous, including keeping a charged cell phone with you at all times and calling 911 when needed. When calling, let the dispatcher know that the person has dementia, and alert them to any guns or ammunition that may still be in the house.

**Resolution:** \_\_\_\_\_  
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\_\_\_\_\_



## Repetition

The person with dementia may do or say something over and over, repeating words, questions or behaviors. These are seldom harmful but may become stressful for caregivers. The reason a person repeats him or herself is that the impaired memory cannot retain the answer, so the question or concern remains.

### **Vignette**

*Ann has recently been concerned about an upcoming visit from her daughter. Though her daughter, Katie, is not scheduled to visit for another two weeks, Ann has begun to repeatedly ask her husband, Bill, when she will arrive. Ann asks several times throughout the day - every day - which has begun to wear on Bill. He finds himself answering impatiently or even ignoring Ann's questions. At the same time, Ann is going into the bathroom much more frequently than she ever has before, every 10-20 minutes.*

### **Step 1: Detect and connect**

- Stay calm and be patient.
- Use the “who, what, where, when, how” assessment to look for triggers and patterns.
- Accept the behavior rather than fighting to stop it. You will need to work with the behavior rather than against it in order to intervene successfully.



### **Step 2: Address physical issues first**

- Changes in the person's physical condition may cause the person to repeat more frequently.
- As always, look for pain first. Explore whether the person may be experiencing pain and make adjustments safely to alleviate the pain.
- Explore the physical environment for triggers and make any needed changes.
- Call on medical professionals to assist if the behavior change took place suddenly. The behaviors you see may be the result of an infection, condition or medication side-effect.



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## Step 3: Then address emotional needs



- Focus on the emotion behind the behavior that the person is exhibiting and say something that recognizes that emotion.
- Briefly answer the person's questions or address the concerns. Keep your answer brief and to the point..
- Repeat the same answer to help the person who may be processing your words slowly and cannot retain them.
- Make use of memory aids like notes, photos and calendars. These help for some people, but not for others.
- Remember that repetition is part of the disease.
- Engage the person in a purposeful activity to redirect his or her focus.

## Step 4: Reassess and plan for next time



- Again, go back to detecting and connecting, joining the person's reality. How does the situation look now to the person with dementia? Do you need to explore other potential causes and solutions? If so, what can you do differently?
- It may not be possible to stop the repetition. If you can create a comforting environment for the person and address the repetition without frustration, you have succeeded.
- It helps to remember that this is a symptom, and it is related to the brain damage that comes with his or her disease progressing. Do what you can to maintain an emotional distance from the behavior.
- Expect the repetition to happen again. If you anticipate and make a plan for it, you can be prepared to handle it well.

**Resolution:** \_\_\_\_\_  
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\_\_\_\_\_

## Wandering

Wandering and getting lost are common among people with dementia and can happen during any stage of the disease. If the person with dementia is able to walk, he or she may wander.

### **Vignette**

*Ann and Bill spent the early years of their marriage in New Jersey. They moved out of the state to their current home 30 years ago. Ann constantly asks to visit New Jersey. She frequently leaves the home in the morning while Bill is showering and states, "I am going to New Jersey". She has been found by neighbors on many occasions at their church, on neighborhood streets, and one time at a very busy intersection near their home. Their daughter, Katie, is quite worried about potential injury. Bill is also worried and is at a loss about what to do. Bill is logical and tries to explain to Ann the reasons they cannot visit New Jersey, though he recognizes that this approach is not working. This approach also tends to make Ann more angry and the wandering incidents increase at those times.*

### **Step 1: Detect and connect**

- Assess who, what, when, where and how to identify possible triggers.
- Join with the person and accept anything that the person says about his or her wandering being goal-directed.
- See if you can uncover what is triggering the person's wandering and why the person may be reacting in this way.



### **Step 2: Address physical issues first**

- As always, look for pain first. Wandering sometimes begins in an attempt to "move away from the pain." If the change is sudden, consult the person's doctor for an assessment.
- Check to see if the person may be reacting to a change or difficulty with something in his or her immediate surroundings.
- Have there been changes in the person's patterns of exercise or daily routine lately?



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- Often a person is responding to an unmet need such as hunger, thirst, having to go to the bathroom, desire to get away from something or someone unpleasant, desire to go home, go outside or to engage with others.
- Make any changes needed to keep the person safe as you continue your assessment.

### Step 3: Then address emotional needs



- Label feelings that you pick up on from the person, such as anxiety, worry, fear, frustration, or boredom.
- Provide reassurance that he or she is safe, that you are together.
- Plan ahead of the first wandering incident. Consider MedicAlert®+ Alzheimer's Association Safe Return®, or an electronic tracking device such as [Comfort Zone®](#) and Comfort Zone Check-In®. (See alz.org's Safety Center for more information.)
- Help the person go safely to what they want to go, or agree to go later.
- Create opportunities for safe wandering.
- Make changes to the person's surroundings to camouflage them. Try putting dark mats in front of doors to make them look like holes to avoid, painting doors and door jambs the same color as the walls, or hanging cloths over door knobs.
- Consider a community day program to provide supervised activities.

### Step 4: Reassess and plan for next time



- Again, ask yourself whether your new response helped. Go back to detecting and connecting, joining the person's reality. How does the situation look now to the person with dementia? Do you need to explore other potential causes and solutions? If so, what can you do differently?
- Once you have settled on interventions that are effective, recognize that the person may wander again. If you anticipate wandering and make a plan for it, you can reduce wandering and know what to do when it occurs.

**Resolution:** \_\_\_\_\_  
\_\_\_\_\_  
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## Intervention Worksheet

Please make copies of this form and use it along with the guidelines on earlier pages to help you sort through behaviors and develop interventions. You may want to share copies with family members, the person's physician, and/or other care providers.

**Name of person with dementia** \_\_\_\_\_

**Your name** \_\_\_\_\_ **Date** \_\_\_\_\_

### Observations

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**Typically occurs**  Morning  Noon  Afternoon  Evening  Night

### Step 1: Detect and connect



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### Step 2: Address physical issues first



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### Step 3: Then address emotional needs



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### Step 4: Reassess and plan for next time



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**Share with:** \_\_\_\_\_



The Alzheimer's Association is the leading voluntary health organization in Alzheimer's care, support and research. Our mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

Our vision is a world without Alzheimer's disease. ®



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