

understanding and responding to dementia-related behavior



curriculum

introduction

The *Understanding and Responding to Dementia-Related Behavior* program of the Alzheimer's Association was designed to provide practical information and resources to help dementia caregivers learn to decipher behaviors and determine how best to respond. The program offers a four-step process to follow, and provides details that may be applied to any behavior. The four steps are:

1. Detect and connect.
2. Address physical needs first.
3. Then address emotional needs.
4. Reassess and plan for next time.

The goal is for participants to thoroughly understand this process and to leave the program feeling comfortable with using the four-step model to intervene with behaviors they may encounter in their caregiving.

The program teaches participants the four steps, and then applies the steps to five of the most common behaviors encountered by caregivers:

1. Anxiety or agitation.
2. Confusion or suspicion.
3. Aggression.
4. Repetition.
5. Wandering.

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instructions

The *Understanding and Responding to Dementia-Related Behavior* constituent education program is designed to be presented by dementia-trained professionals. The program content and the anticipated questions from participants are such that this dementia care training is necessary in order to provide accurate and meaningful information.

This program contains videos of caregivers and professionals discussing aspects of providing care for people with dementia when they encounter dementia-related behavior. Instructions for downloading the program and maximizing playability are found on Insite listed under Education Programs at: https://insite.alz.org/downloads/programs/programs_downloading_instructions.pdf.

The program contains the following components:

- A PowerPoint presentation.
- A Workbook.
- Handouts in 2, 3 and 6 slides per page formats.
- A customizable flier.
- A customizable poster.
- A customizable promo card.
- A sample newsletter item.

The *Understanding and Responding to Dementia-Related Behavior* program is offered as a one-hour program that includes time for gathering and introductions at the beginning, as well time for questions at the end. If more time is available, presenters may use the "Presenter Options" offered throughout the curriculum as ways to encourage further participant interaction.

acknowledgements

Understanding and Responding to Dementia-Related Behavior was developed with a workgroup representing chapter offices throughout the country. The Alzheimer's Association would like to thank the following individuals who contributed to the development of this program:

Chapter workgroup participants include:

Diane Baughn, MA, Education and Training Services Manager, Southeastern Wisconsin Chapter

Amy Miller, MSW, Director of Family Services, Colorado Chapter

Kathryn Nederostek, MGS, Director of Programs, Utah Chapter

Holly Pobst, BS, Education Manager, San Diego Chapter

Ronda Randazzo, MSW, Manager, Care Consultation, Massachusetts/New Hampshire Chapter

Deborah Richman, BS, Vice President, Education and Outreach, Minnesota/North Dakota Chapter

Denise Saxman, MSW, Associate Director of Family Programs, Greater Indiana Chapter

Julie Shatzer, MSW, Director of Programs, Central and North Florida Chapter

Cathy Sullins, Education Coordinator and William K. Warren Foundation TrialMatch® Fellow, Oklahoma Chapter

Our sincere thanks go to our gracious video participants living with Alzheimer's and their family members, who have been so candid and generous with their thoughts and feelings. Thanks also go to our National office staff member who was interviewed as well.

The participants in this project include:

Sandra H. Farrow, Caregiver

Sam Fazio, Director, Special Projects, Alzheimer's Association, National office

Rose Pagonis, Caregiver

Beverly Rogers, Caregiver

National Office staff involved with this project include:

Ellen Carbonell, Associate Director of Family Programs

Ruth Drew, Director of Family and Information Services

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Slide 1

Welcome to the *Understanding and Responding to Dementia-Related Behavior* program presented by the Alzheimer's Association.



Slide 2

Today, we will review the challenging behavioral aspects of Alzheimer's disease and strategies to use to help address them. By the end of today's program, you will be able to:

- **Identify common triggers for behaviors** associated with dementia.
- Explain the process for **assessing and identifying challenging behaviors**.
- List strategies to **address some common dementia-related behaviors**.



Slide 3

Some of the most difficult behaviors for caregivers to understand and address arise in the **middle stage** of the disease.

- **Behavioral symptoms can be caused by physical discomfort**, such as fatigue, hunger, thirst, constipation, full bladder or an uncomfortable room temperature.
- **Behaviors may also be triggered by overstimulation, sadness and loss, boredom**, isolation or changes in routine or living situation.

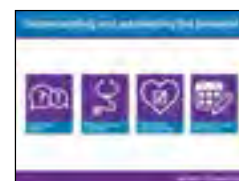
understanding dementia-related and responding to behavior

- Although the **causes may be hard to sort out**, it is helpful to take the steps outlined in these next slides to understand and respond to needs expressed through behaviors. We will present an outline of steps to take, and will then apply those steps to the most challenging behaviors that caregivers commonly face.

Slide 4

Today, we will explore how to understand and address common dementia-related behaviors by using this four step process:

1. **Detect and connect**
2. **Address physical needs first**
3. **Then address emotional needs**
4. **Reassess and plan for next time**

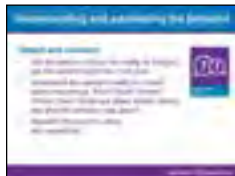


Presenter's note:

This is the time to direct participants to their workbooks.

1. *Inside the front cover, they will find an overview of the four step model, and they can use this to follow along as you present the content.*
2. *The following pages contain the model as applied to the behaviors covered in the remainder of the program.*
3. *Inside the back cover, they will find a blank Intervention Worksheet that they can copy and use to help them work through the steps with behaviors they encounter in their caregiving. They may want to share their completed sheets with others who provide care for the person, such as a doctor, paid caregiver, day center, or other family members or friends.*

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Slide 5

Detect and Connect

The first step in understanding and addressing behaviors is to detect and connect by **joining the person in his or her reality**. This means seeing the world through his or her eyes rather than your own.

- When we remember that **behavior is a form of communication**, we know that if we could see the world through the eyes of the person with dementia, and if we experienced what they experience in the way they do, the behavior would make perfect sense.
- Since **they are the ones with the disease**, we can't expect them to accommodate our needs. Instead, **we must try to enter their world**, connect with them as they are, and do our best to **decode what they are expressing**.
- **Sometimes, we simply can't figure out where the behavior is coming from** or what the person is communicating through the behavior.
 - However, it is **our job to make every attempt to understand** the behavior before intervening so we can know how to help.

To understand the behavior, start with some detective work to try to determine the trigger for the behavior. Ask yourself:

- **Who was present** when it took place?
- **What happened just before the behavior** began? What were you doing just before the behavior began? What happened immediately after the behavior took place?

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- **Where did the behavior take place?** What was the person seeing, hearing, touching?
- **When does the behavior tend to occur?** Is there a particular time of day when it takes place?
- **How did you react?**

Connect with the person as you assess the situation.

- **Approach the person with respect** and treat him or her as you would like to be treated in the same situation.
- Begin by **coming to the person from the front**, and identify yourself if necessary. Move to his or her physical level and use eye contact and body language to convey a friendly approach.
- **The person will respond much more to your tone and body language than your words**, so it's important to be kind and helpful both in your language and your emotional state.

Presenter's note:

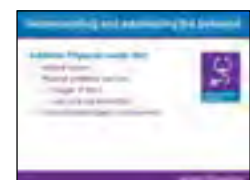
More information about connecting throughout the stages is available in the Association's Effective Communication Strategies program. This is the spot to promote upcoming offerings of the program through your chapter.

Slide 6

Address Physical Needs First

Next, we address the person's needs, starting with the physical.

- Always begin by exploring any needs that may be related to **physical pain or a medical condition**. Consult a physician to identify causes related to medications or illness.



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- **Note any signs of injury** due to incidents such as a recent fall and consult the person's physician with any questions or concerns.
 - People with Alzheimer's disease often experience **pain from undiagnosed urinary tract infections**, compression fractures, arthritis, poorly fitting dentures, indigestion, constipation or other **medical conditions**.
 - In addition, behavior may change due to a **reaction to a new medication** or interaction between several medications.
 - Their needs may not be recognized due to the **person's inability to recognize or talk about his or her symptoms**.
 - **Note any unusual behaviors or symptoms and report them promptly to the person's doctor** to treat or rule out any medical causes of the person's pain.
-
- Second, check for **physical discomfort due to environmental issues** like restrictive clothing, lighting problems or glare, or uncomfortable room temperature.
 - **Additional common causes of discomfort** include hunger, thirst, the need to stretch and move, the need to use the bathroom, the room being too bright or dark, too noisy or quiet, being in an uncomfortable position, or too much commotion.
 - **Adjust the environment as necessary** to make the person more comfortable.

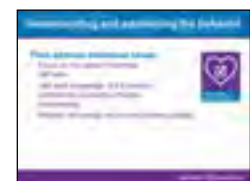
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During the physical assessment, **continue to connect** with the person and maintain a calm, soothing presence. This is particularly useful for helping the person with dementia to reduce any agitation or upset related to the pain.

Slides 7

Then Address Emotional Needs

Next, we address the person's emotional needs.



- Think about **how the situation feels to the person** – this is usually the basis for his or her behavioral reaction.
- Then, **focus on those feelings** in your response **instead of on the facts** of the situation.
- **Avoid correcting** people if what they say is inaccurate. Remember that you are connecting with them where they are. Telling them they are wrong will only escalate the situation and convey that you don't understand. He or she will try harder to convince you and get more upset.
- **Let the person know you are with him or her** and that you are safe together.
- **Reinforce that you are there to help** and that you will try to make changes to make the person more comfortable.
- Although you may not understand the exact meaning of the person's message, you can usually **identify the feeling behind the behavior**. **Address the emotion** behind the behavior to help the person feel less overwhelmed and alone. This will allow both of you to de-escalate the situation together, freeing up energy to direct elsewhere.

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Even if you are unable to understand what the person is trying to convey, he or she will know that you are trying, which may reduce frustration and anxiety.

- Finally, **help the person redirect some of the energy** he or she is expressing through the behavior by leading him or her toward **behavior that is soothing** and enjoyable.



Slides 8 and 9

Video intro

In this video, Rose talks about redirecting some of her mother's agitation into activities that kept her engaged with the family.

View film clip

Presenter's note:

Please insert your own comments about the video clip here.

Important points from the film:

In this video, Rose addresses creating activities to allow her mother to:

- Stay busy and channel her energy into tasks.
- Keep a routine that worked for her.
- Continue to contribute and feel needed.



Slide 10

Reassess and plan for next time

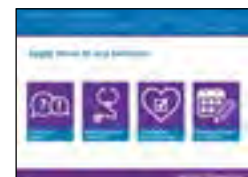
The final step in the process is to **ask yourself whether your new response helped.** |

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- 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?**
- Once you have settled on interventions that are effective, recognize that **this type of issue may arise again**. Plan to **reassess at periodic intervals**. Your intervention plan may include:
 - How to recognize the signs of the issue returning.
 - How quickly you need to respond.
 - **What to try and in what order.**
 - How to assess for the effectiveness of your interventions.
 - **What to do if the situation escalates** or your interventions are ineffective.
 - **Who can help you get the assistance that the person needs.**

Slide 11

These steps can be applied to any behavior experienced by someone with dementia. Now, we'll look at how the steps can be applied to **some of the most common dementia-related behaviors**.



Slide 12

Applying the steps: Anxiety or agitation

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

When someone with dementia is restless or pacing, distressed, or excessively reliant on caregivers, he or she may be experiencing anxiety or agitation.



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Slide 13

Let's take a look at Ann's situation, and then we'll explore how taking the four steps we outlined can help. See if you can apply the steps to this vignette.

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.

Presenter's Note:

As you go through the following steps, periodically mention how they relate to the vignette. You may want to ask participants to raise their hands when they see how a bulleted point applies to Ann's situation, and then either mention the connection yourself or ask the participant to do so.

Option for program expansion:

If you have more time available, you may choose to engage your participants in role plays of the vignettes for some or all of the five behaviors covered in the remainder of the program. To do this:

- 1. Have everyone read the vignette for this behavior in their workbook.*

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2. *Ask for volunteers who have experienced this behavior in their caregiving to help you present the behavior in a role-play. If no one has had that experience, ask for a volunteer to imagine what it might be like and play that role.*
3. *Have the person act out the role of the person with dementia, and you will act as the caregiver. As you interact, point out each step you are taking and how you are using the bullets below in your interaction. After each section, review any bullet points that you have not touched on in the role-play.*

Step 1: Detect and Connect

- Listen to the frustration and try to **understand the feeling**.
- Try to **identify any triggers** for the behavior.
- Ask yourself **who, what, where, when and how questions**.
- **Check for sundowning**: difficulty in the late afternoon and early evening.
- Explore whether these behaviors occur with **particular people or around certain activities**.

Step 2: Address physical issues first

- **Assess for pain, infection, medication interaction or other medical issue** and intervene as needed.
- Many times, abrupt surges in agitation can result from pain from medical conditions, particularly from **urinary tract infections**, which occur frequently in older people. If the shift occurs suddenly, check with a doctor for an assessment.

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- Be sure the person is **involved in activities** 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**. This can trigger concern in the person that can escalate to anxiety or agitation. To avoid this, provide the person with access to appropriate, 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, provide fluids** throughout the day and be careful to include **sufficient exercise**. You can also ask a dietitian to work with the person's physical therapist or another member of the person's medical care team.
- Explore the area surrounding the person and try to see anything that may have triggered **physical discomfort or distress**.

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.** Walk with someone who is walking, matching his or her pace. If the person is speaking loudly or rapidly, keep your volume and pace of speech up as well, maintaining a calm voice and using reassuring words.

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- If you can't make a change in the situation that reduces the anxiety, **focus on changing the person's level of agitation** by comforting or distracting him or her.
- Once the level of agitation is reduced a bit, offer to **engage in a soothing activity** that the person tends to enjoy.
- If he or she is fearful, lonely or sad, **providing reassurance** and companionship can help. When the person senses that someone understands, is in agreement, is there to help, and is on his or her side, he or she will often become calmer and more relaxed.

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.

Slide 14

Applying the steps: Confusion or suspicion

When someone with Alzheimer's disease is confused, he or she may not recognize familiar people, places or things. When this confusion is accompanied by suspicion, the person may accuse others of stealing, being unfaithful, etc. It can be very difficult for caregivers when the person cannot remember who that caregiver is or what the caregiver's character is like.



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Slide 15

Let's take a look at Ann again, as she begins to experience some confusion and suspicion, and then we'll explore how taking the four steps we outlined can help. See if you can apply the steps to this vignette.

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.

Presenter's Note:

As you go through the following steps, periodically mention how they relate to the vignette. You may want to ask participants to raise their hands when they see how a bulleted point applies to Ann's situation, and then either mention the connection yourself or ask the participant to do so.

Option for program expansion:

If you have more time available, you may choose to engage your participants in a role play of this vignette.

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.

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- Try to discern whether the person is **reacting to something in the present or is instead reacting to something imagined or in the past**.
 - **If the trigger is current, explore how the person is interpreting the occurrence.** For example, if the person has misplaced something, he or she may worry that it has been stolen.
 - **If the trigger is something imagined or in the past, see if you can understand what that situation meant to 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, see if you can intervene** in a way that makes the person more comfortable.
- If the person is being given **pain medication, consult with his or her doctor right away** about possible side effects. In addition, ask about potential interactions between medications and possible side effects.
- **Assess for physical discomfort** due to the environment, overstimulation, fatigue, etc.
- **Modify the environment** if needed (take down mirrors if they seem to be problematic, upgrade lighting, etc.)
 - In the situation described in the vignette, Ann was seeing the family's reflection in the window, and interpreted it as strangers looking in at them. This was avoided by being sure to close the drapes each evening.

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- Respond with a **brief and accurate explanation, but avoid arguing.**
- **Offer corrections as gentle suggestions or answers.** If you escalate your energy level, the person will match that and increase it even further.
- **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.**
- 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, acknowledge that you understand 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

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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 for addressing that.

Slide 16

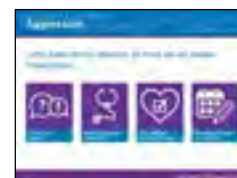
Applying the steps: Aggression

Sometimes, a person with Alzheimer's can experience aggressive behavior, which may be verbal, physical or both. There may be a trigger for the behavior that you can identify, but there are times when it may seem to appear for no reason.



Slide 17

Let's take a look at Ann and Bill as they deal with incidents of Ann's aggressive behavior, and then we'll explore how taking the four steps we outlined can help. See if you can apply the steps to this vignette.



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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.

Presenter's Note:

As you go through the following steps, periodically mention how they relate to the vignette. You may want to ask participants to raise their hands when they see how a bulleted point applies to Ann's situation, and then either mention the connection yourself or ask the participant to do so.

Option for program expansion:

If you have more time available, you may choose to engage your participants in a role play of this vignette.

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, but rather an automatic reaction to something the person is perceiving.

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- 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 understand and are there 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 and **make any adjustments** you can make safely.
- **Be sure to protect everyone involved** so no one gets hurt. You may need to ask children to leave the room or ask for additional people to provide assistance. Part of your role here is to ensure everyone's safety.

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. Also, be aware that some triggers that may not be directly clear to you.

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- **Focus on feelings, not facts.**
- **Be positive and reassuring.** Let the person know that you are there for him or her, and that you will stay to help work the situation out.

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.
 - The best way to avoid a difficult or even dangerous situation is to **take some steps to ensure safety even before the first incident takes place.** These can include:
 - **Alerting neighbors** about the person's condition and anticipated behaviors.
 - If you have a **positive relationship with local first responders** (EMTs, police, etc.), you can **let them know** about the person's diagnosis so they can be prepared in the event of a call.
- **Keep a charged cell phone with you** at all times. You may also need to purchase two batteries so you can change them out promptly when they lose their charge.

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- **Get rid of the guns in the house.** Even though there is no ammunition, if Ann appears to be threatening in public and is carrying a gun, police must assume that the gun is loaded and take appropriate action. This could have disastrous results.
- **Consider a personal security alarm** for accessing help when needed.
- At some point, the person may not be able to be cared for at home. Finding care for people with aggressive behavior is not easy. **Meet with chapter staff to discuss alternatives** in the area and plan ahead.

Slides 18 and 19

Video intro

Now, let's listen to Rose again as she talks about how she and her husband dealt with her mother's aggressive behavior.



View film clip

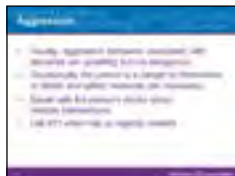
Presenter's note:

Please insert your own comments about the video clip here.

Important points from the film:

- It can help a lot to have others participating with caregiving so you can give each other breaks when needed.
- Sometimes, those with more emotional distance from the person or the situation can take over for a while during times when the primary caregiver feels overwhelmed.
- Remember that even though the person is acting this way because of the disease, you will have feelings that need to be attended to.

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Slide 20

When aggression gets dangerous

Usually, behaviors associated with dementia may be upsetting but are harmless. But this is not always the case. In more rare situations, a person may become dangerous to him or herself or to others.

If the person is putting him or herself or other people in danger, it is crucial to get help immediately. **Call 911** when more help is urgently needed to contain the person's risky behavior. It can feel scary or even silly to be doing this when you are trying to deal with a family member's behavior, but 911 is meant to keep everyone safe. **It's your right and your responsibility to call when the situation has escalated to a crisis level and people's safety is at risk.**

When you make the call to 911, **be sure to let the dispatcher know that the person has Alzheimer's or another form of dementia.** This will ensure that the right people arrive and don't make the wrong assumptions.

When the emergency responders arrive, they will take the person to a local emergency room for assessment. **Be sure that everyone involved knows the person's diagnosis** so that the appropriate interventions can be made.



Slide 21

Applying the steps: Repetition

People with Alzheimer's disease may repeat words, questions or behaviors. This can become frustrating for those who have the most contact with the person.

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Slides 22 and 23

Video intro

In the next video, Dr. Sam Fazio addresses repetition.



View film clip

Presenter's note:

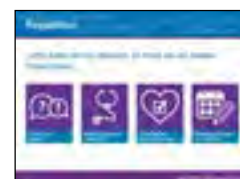
Please insert your own comments about the video clip here.

Important points from the film:

- Repetition is common among those with dementia, and can be very frustrating for caregivers.
- Avoid correcting or trying to convince the person of your viewpoint.
- Remember that the person cannot remember asking the question earlier.

Slide 24

Let's take a look at Ann's repetitive behavior, and then we'll explore how taking the four steps we outlined can help. See if you can apply the steps to this vignette.



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.

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Presenter's Note:

As you go through the following steps, periodically mention how they relate to the vignette. You may want to ask participants to raise their hands when they see how a bulleted point applies to Ann's situation, and then either mention the connection yourself or ask the participant to do so.

Option for program expansion:

If you have more time available, you may choose to engage your participants in a role play of this vignette.

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

- As always, **look for pain first.** Explore whether the person may be experiencing pain and make adjustments to safely 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, such as a urinary tract infection, another medical issue, or a medication side-effect.

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Step 3: Then address emotional needs

- Focus on the emotion that the person is exhibiting, whether it is anxiety, frustration, fear, etc. **Say something that recognizes that emotional state** to help you move to the next step in your intervention.
- Keep in mind that **the emotion behind the behavior** may be fueling the repetition. Addressing the emotional need may help diminish repeated questions, statements or behaviors.
- **Briefly answer the person's questions** or address the concerns.
- **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, though not for others.
- Remember that **repetition is part of the disease**.
- Engage the person in a **purposeful activity** to redirect his or her focus.
- Turn the action or behavior being displayed into an activity with a positive focus. It can help to **offer a repetitive activity**, like wiping countertops, folding towels, sorting laundry by color.

Step 4: Reassess and plan for next time

- Finally, **ask yourself whether your new response helped**. Is it working or do you need to explore other potential causes and solutions? If so, what can you do differently?

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- 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**. This may mean teaching yourself to adopt a calm stance, using deep breathing or reciting a meaningful phrase or prayer. Do what you can to stay centered on the thought that this reflects the disease, not the person.
- **Expect the repetition to happen again.** If you anticipate and make a plan for it, you can be prepared to handle it well.



Slide 25

Wandering

At some point in the course of their disease, approximately 60 percent of people with Alzheimer's disease or other forms of dementia will wander. This behavior may take place without warning, so many families are unprepared.



Slides 26 and 27

Video intro

Next, we'll see Beverly talking about a time when her husband, Amos, wandered.

View film clip

Presenter's note:

Please insert your own comments about the video clip here.

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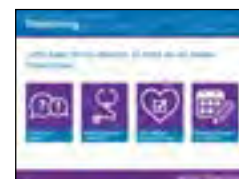
Important points from the film:

- Wandering can be dangerous for someone with dementia.
- Beverly saw her husband leave and knew where he was going. If you didn't see the person leave or don't know where he or she went, you should **call the police immediately**.
- In your Workbook, you will see how to help protect the person by using some of the tools offered by the Alzheimer's Association, including MedicAlert®[®] Alzheimer's Association Safe Return®[®] for both the person with dementia and the caregiver.

Slide 28

Applying the steps

Let's take a look at Ann and Bill as they deal with incidents of Ann's wandering, and then we'll explore how taking the four steps we outlined can help. See if you can apply the steps to this vignette.



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.

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Presenter's Note:

As you go through the following steps, periodically mention how they relate to the vignette. You may want to ask participants to raise their hands when they see how a bulleted point applies to Ann's situation, and then either mention the connection yourself or ask the participant to do so.

Option for program expansion:

If you have more time available, you may choose to engage your participants in a role play of this vignette.

Step 1: Detect and connect

- Assess who, what, when, where and how to **identify possible triggers**. His or her reasons for wandering may not be logical to you.
- Join with the person and **accept anything that the person says about his or her wandering being goal-directed**.

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?
Often a person is **responding to an unmet need** such as hunger, thirst, having to go to the bathroom, desire to get

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away from something or someone unpleasant, desire to go home, go outside or to engage with others.

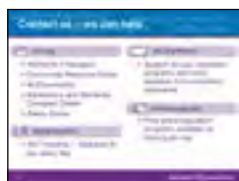
- **Make any changes needed** to keep the person safe as you continue your assessment.

Step 3: Then address emotional needs

- Is the person feeling **bored or under-stimulated**?
- **Name the feelings** that you pick up on from the person, by saying something like, “You seem sad” or “You look scared.”
- **Provide reassurance** that he or she is safe, that you are together.
- Plan ahead of the first wandering incident and put plans in place.
 - 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 about these tools and other ways to ensure safety.)
- If possible, **help the person do what they want**. If they want to go outside, grab your coats and go with them for a walk or a drive. If that is not possible, agree and delay. “Sure, a walk would be great, but it’s almost lunchtime. OK if we go after lunch?”
- **Create opportunities for safe wandering**, such as an enclosed garden with a circular walkway.

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- **Suggest doing something physical together** during times when the person is typically the most restless.
- **Make changes to the person's surroundings** that can help reduce the risk of wandering. Some ideas include:
 - **Putting dark mats in front of doors** to make them look like holes, which the person might avoid.
 - **Camouflaging doors and door jambs by painting them the same color as the walls.**
 - **Hanging towels or cloths over door knobs** to disguise them.
- Provide a **structured routine for the day**. In doing so, you will offer things for the person to plan on throughout the day and can alleviate any boredom that may trigger wandering behavior.
- **Consider a community day program** or other day structures that provide supervised activities for the person to engage in. This higher level of oversight, activity and exercise can also provide a way for the person to discharge some energy throughout the day, which can help with sleeping through the night and avoiding wandering.



Slide 29

No matter whether you want information or support; whether you have questions about memory loss or a dementia of any kind; or whether you are a professional, a researcher, a caregiver or a person diagnosed with Alzheimer's disease or another form of

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dementia, the Alzheimer's Association has resources for you and is available to help.

In addition to our live programs, we have a rich website at alz.org. Visit our website to get tips about finding and providing care, read about the latest research, and find the tools for your wellbeing. Spend some time exploring all we have to offer for you at alz.org.

One of the online tools that you'll find on our website is Alzheimer's Navigator. We can help you map out a plan to approach Alzheimer's by visiting the Web page at alzheimersnavigator.org. Alzheimer's Navigator helps guide you to answers by creating a personalized action plan containing information, support and local resources. You can then share your plan with your friends and family, linking them to the materials customized for your situation.

By visiting our Community Resource Finder online tool at communityresourcefinder.org, you can search for local community living services, day programs, medical resources and more. Whether you are in the area or across the country, you can find services to help someone living with dementia and make the contacts you all need to ensure safety and comfort.

A rich supplement to our local supportive programs is ALZConnected, our online message boards with over 50,000 members who share their thoughts, questions and ideas with each other 24 hours a day. Whether you are living with dementia or are close to someone who is, you can come on to read or post about your concerns. Let ALZConnected help you develop plans, find support and discover new coping techniques by connecting with others who are living with dementia or are partners in caring.

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Our 24/7 Helpline offers dementia-trained professionals to talk with any time, day or night, every day of the year. Call us at 800.272.3900 when you need information about the disease and meeting its challenge, links to resources or a supportive ear during difficult times. We are here to help.

The Alzheimer's Association has chapters all through the country, where we offer education programs, support groups, and much more. To find a chapter anywhere in the U.S., go to alz.org/findus, where you can search by state or zip code. Once on the chapter's web page, you can see what is being offered in that area.

Finally, the Training and Education Center of alz.org is where you can access programs like this one from the convenience of home. Just go to alz.org/training, and you can find programs and materials that offer the most current information about dementia, treatments and care.

Please contact us and let the Alzheimer's Association partner with you to help ensure your wellbeing.

Presenter's note:

Here is the spot to highlight what you are doing at your chapter, including upcoming programs, events and resources specific to the location of this presentation. Flyers and brochures from your chapter can be placed on the resource table along with the Know the 10 Signs and Principles for a Dignified Diagnosis materials.



Slide 30

You can use your voice, your motivation, your interest and your skills to help find new treatments and to enhance services for all people affected by dementia.

Clinical trials research studies are being conducted all over the world to find treatments that are safe and effective. Clinical trials are the best way for researchers to find new ways to detect, slow, treat and hopefully someday prevent Alzheimer's disease. The Alzheimer's Association's TrialMatch is a free clinical studies matching service that connects individuals with Alzheimer's, caregivers and healthy volunteers to local clinical trials seeking participants. When you join a clinical trial, you have an opportunity to participate in vital research that could change the course of Alzheimer's disease and improve the lives of all those it affects. Visit TrialMatch online at trialmatch.alz.org or call our Helpline at 800.272.3900 to get started making a difference.

The Walk to End Alzheimer's and The Longest Day are opportunities for the local community to join together in the spirit of grassroots advocacy that is central to the mission of the Alzheimer's Association. Forming a team to support a friend or family member is a direct way to show your concern for the person as well as for the cause, and those who live with the impact of these diseases in their lives are tremendously grateful.

We also encourage you to join us in providing education and support programs to families in your area who are living with Alzheimer's and other forms of dementia. Whether you are a person with the disease, a care partner or caregiver, or a professional in the field, you can volunteer to use your knowledge and compassion to have a profound impact on those whose lives are affected by the disease.

Presenter's note:

This is the time to highlight volunteer activities at your chapter and to circulate recruitment materials.

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You can also join us to speak up for the needs and rights of people with Alzheimer's and their families, and to help persuade state and federal Congress to increase funding for research and programs. Many caregivers and people with the disease find the experience of advocating to be therapeutic, and it puts a human face on complex policy issues for our legislators.

We need you to help us change the course of Alzheimer's disease for everyone affected, and we welcome you to join us in making a difference.



Slides 31 and 32

Video intro

In our final video, Sandra talks about not always knowing what to do for her mother.

View film clip

Presenter's note:

Please insert your own comments about the video clip here.

Important points from the film:

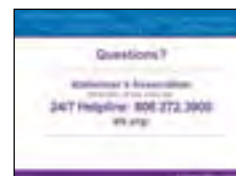
- The behavior of someone with dementia is not always predictable.
- You may not always know how to create the response you're looking for.
- Continuing to be present with the person and attempting to connect can often be felt by the person, even if he or she is not able to convey that to you.

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Slide 33

Addressing dementia-related behaviors can be one of the biggest challenges you will encounter as a caregiver. Please know that you are not alone. On this slide, you can see our web address and our toll-free 24/7 Helpline number. It can help to have a dementia-trained professional to talk with when you feel overwhelmed or at a loss for what to try next. Call or contact us anytime. We are here to help you, your family and anyone you know who is affected by Alzheimer's or dementia.

Are there any questions?



Slide 34

(no text)

